Medical Sociology Study Group

Annual Conference Programme

13 – 15 September 2023
University of Sussex

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WEDNESDAY 13 SEPTEMBER
13:25 -13:55

Room G36 - Pedagogy & Methods

The #longcovid revolution: A reflexive thematic analysis

Melody Turner, Helen Beckwith, Barry Coughlan, Elvira Perez Vallejos, Tanisha Spratt

(The University of Cambridge)

Research has identified long covid as the first virtual patient-made condition (Callard & Perego, 2021). It began with Twitter users sharing their experiences with the hashtag #longcovid. Studies on #longcovid have analysed subsequent tweets collected in 2021 and 2022. This article differs by focusing on the initial tweets containing #longcovid in 2020, from the first tweet in May 2020, until August 2020, when the World Health Organization formally acknowledged the condition.

Reflexive thematic analysis was conducted using the first author's experience with long covid. The epistemological framework was derived from Ian Hacking's (1999) perspective on social constructionism, as the social construction of long covid was both ontologically subjective (it was created virtually by Twitter users) and epistemologically objective (it defined a real-world medical condition).

Over 31,000 tweets containing #longcovid and all of Hacking's grades of social constructionism were identified. The themes reflected that long covid was a multi-system, cyclical condition, initially met with stigma and misunderstanding from friends, relatives, and colleagues.

The findings add to the existing literature (Ladds et al., 2020; Rushforth et al., 2021) by suggesting that Twitter users raised awareness of their condition by providing consensus on their experiences of long covid. This generated a collective social movement. Together, they overcame ironic and indifferent attitudes toward their condition by sharing supportive tweets containing emotional warmth. They campaigned for their healthcare needs using a newly generated hashtag of #researchrehabrecognition. Future research on novel conditions should consider various research paradigms to encourage healthcare bodies to identify marginalised groups.

Room 155 - Citizenship & Health

Exploring the theory and practice of patient and public involvement in health research in Denmark: A qualitative study of the funding landscape

Jonas Stage, Glenn Robert, Oli Williams

(Roskilde University & Kings College London)

Over the last two decades, patient and public involvement (PPI) has become central to the discourses (if not the practices) of healthcare research and policy making internationally. PPI signals an aim to produce knowledge and improve health services by involving patients, citizens, and stakeholders in research processes. This article explores some of these developments in the Danish healthcare sector – a field where PPI has only recently started to gain traction - by exploring the rationales for encouraging PPI as provided by senior managers within funders. In this paper, we use the sociologist Fran Collyer's understanding of the healthcare sector as a field and the central actors' social action to ask 1) where do funders come from 2) what are their rationales underpinning involvement and 3) how may funders theory and practice of involvement shape the development of PPI in health research in the healthcare sector. We use documentary materials, both primary and secondary, and qualitative interviews with senior managers at 7 funders. The finding shows a dominating technocratic value ascribed to involvement, and with a lesser extend a democratic value. Additionally, funders use participatory practices to accumulate legitimacy and signal credibility in the wider research infrastructure. The findings demonstrate funders relationship within the wider systems of which they are a part, where the cultural (re)production of PPI across a transnational boarders might shape what PPI 'is' and 'becomes' in Denmark. We identify a potential avenue by learning from hard-earned experience from international scholars to avoid reproducing the same mistakes.

Room 135 - Inequalities & Intersectionality

'You can be in hell and they still refuse to help': Racially minoritised people with Long Covid reflect on care and support experiences

Damien Ridge, Nina Smyth, Nisreen Alwan, Carolyn Chew-Graham, Dipesh Gopal, Tom Kingston, Rebecca Band, Alexa Wright, Patricia Gaszczyk

(University of Westminster)

Background: Around 2 million people in the UK experience Long Covid – a patient-preferred term - ongoing, multiple symptoms following SARSCoV2 infection. We explored experiences of Long Covid in racially and ethnically minoritised people in the UK, including healthcare experiences, and the extent to which the offered care matched perceived needs.

Methods: We used purposive sampling to recruit 29 minoritised participants for semi-structured interviews, achieving a good balance of genders, ethnicities, ages, and socioeconomic categories. A Patient Advisory Group (PAG) shaped the research every step of the way.

Results: Suspected racism in healthcare was highlighted throughout the narratives, with participants believing they were treated with less empathy and more harshly than their white counterparts. This created a sense of a lack of safety in consultations. Most of our participants described struggling to get help from primary care, as well as experiencing trivialisation and 'gaslighting'. Nevertheless, some participants reported recognition and proactive support (e.g., especially from racially minoritised practitioners). Participant narratives elaborated on the perceived power they believe GPs wielded over them including limiting referrals and prescriptions, but especially in terms of whether their suffering was legitimised or dismissed. Those with resources frequently fought to access care to meet their needs, or had advocates. Others researched their own treatment plans through self-management and private care, for example.

Conclusion: Our findings suggested recognition of suffering is frequently withheld, yet this legitimisation would, in itself, go a long way to ease the suffering of racially and ethnically minoritised people living with Long Covid.

Room G31 - Diagnosis, Screening & Treatment

Risky bodies: BRCA testing, previvors, and the reification of risk

Jackie Hogan (Virtual presentation)

(Bradley University)

With the intensification of surveillance medicine in the late 20th century, risk itself is now often conceptualized as a disease in need of treatment, and as diagnostic tools become more sophisticated, increasing numbers of people are identified as medically "at risk." In this paper, I examine the disciplining function of surveillance medicine and the reification of medical risk. Specifically, I analyze internet discourses around prophylactic mastectomy, prophylactic oophorectomy, and other interventions for individuals deemed to be at heightened risk of hereditary breast and ovarian cancer. Of key concern are the messages health information-seekers receive when they are grappling with difficult medical decisions, and the implications of such messages for individual and public health outcomes. The data reveal that consumers are exposed to substantial amounts of intervention-positive messaging, and that messaging is more intervention-positive for higher revenue interventions. Moreover, risk is reified in online messaging in ways that stoke women's fears and alienation from their own bodies. Specifically, the reification of risk and the conflation of risk with cancer itself serve to reinforce the notion of an "enemy within." Such discourses encourage women to see their own bodies as foes. Women are told that surgically reducing, chemically altering, or strictly surveilling their bodies is the only path to well-being and empowerment. Through the operations of the market, and discourses of science, medicine, the public good, and individual choice, social control appears merely rational, natural, and necessary. Medical risk discourses naturalize subjugation to market forces.

Room G35 - Embodiment & Emotion

Anger as a symptom of disease? Emotional labour in short-term reablement care in denmark

Michelle Vestbo-Nielsen, Nete Schwennesen, Karen Christensen, Line Lindahl-Jacobsen

(Roskilde University, Department of People and Technology)

Demographic aging and a rising number of citizens with chronic and multi-diseases drive an increased focus on reablement as a part of care work in Denmark and the Western world. Drawing on an ethnographic field study in a Danish short-term reablement care home, this paper explores emotional labour (Hochschild 1979;1983) as it takes place in relationships between older people and health care professionals and examines how emotions of anger displayed by older people are acted on and narrated by health care professionals. Extending the work by Thuesen et al. (2021), who have demonstrated, that reablement approaches in Denmark reflect biomedical theories of aging and physical improvement and demands for efficiency (Thuesen et al., 2021), the analysis shows how emotional labour is enrolled in professional power structures and how emotions of anger are seen as symptoms of disease and controlled rather than engaged with. In doing so, this paper illuminates how emotional labour plays an essential part in short-term reablement care both as extremely demanding work for professionals resulting in care practices that challenge that people are human beings in their own right.

Room 115 - Open

The authority to care: Gendered relations shaping women's reproductive healthcare in rural India

Alankrita Anand

(University of York)

Access and utilisation have been critiqued as inadequate measures of health and well-being, particularly in resource-poor settings and among marginalised groups, and have been problematised by studying the demand-side factors that influence them, especially social identity and perceptions of health and care. This paper responds to and builds on the body of work studying women’s access to reproductive care, by studying the conditions of access and placing care in the gendered relations of the household, arguing that it is husbands who have the authority to (do) care. The paper draws on my ongoing doctoral research studying women’s claims on care and negotiation of household dynamics in rural India, centering women married as minors - by force or choice - as they are not entitled to maternal health schemes and have contentious legal marital status. Women, however, make claims on care that encompass value for their lives, moral responsibility for their welfare, and love as partners. In this context, the paper argues that the authority of husbands to do care manifests as responsibility and love, but also as power, and leads to practices of both care and neglect, sometimes in a contiguous and overlapping manner. The paper then discusses women’s response to authority and to (the receipt of) care itself, based on study data on instances of conception, contraception, and abortion. The methodology involved a collaborative pilot study with a field partner, 32 in-depth interviews and six focus group discussions, and the data is being analysed drawing on constructivist grounded theory.

Room 118 - Experiences of Health & Illness – Special Event

Using patient experiences to interrogate Long Covid across the life course: chaos, regression, disability, and recovery

Cervantee Wild, Alice Maclean, Sarah Nettleton, Kate Hunt, Sue Ziebland, Alice Maclean, Louise Locock, Callum O'dwyer, Sarah Nettleton, Sue Ziebland, Cervantee Wild, Alice Maclean, Cervantee Wild, Sarah Nettleton, Sue Ziebland, Kate Hunt, Annelieke Driessen, Cervantee Wild, Eilidh Anderson, Sarah Nettleton, Pat Hoddinott, Callum O'dwyer, Sue Ziebland, Lisa Hinton, Kate Hunt (University of Oxford & University of Stirling)

Long Covid is an activity-limiting condition that impacts participation in the labour market and involves over 200 unpredictable and fluctuating symptoms that span 10 organ systems. 'Episodic disability' has been shown to be an apt theoretical framework to conceptualise the multidimensional, fluctuating symptoms of Long Covid. However, no qualitative research to date has utilised 'episodic disability' to comprehend the challenges that those with Long Covid encounter when returning or attempting to return to paid employment.

Drawing on 65 narrative interviews, conducted between 2021-2022, from three separate UK studies involving adults with Long Covid, this presentation shows how participants experienced a reduction in social value or 'spoiled identity' due to being unable to return to their previous working capacity. Participants also experienced the 'uncertainty' of existing in-between illness classifications, which made it challenging to claim 'disability' status when returning to work, resulting in repeated absences and unsuccessful attempts to return. While participants who could mould their work around their fluctuating capacity experienced their working environment as enabling, others were rendered 'bodies-at-odds' with their working environment. The additional 'adjustment' and 'administrative' work involved in navigating disabling systems required participants to carefully balance and prioritise workloads to avoid relapse. Utilising the concept of 'episodic disability' offers evidence that the workplace can be a disabling force that relies on those with Long Covid to conduct additional rehabilitation work to return with little guidance or support.

NB. Eilidh Anderson is a first-time presenter

Using patient experiences to interrogate Long Covid across the life course: chaos, regression, disability, and recovery

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(University of Oxford & University of Stirling)

The Covid-19 pandemic has been dominated by discussions of mild and short-lasting cases or acutely serious or lethal forms of the disease, with less attention paid to long-term Covid-19 symptoms ('Long Covid'), particularly in children. This analysis of the experiences of n=39 children and teenagers with Long Covid in the UK and their parents/caregivers, argues that they encounter a 'double invisibility' on account of the condition's limited social currency and their status as less agentic members of society. Analysis of our qualitative interviews demonstrates that participant experiences were shaped by the convergence of three strands of the dominant pandemic narrative: that Covid-19 is mild and everyone recovers; that children are not badly affected by Covid-19; and that the pandemic is essentially 'over'. Drawing on Frank's chaos narrative, we argue that Long Covid is rendered invisible in much of the public's consciousness. As a result, children, teenagers and their parents encountered significant challenges in making their illness experience visible. They struggled to signal the severity of the condition and elicit care in the same way that could be expected of other (longer established, better understood or more visible) conditions. This was exacerbated by deep-rooted assumptions and stereotypes about (unwell) children and teenagers, and their parents, and their questionable candidacy as reliable, trustworthy patients, with implications for help-seeking. The occurrence of Long Covid in children therefore threatens key aspects of the dominant pandemic narrative, some of which have persisted from the early stages of the pandemic into 2023.

Using patient experiences to interrogate Long Covid across the life course: chaos, regression, disability, and recovery

Cervantee Wild, Alice Maclean, Sarah Nettleton, Kate Hunt, Sue Ziebland, Alice Maclean, Louise Locock, Callum O'dwyer, Sarah Nettleton, Sue Ziebland, Cervantee Wild, Alice Maclean, Cervantee Wild, Sarah Nettleton, Sue Ziebland, Kate Hunt, Annelieke Driessen, Cervantee Wild, Eilidh Anderson, Sarah Nettleton, Pat Hoddinott, Callum O'dwyer, Sue Ziebland, Lisa Hinton, Kate Hunt

(University of Oxford & University of Stirling)

As the Covid-19 pandemic burgeoned during 2020, attention focused largely on the scale and rapid spread of Covid-19 and its potential to cause life-threatening illness or death amongst the elderly and chronically ill. Although the experience of people with long-lasting symptoms is now more visible, young adults have been overlooked. Here we explore their experiences of Long Covid in relation to theories of biographical disruption. Drawing on in-depth, narrative interviews with 15 adults who became ill with Long Covid in their twenties, we discuss the contextual factors which make the naming and understanding of their illness-induced biographical disruption challenging. First, adults in their twenties are often at a crucial stage in forming or solidifying (presumed) adult lifecourse trajectories. Secondly, the recency and novelty of Long Covid itself does not allow for comparison with an existing ‘grand narrative’ of recovery, so the future course of their illness is not just unknown for them as individuals; there is no prognostic map against which to assess their illness experience. Thirdly, the lives of people with Long Covid have been disrupted in the context of global societal disruption by the same virus, rendering their own experiences both topical yet invisible. We propose that, for these reasons, existing adaptations of the sociological concept of biographical disruption are problematic for this group, and we discuss why the term ‘biographical regression’ may more accurately reflect the experiences of young adults with Long Covid in the early stages of the Covid-19 pandemic.

Using patient experiences to interrogate Long Covid across the life course: chaos, regression, disability, and recovery

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(University of Oxford & University of Stirling)

Recovery is an important construct within medical sociology which can be used inconsistently, without sufficient nuance or precision. This can result in ‘epistemic injustice’ where some accounts of recovery are privileged, while others are neglected or rejected. Drawing on narrative interviews (n=95) conducted in the UK between February 2021 and July 2022, this paper investigates the construct of recovery by comparing accounts from adults admitted to ICU with COVID (n=32) and with Long Covid (n=63) defined as ongoing symptoms for at least twelve weeks post-infection.

Comparative analyses generated descriptive themes: ‘defining loss and the object of recovery’; ‘markers and measures of recovery’; ‘doing the hard work of recovery’; and ‘recovery in a changed world’. While both groups were existentially changed by COVID and needed to undertake the work of recovery, there was evidence that they moved towards ‘recovery’ from different ‘baseline’ positions with varying temporal and directional trajectories. The fact that COVID ICU patients had witnessed the deaths of others in their unit yet had avoided death themselves led to a presumption that they would need time to recover and systems existed to support them, albeit within a healthcare landscape overwhelmed by the pandemic. Long Covid patients by contrast had a then little understood (often invisible) condition for which no definitive diagnostic tests existed, and healthcare knowledge and services were lacking. While they also experienced significant losses in their daily lives, their need to recover was less well recognised and there was no ‘map’ to guide them in regaining health.

Room G22 - STS & Medicine

Trichomonas vaginalis’s racialising assemblages – how the geographical vicissitudes of race come to matter in Sexual health care

Ulla Mckinght, Catherine Will, Bobbie Farsides

(University of Sussex)

This paper is premised on ethnographic observations and interviews with Health Care Providers in Sexual Health Clinics in four National Health Service trusts in England as the providers reflect upon the controversial practice of using various racialised categories as markers of vulnerability to Trichomonas vaginalis (T. vaginalis), infection, the most common non-viral sexually transmittable infection (STI) world-wide. This practice is a consequence of the way in which institutional boundaries and (geographical)borders are created, maintained and come to matter. In other words, the practice has to do with the way in which various categories are enacted in practice and used as markers of vulnerability to infection. We draw on the concepts of ontological multiplicity and assemblage to contend that T. vaginalis becomes racialised through these processes and (the geographical vicissitudes of) race become the explanation for vulnerability to T. vaginalis infection. In so doing, we argue that the onto-epistemology of T. vaginalis, is racially assembled. As such the assemblage forecloses the exploration of T. vaginalis – where it may or may not be and why it might (not) be there – without evoking and thus enacting, the racialised assemblage as the cause (or source) of illness. The paper contributes to Sociological understandings of disease by showing how race is part of disease even when it is seemingly absent and this has important effects on the experience of illness and on efforts to prevent STIs, reduce racialised health inequalities and mitigate the risks of antimicrobial resistance (AMR).

Room 144 - Professions

Understanding and Supporting NHS Employees with Long COVID Return to and Remain in Work – key barriers and facilitators

Emma Maciver, Nicholas Norman Adams, Diane Skåtun, Virginia Hernandez Santiago, Catriona Kennedy, Flora Douglas, Nicola Torrance, Aileen Grant

(RGU)

Long COVID (LC) is a debilitating illness with complex and dynamic symptoms affecting all aspects of personal and work life. The process and implications of returning to work following chronic illness have been considered across various conditions, however published literature exploring LC is sparse.

Person-environment fit (PEF) theory has been used to unpick the employer-worker dynamic in the process of returning to work, providing an analytical framework which offers both an understanding of and practical means of supporting this process towards a positive outcome for both parties.

We apply this framework to NHS workers suffering LC; utilising PEF theory as a lens to provide a sociological perspective to interrogate experiences of returning to and remaining at work, while experiencing often fluctuating, complex and debilitating symptoms. Findings are based on a longitudinal, in-depth interview study exploring impacts of LC on 50 NHS Scotland workers in clinical or ancillary roles.

This study highlights the importance and interplay of key factors facilitating successful return to work: improvements in symptoms; specific supports and understanding; workplace flexibility; and considerations around professional role and identity. Understanding and addressing these factors is imperative as around 10,000 NHS employees in UK are off work because of their LC, at a time of acute crisis in NHS with understaffing and unprecedented demand. Key outcomes around how workplaces must adapt to facilitate reintegration of workers experiencing LC are discussed, and some additions to theory to allow for further application to understanding the impact of LC upon return to work.

WEDNESDAY 13 SEPTEMBER
14:00-14:30

Room G36 - Pedagogy & Methods

Long Covid: A twitter informed phenomenological rhythmanalysis

Sam Martin, Emma Uprichard

(Vaccines and Society Unit, University of Oxford)

Long Covid has been referred to as a looming crisis in national health and employment worldwide. Estimates for the UK are that at least 2 million people have been affected, with 17 million people in Europe and around 145 million globally. Although much is still unknown, a consensus is emerging in how it shares a lot in common with ME/CFS (Myalgic encephalomyelitis/Chronic Fatigue Syndrome) and other post-viral chronic illnesses. Whilst most research in this area focuses on causes, symptoms and treatments, this paper is unique in its focus on the experiences of time by those with Long Covid. Drawing on Twitter data since 2020, we use Lefebvre's rhythmanalysis to empirically depict the phenomenological temporal experiences of those living with Long Covid. We show that, like many chronic illnesses, Long Covid is a deeply complex temporal experience, whether it be through the 'before and afters' of the individuals going through their own 'biographical disruption' of living with a new chronic illness; learning about and adapting to the complexity of pacing, planning and preparing with variable and unpredictable energy reserves and fluctuating symptoms; or the changeable mundane everydayness of living with Long Covid. The paper concludes that focusing the temporal experiences of living with Long Covid allows us to not only better understand what this group of individuals may be going through, but also the growing need to pay attention to the politics of time and illness as a way of revealing subtle yet important social divisions across societies.

Room 155 - Citizenship & Health

'Off Grid' Donor Identity Disclosure: what happens when people trace their egg or sperm donor through social media or genetic testing?

Roisin Ryan-Flood

(University of Essex)

This paper explores the experiences of those who are affected by donor identity disclosure through 'off grid' means in the UK, drawing on qualitative research funded by the British Academy. Legal frameworks prohibit seeking donor identifying information until a donor conceived person reaches the age of eighteen (and deny access to donor information to those conceived prior to 2005). Nonetheless, increasingly donor conceived people, or their parents, are attempting to access information about their own or their child/ren's biological roots either through social media sites or genetic testing. Using qualitative interviews, this project investigates the experiences of those who are affected by this form of donor identity disclosure (e.g. donors, donor conceived people and/or the parents of donor conceived people), experiences which are rarely heard in the public sphere. Issues arising include consent, ethics, identity and connection. The paper explores new understandings of the role of digital intimacies and genetic testing in contemporary life, as well as the changing context for assisted reproduction and intimate citizenship.

Room 135 - Inequalities & Intersectionality

Resources, resilience and wellbeing: Insights into the lives of migrants at risk of vulnerability

Antje Lindenmeyer

(University of Birmingham)

The wellbeing of migrants is a complex field, with migrants aiming to increase wellbeing while experiencing loss of social networks; access to services is often restricted to discourage migration (Napier 2014). Definitions of subjective, material and relational wellbeing (Sumner & Mallett 2011) are linked to the concept of resilience, which in turn includes the ability to individually mobilise and collectively negotiate for material and non-material resources (Unger 2008).

In this paper, we draw on free-text notes from consultations between Doctors of the World UK caseworkers and their service users. DOTW UK are a charity providing medical care, information, and support to people unable to access NHS services, many of whom are undocumented migrants. We aim to explore links between material and immaterial resources, resilience and wellbeing in this seldom heard group of people at risk of vulnerability. A thematic domain analysis (Braun & Clarke 2020) identified a range of resources important to service users (earnings, migration status, housing, social support, access to healthcare) but also links between especially material and social support which often clustered around housing, while lack of access to NHS care had major financial implications.

This study provides important insights into the ways in which migrants at risk of vulnerability mobilise resources and actively try to create a liveable environment. However, these resources are very precarious and arrangements to share resources can also lead to dependency and exploitation. More research is needed into these dynamics and the potential for created social support to improve wellbeing.

Room G35 - Embodiment & Emotion

Ambivalent Care: Rethinking Gender and Embodiment in Chronic Illness Experiences and Care Practices in India

Avilasha Ghosh

(Indian Institute of Technology Delhi)

The proposed paper discusses the unequal gender relations in chronic illness experiences and caregiving practices in India. Focusing on the ways in which patients from different socio-economic backgrounds navigate diabetes and primary healthcare in Delhi, the paper highlights the centrality of gender and kinship in people’s care relations and health-seeking behaviours around chronic illnesses. Using an intersectional approach and mixed method ethnography, the arguments in the paper draw from qualitative interviews with diabetes patients and their families in private homes, clinics, and hospitals. Care in chronicity involves a lot of hard work and emotion management, and usually involves women in Indian conjugal families. The paper argues that unequal caregiving responsibilities between male (care recipients) and female members (care givers) in Indian families, across economic classes and religious communities, severely impact women’s self-care practices and decisions around chronic diseases and the healthcare system, often to the point of risking their own health and normalising suffering. I further examine how unreciprocal care relations in diabetes management impact women’s labour, health, interpersonal relations, and subjectivity in everyday life through a symbolic lens of power, embodiment, and subjecthood. In so doing, I draw attention to the multifarious meanings of care, both for the caregiver and care receiver, and how we might think of care and embodiment in an uneven, messy landscape of illness and gendered suffering in India.

Room 115 - Open

Situational context of Home-based Sexual Education in urban slums of Ibadan, Nigeria – Evidence from a qualitative study

Taofeek Aliyu

(Obafemi Awolowo University, Ile-Ife, Nigeria)

Little is known about how events in slum settings interfere with informal sexual education in Nigeria. This study explores the influence of situational context on parent-adolescent communication about sexual and reproductive health (SRH) issues in the urban slums of Ibadan, Nigeria. A qualitative exploratory study was conducted in the Southeast and Northeast local government areas of Ibadan. Eight (8) vignette-based focus group discussions (FGDs) with parents and adolescents of both sexes were conducted in addition to four (4) key informant interviews (KIIs) with community and women's leaders. Interviews were audio-recorded, transcribed, and translated into English. Descriptive and interpretative analyses were conducted with the aid of ATLAS Ti 9 software. Findings portray SRH meanings and experiences, intergenerational cultural norms, and expectations for SRH, gender double standards in SRH discussion, streetwise SRH knowledge, and social media exposure to SRH as contexts that interfere with parent-adolescent communication on SRH issues. The findings show that although parents and teenagers understood SRH issues and their consequences, there was no effective communication about them. Also, the conversation between parents and adolescents promotes gender inequalities as different SRH information is passed to adolescent girls and boys. Streetwise SRH knowledge was identified to impede effective parent-adolescent conversation on SRH issues. Social media exposure had a significant impact on where teenagers got their unfiltered SRH knowledge, interfering with and distorting SRH discussion between parents and adolescents. Interventions that enable parents to give and allow their children early access to appropriate SRH knowledge, considering their context, are urgently needed.

Room G22 - STS & Medicine

Viral dating: experiences and effects of dating apps among heterosexual and lgbt+ people during covid-19

Jaime Garcia Iglesias, Stephanie Cahill, Jaime Garcia Iglesias, Brian Heaphy, Neta Yodovich, Thomas Carpino

(Johns Hopkins University | University of Manchester)

COVID-19 transformed practices of intimacy globally (Preciado 2020, Jones 2020) and coincided with an expansion of dating apps—digital tools to meet others (Race 2015). Relying on a nation-wide survey of adults aged 18 and older (n=824) in the United Kingdom who used dating apps during COVID-19, we explore how dating app use during COVID-19 affected intimacy, comparing heterosexual and LGBT+ people—groups with historically different intimacy practices and distinct experiences of COVID-19 (Heaphy 2018, Garcia-Iglesias 2020).

This paper presents findings on experiences and motivations of heterosexual and LGBT+ individuals, including frequency and reasons for using dating apps before and during COVID-19. Using Pearson chi-squared and regression analysis, we evidence how LGBT+ individuals were significantly more likely to ‘shield’ during COVID-19 and be ‘highly digitally connected’—meaning that they built extensive online connections. Our research has also found that LGBT+ people were more likely (X^2 p-value <0.01) to experience stigma and discrimination when using dating apps due to ethnicity, age, body, HIV-status, and disability.

We rely on existing sociological literature—which highlights differences between heterosexual and LGBT+ experiences of intimacy and the unequal distribution of the impacts of COVID-19—to analyze these findings, suggesting that dating app use may have positive effects during periods of social distancing but are not evenly distributed among populations. Further, this is complicated with potential negative effects due to experiences of stigma in the digital environment. To our knowledge, our study is the first UK-wide empirical approach to the complex ways in which dating apps have impacted intimacy during COVID-19.

Room 144 - Professions

“i’ve got lots of conflicts in my head”: good intentions, bad outcomes and the conflicting feelings experienced by psychiatrists when diagnosing personality disorders in the UK

Amber Mulcahy

(King's College London)

Borderline Personality Disorder (BPD) is a highly controversial psychiatric diagnosis characterised by symptoms of self-harm, emotional dysregulation, uncontrollable anger, unstable sense of self and stress-induced paranoia or dissociation (APA, 2013). Despite recent attempts within the healthcare system to advance the way that we think about BPD in the UK, it remains one of the most stigmatised mental health diagnoses within healthcare settings (Markham, 2009). The diagnosis is often linked to terms such as ‘attention seeking’ or ‘manipulative’ (Veysey, 2014), despite the considerable suffering those with the diagnosis endure.

In this paper I present preliminary findings from my PhD study in which I am taking a feminist epistemological approach to the experience of diagnosing (psychiatrists) and living with (service-users) a label of Borderline / Emotionally Unstable Personality Disorder. Data explored here has been gathered from 15 semi-structured interviews with psychiatrists with a diverse range of experience, including leading figures in the field of personality disorders and critical psychiatry.

I examine the conflicts that occur when diagnosing and working with people diagnosed with personality disorders. Concurrently, psychiatrists report hoping they “do most things with a good heart”, that they are “very aware that putting it (a diagnosis of BPD) on someone’s notes will impact their care” but that as a doctor, following the medical model is what they do, so what choice do they have?

WEDNESDAY 13 SEPTEMBER
14:35-15:05

Room G36 - Pedagogy & Methods

Governance and organization of life: public hospitals as a space for ethnographic exploration.

Francisca Benitez

(Universidad Adolfo Ibáñez)

The aim of the current presentation is to analyze the theoretical and methodological implications of the ethnographic approach to investigate the daily management of life in the emergency wards of public hospitals.

The COVID-19 pandemic, which began in 2020, has exacerbated and revealed the profound conditions of inequality in contemporary societies. For the Chilean case, the development of neoliberalism has increased social vulnerability and inequality of access to health (Gamlin and Berrio 2020; Rotarou and Sakellariou 2017). In this sense, it was possible to observe that the groups of society most affected in terms of mortality by the recent pandemic were the poorest groups in the country (Bilal, Alfaro, and Vives 2021; Canales 2021; Núñez-Cortés et al. 2021). The present context has articulated an exceptional moment to comprehend the crude and diverse situations of inequality that societies have faced as a result of the pandemic. For this reason, it is crucial and essential for medical sociology to reflect on and consider the development of new methodologies and epistemological frameworks for research. Public hospitals and their emergency rooms are a key space for ethnographic exploration to understand the current post-pandemic scenario (Bratton 2021, Fassin, Fourcade 2021) in which to (i) interrogate processes of violence and vulnerability that cross, materially and symbolically, people's bodies (Bridges, 2011b) and (ii) understand how the state manifests itself and is continuously produced in everyday life (Das & Poole, 2008).

Room 155 - Citizenship & Health – Special Event

Overcoming the challenges of multi-stakeholder collaboration to improve health and social care: translating Elinor Ostrom's theory of collaborative group working into practice

Oli Williams, Glenn Robert, Bertil Lindenfalk

(King's College London and Jönköping University)

Increased attention on the roles patients and citizens could play in health research and healthcare improvement led to a so-called ‘participatory turn’. This increased interest in methods for citizen engagement, public participation, and involvement of people with relevant lived experience. This has been accompanied by raised expectations within and outside academia for decision-making processes in research to involve multiple stakeholders representing a diverse range of interests, expertise, and experience and for these collaborations to have ‘impact’.

Attempts to respond to these expectations have highlighted how challenging this form of collaboration can be. Tokenism, poor practice, and missed opportunities are commonplace. Clearly structures, methods, and resources to support more inclusive, equitable, and effective research are some way behind the 'participatory turn'. Attending to this, we are exploring the potential utility of political economist Elinor Ostrom's Nobel Prize-winning research on collaborative group working.

Ostrom studied how different groups around the world collectively managed ‘common pool resources’ (e.g., forests) and found that the presence (or absence) of 8 principles largely determined the effectiveness of their collaborative efforts. Ostrom later advocated for using these principles as ‘a practical guide for increasing the efficacy of groups in real-world settings'. A decade later, their potential utility remains almost entirely untested.

This interactive workshop will: (1) outline Ostrom's theory and its relevance to the 'participatory turn' (2) discuss the challenges of translating Ostrom's theory into practice (3) share our attempts to create user-friendly resources to achieve this aim and (4) invite you to engage with early prototypes.

Room 135 - Inequalities & Intersectionality

"Everything for the baby… I feel like I wasn't existing": Making decisions about infant feeding when living with HIV in the UK

Bakita Kasadha, Shema Tariq, Nell Freeman-Romilly, Angelina Namiba, Catherine Pope, Lisa Hinton, Farai Nyatsanza, Tanvi Rai

(University of Oxford)

'Breast is best' infant-feeding campaigns overlook people who face complex infant-feeding decisions. For women with HIV, the risk of transmitting the virus via breastfeeding is significantly reduced by maternal antiretroviral therapy but is not zero. Therefore, the UK HIV and infant-feeding guidelines recommend exclusive formula feeding, although women can be supported to breastfeed if they adhere to certain biomedical criteria and agree to additional clinical surveillance.

Pregnant women with HIV in the UK are disproportionately from racially minoritised migrant groups, predominantly of Black African heritage. While the UK has one of the lowest breastfeeding rates globally, breastfeeding is normalised across African cultures. Meanwhile, HIV remains stigmatised and formula feeding can signal an HIV diagnosis.

We explored decision-making about infant-feeding in interviews with 36 new mothers living with HIV in the UK. Participants' accounts of transitioning into motherhood and deciding how to feed their babies, was foreground by their intersectional social identities, in terms of HIV, race, gender, migration status, economic security and relationship status. We build on Mc Knight's (2020) analysis of how the 'HIV diaspora' experience 'ontologically multiple HIVs' such that navigating infant-feeding choices involved difficult trade-offs and immense potential hazards. This was due to the divergence between UK guidelines and cultural expectations while navigating extra surveillance, silencing and censure they faced in healthcare interactions, within the context of negotiating infant-feeding decisions with the father of their infants while occupying disadvantaged positions in UK society that identify them as part of 'suspect communities' (Pantazis and Pemberton 2009).

Room G31 - Diagnosis, Screening & Treatment

Diagnosing UTI: 'When all you have is a hammer, everything is a nail'

Eleanor Kashouris

(University of Sussex)

Based on interviews with patients and healthcare practitioners (HCPs), as well as analysis of diagnostic rationales as part of my doctoral project on urinary tract infection (UTI) in the NHS, this paper addresses the contentious issue of diagnosis. The first-line treatment for UTI is antibiotics and diagnosis of UTI appears as a major issue in patient mobilisations as well as in national antimicrobial stewardship (AMS) programmes.

Rather than understanding diagnosis as a linear progression, where treatment is the product of classification (a logic pictorialized in diagnostic algorithms), I argue that diagnosis of UTI is teleologically related to treatment options. A diagnosis of UTI is often a post-hoc rationalisation of an antibiotic prescription by HCPs, patients, and in clinical policy. Therefore, I recommend that the sociology of diagnosis reconsiders the exact role for diagnosis within treatment trajectories.

In analysing the effects of diagnosis done in this way, I theorise that patients often experience poor care when they seek help for urinary symptoms not because of a classification error but because care for urinary symptoms is extremely circumscribed by antibiotics. Moreover, I argue that AMS interventions aiming to more effectively target empirically prescribed antibiotics for UTI have the potential to exacerbate this because of the way they pull one clinical diagnosis (UTI) out of that which clinical diagnoses depend on; symptoms. In this way, I contribute to the sociology of diagnosis and start to explore what the implications of this analysis would be for clinical practice as antibiotics come under increasing pressure.

Room G35 Embodiment & Emotion

Weight bias and discrimination experiences among Chilean university's students

Maria Jesus Vega-Salas, Danae Hermosilla-Llanca, Valeria Aviles-Peña, Camila Ulloa-Vallejos

(Pontificia Universidad Católica de Chile)

Weight bias devaluates the social identity of individuals based on their body weight or shape. Deviations from the body's ideals are expressed as discriminatory and prejudiced attitudes within social contexts. Weight bias has been identified in educational, healthcare, and workplace settings. Despite the widespread research about the consequences of excess weight on health, few studies have explored the social consequences derived from this condition.

Chile experienced a rapid increase in excess weight, exemplified by 74% of the population aged over 15 years under an overweight or obesity condition. Focusing on university students, a group under a pivotal stage regarding their body appearance, this study aims at assessing weight bias and its association with sociodemographic, body weight, and academic characteristics.

An online survey including 286 students attending a Chilean University was conducted to analyse the self-report of experiences of weight discrimination in different settings and the implicit bias towards people with obesity using the Beliefs about Obese Persons Scale (BAOP) scale. An overall high BAOP score was found. Yet, students reporting weight discrimination at home presented lower BAOP scores, which were stronger among women but not men. No other significant associations were found for weight discrimination in other settings, nor sociodemographic, academic, or body weight-related measurements.

These findings suggest that weight bias towards others is related to weight-based discrimination experiences at home among women but not men. Further research is needed for understanding how experiences of weight discrimination shape prejudiced attitudes toward others and the role of gender in weight bias.

Room 115 - Open

Connecting the everyday harms of smoking to colonialism and its aftermath: plans for a qualitative research project.

Edward Wright, James Heydon

(University of Nottingham)

This paper presents plans for a new qualitative research project seeking to 'connect' (Bhambra, 2014) the harms of smoking to the coloniality of the tobacco industry. Its theoretical grounding is in Wright's (accepted, forthcoming) work on decolonizing zemiology – the study of social harm – in which the harms of tobacco are discussed, amongst a plethora of other social issues. As Wright argues 'underpinning the physical harms of smoking is a colonial arrangement'. The connections between the harms of tobacco in contemporary society and the colonial arrangements that sustain them, however, are not widely acknowledged. This current research extends a decolonial zemiological agenda, but through a focus exclusively on tobacco smoking and the tobacco industry. Overall, the aims of the project are to explore and explain how the harms of smoking are underpinned by colonialism, to understand how this does and does not figure within everyday knowledges on smoking, and to contribute to and shape the public discussion on the harms of smoking, accounting for colonialism and its legacies. To do this, a theoretical account of how tobacco fits within and reproduces colonialism is provided, and following this, plans for a qualitative, empirical research project are outlined. This will include interviews with smokers, and visual/urban ethnographic research, data from which will be analysed in relation to aforementioned theorisation. Through this project, it is hoped that public discourses on smoking as a public health issue are augmented, connecting the harms of smoking to a wider colonial aetiology.

Room G22 – STS & Medicine

Between evidence-based and data-driven health care: Shifting standards, markets and participation practices

Tiago Moreira, Alina Geampana

(Durham University)

What is the relationship between evidence-based and data-driven health care? In this paper, we address this question from a sociological perspective, exploring the epistemic, institutional and political processes that bring each of these types of health care to bear. We draw on the contrast between two empirical cases studies: reproductive medicine, an area where there is increased use of big, user-led data to obtain regulatory approval and capture markets, and evidence-synthesis communities, and how they have responded to the challenge of big data in the last decade to develop new analytics and review methodologies. We propose a model to understand these transformations that focuses on the shifting configuration between market, standards and democratic legitimacy in contemporary health care. Specifically, we argue that data-driven health care poses challenges to the effective balancing between commercial technology development, standardisation and patient-centredness in medicine, whereby existing standardisation configurations are challenged and/or adapted in view of rapid market expansion and the participatory promises of user-led data. In doing so, we highlight where tensions arise between evidence-based-medicine (EBM) imperatives and data-driven health care and locate productive convergence zones. We conclude with a discussion of potential implications for the future of EBM in the age of big data.

Room 144 - Professions

'We came back in the following day and did it all again': Distress and resilience in care homes during the COVID-19 pandemic

Siân Russell, Zoë Cockshott, Rachel Stocker, Barbara Hanratty, Nancy Preston

(Newcastle University)

UK care homes experienced increased resident mortality, rapid policy changes, and restrictions relating to infection control during the COVID-19 pandemic. We explored the impact of these changes on care home staff, via semi-structured interviews with care home carers (n=9), managers/duty managers (n=7), and community nursing staff (n=10).

A reflexive thematic analysis generated three key themes: 1) Emotional impact of working through Covid-19: care home staff experienced anxiety and distress due to uncertainty early in the pandemic; concerns about their own health and that of their families and colleagues, as well as the rapid deterioration and deaths of residents; and significantly increased workload. Adding to this was a belief that care homes were viewed negatively in the media and by the public. 2) Coping Mechanisms: care home staff discussed formal psychological support from their employers and "pulling together" and supporting each other like a "family". Staff were also motivated to keep going due to a sense of duty and the importance of their work. 3) Resilience in a time of crisis: this core theme, informed by the other two themes, is characterised by a continued sense of responsibility and duty towards their work despite growing emotional fatigue as the pandemic continued.

This paper presents insights into the emotional demands of the pandemic on care home staff, their impact, and ways that staff sought to manage them. It also raises wider questions about the often-diminished cultural status of care work, which may have enhanced the distress felt by care staff.

WEDNESDAY 13 SEPTEMBER
15:10-15:40

Room G36 – Pedagogy & Methods

'Knowing me, knowing you': patient-led methodology as an approach for researching health and illness

Amelia Talbot, Laura Heath, Kamal Mahtani, Charlotte Albury

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

Patient and public involvement (PPI) is when patients, carers, organisations representing patients, and the public contribute to the development and delivery of research. PPI has been shown to bolster the relevance of research to patients; it can lower research waste and provide pathways to access participants. On the one hand, studies have shown continual support for PPI from researchers and PPI participants. For example, participants in one study described bringing a fresh, 'insider' perspective of a condition unbenounced to the researchers. On the other, mandates to do PPI have led to persistent critiques of PPI becoming a tokenistic exercise. Indeed, some reviews of researcher perspectives show recurrent concerns around the representativeness of PPI and researchers sharing control over research. In response to these critiques, the late sociologist Rosamund Snow pioneered patient-led methodology. Patient-led methodology refers to research led by people with lived experience of a condition who actively use those experiences in their research. The patient's familiarity with their own experience provides a unique vantage point from which they can understand and recognise important phenomena to be studied and scrutinised. This paper will introduce patient-led methodology, including my (AT) experiences developing and working as a patient-led methodologist. I will discuss how patient-led methodology emerged out of critiques against PPI and discuss the strengths and limitations of the approach. I will end with a call for action for more support for patient-led methodologists and, as Greenhalgh argued, an institute for patient-led research.

Room 135 – Inequalities & Intersectionality

Weight stigma, welfare stigma, and political values: evidence from a representative British survey

Amanda Hughes, Daniel Mcarthur

(University of Bristol)

Obesity-related stigma is increasingly recognised as a public health issue, with implications for the mental and physical health of people with and without obesity. However, little is known about what drives inter-individual differences in obesity-stigmatizing views, and how they vary across the population.

In a representative sample of British adults aged 18-97 (N=2186), we explore predictors of weight-stigmatizing attitudes. We consider demographics, socioeconomic position, factors linked to one’s own weight and health, and beliefs about the causes and consequences of obesity. We explore the role of core political values, and views about welfare recipients, who are frequently linked with obesity in political discourse. Finally, we assess to what extent demographic differences in weight-stigmatizing attitudes are explained by individual BMI, attitudes, and beliefs.

Consistent with previous studies, women were less weight-stigmatizing than men. People in their 50s and 60s were less weight-stigmatizing than younger or older adults. Adjusted for age and gender, an index of weight-stigmatizing views was positively associated with income, and highest in intermediate categories of education and occupational social class. Weight-stigmatizing attitudes were associated with more right-wing values, more authoritarian values, and more stigmatizing views about welfare recipients. Factors including own BMI, beliefs about causes of obesity, welfare-stigmatizing attitudes and authoritarian values contributed to socioeconomic differences.

Weight-stigmatizing attitudes show clear differences between demographic groups, but also vary according to wider social attitudes, beliefs, and a person's core political values. Efforts to reduce weight stigma, and other kinds of stigma, may be more effective if they recognise these links.

Room G31 – Diagnosis, Screening & Treatment

"It's just a feature of mine, like the colour of my eyes": Russian Women Navigate Genetic Risk and Gendered Disposability

Samantha King, Natalia Mukdina

(Queen's University)

This paper responds to the call for scholars to engage with questions of breast cancer risk, genetic testing, and care in local contexts, where the transnational scope of BRCA genetics is differentially enacted and reworked. Our analysis emerges from interviews with thirty-six women from across Russia who were tested for the BRCA 1-2 mutation between 2012 and 2022. We explore how participants navigate genetic risk and responsibility in a context where testing, screening, and preventative interventions are scarce and women feel increasingly disposable. Faced with crumbling healthcare infrastructure, under-resourced doctors who downplay the usefulness of genomic testing, and a sense that "the state wants people like cancer patients just to die," our discussion highlights the ways in which these women attempt to govern their futures and those of their kin. Common approaches, which traverse the socio-economic disparities that characterize our group, include: conducting independent research; seeking private testing and treatment; leveraging unofficial payments, gifts, and family and friendship networks; and traveling within Russia or abroad for services. Here, women emerge as expert consumers committed to managing their vulnerability efficiently, through objectivist biomedical means associated with western modernity and capitalist notions of time. This stands in contrast to their doctors' economically-conditioned investment in common sense and lay knowledge shot through with traditionalist notions of normative femininity and Russian nationhood. In this environment, the identification of a gene mutation is transformed from "just a feature," like the colour of one's eyes, to a way for women to challenge state-sanctioned neglect and disposability.

Room G35 Embodiment & Emotion

Wild Vessels: Gendered Experiences of Recurrent Vulvovaginal Thrush

Tori Ford, Sue Ziebland, Sarah Tonkin-Crine, Gail Hayward, Abigail Mcniven

(University of Oxford)

Background - Seventy five percent of people assigned female at birth will experience vulvovaginal thrush at least once, mostly acute episodes easily remedied with antifungal treatment. However, up to 6% experience recurrent thrush, where symptoms recur over numerous years. These infections can render patients more vulnerable to poor mental health, sexual dysfunction, and disengagement from healthcare. There is a gap in the literature regarding how gender diverse patients understand, prioritise, and manage this condition.

Aim - To uncover how gender relates to experiences of recurrent vulvovaginal thrush.

Method - I conducted in-depth qualitative interviews with 32 people assigned female at birth. This study included women, non-binary, and gender diverse people. I conducted thematic analysis employing a feminist phenomenological lens to understand gendered experiences.

Results - This presentation will explore how patients identify, label, and understand recurrent vulvovaginal thrush through gendered narratives. Existing narratives around gynaecological health often centre around stories of "broken women". Interviews with non-binary and gender fluid people challenge these notions by rejecting traditional gender roles and expectations. Interviewees explored challenges related to the social and commercial understandings of thrush, experiences of seeking care and treatment, and relationships with one's body and self.

Conclusions - This study uses patient voices to fill knowledge gaps and produce research that is informed by and responsive to patient experiences, priorities, and concerns. Presenting this work with conference participants will help us gain feedback on our analysis and further shape our research.

Room 115 - Open

Narratives of health and good parenting among vaccine hesitant mothers in Flanders

Esther Lermytte, Maaike Paredis, Piet Bracke, Melissa Ceuterick

(Ghent University)

Parenting practices and decision-making according to certain expectations and moral obligations have become increasingly important in order to be a ‘good parent’. As the responsibility of health has shifted from the state to the individual under processes of healthism, parents become hypervigilant at managing their child’s risk. Under these conditions, some parents question whether vaccination is the right choice for their child. The literature suggests that these ideologies of responsibility for child health affect mothers in particular. This research aims to study how mothers navigate vaccine hesitancy with regard to discourses around good parenting. Concretely, we want to investigate how accounts of childhood vaccine hesitancy are linked to the discursive identity construction of the ‘good mother’. Critical discourse analysis is used to analyze 15 interviews with vaccine hesitant mothers, elucidating how their accounts of childhood vaccination are affected by broader societal discourses on motherhood and child health and how these societal discourses are then internalized and perpetuated in their discursive construction of the good mother.

Room 118 - Experiences of Health & Illness

Experiences of life with long term conditions in Africa: a meta-ethnography

Nozgechi Phiri, Sally Wyke, Amelia C Crampin, Christopher Bunn

(Malawi Epidemiology and Intervention Research Unit)

Background - Long-term conditions are a growing burden for African countries, producing a ‘double burden’ of non-communicable and communicable disease, placing pressure on already strained healthcare services and communities. A growing body of research has characterized how long-term conditions are experienced across the region, but no syntheses have been attempted. Our study investigates commonalities and differences in experiences of long-term conditions in Africa.

Methods - We conducted a meta-ethnography of qualitative research that presented findings relating to lived experiences of long-term conditions in Africa, following the eMERGE guideline. We searched Embase, OVID MEDLINE, PsychINFO, Allied Health Literature (CINAHL), SocINDEX and African Index Medicus databases. After screening, full texts were coded in NVivo 12 for first and second order constructs, which were analyzed inductively to generate third order synthesis.

Preliminary Findings - Our search identified a total of 8,483 records. After screening, 50 were included in the review. Research addressed experiences of 17 diseases categories in 13 countries. Our preliminary analysis suggests that literature to date offers insight into how people across Africa make sense of long-term conditions, how social contexts shape illness experience, how life with long-term conditions reconstructs the self and how these shape illness (re-)actions.

Preliminary Conclusions - Literature on life with long term conditions across Africa is substantial and there is significant theoretical affinity between this research and established sociologies of chronic illness. However, the diverse contexts covered by the review demand theoretical developments to account for the specificity of chronic illness experiences across African countries.

Room G22 - STS & Medicine

The issues with seeing antimicrobial resistance through the eyes of a fastidious and simple organism

Catherine Will

(University of Sussex)

Mycoplasma genitalium (M. genitalium) is not visible under microscopy: it reproduces slowly so traditional cultures take at least 6 weeks. It is extremely 'simple' yet linked to at least 250 genes. This paper explores the articulation of these bacteria with the history of Neisseria gonorrhoeae (N. gonorrhoeae), exploring cross-national comparisons including research in Scandinavia, Switzerland and the UK. These frame our exploration of how race, racialisation and the global distribution of the bacteria make such research possible and help constitute or enact them as a relevant topic in antimicrobial resistance (AMR). This means taking account of the ways in which when it was 'discovered' it was already resistant to common treatments - like azithromycin and ceftraxione - that are used for N. gonorrhoea, so that currently testing and treating M. genitalium risks intensifying this resistance, explored through the work of John Law and Vicky Singleton on 'new scientific objects'.

We also use work by Solveig Joks (a researcher from the Sámi Artic people) and John Law to consider how global population distributions and colonialism affect M. genitalium, and how better relationships could be produced with Indigenous groups and other minorities, if it were conceptualised as made by minorities, so that more 'care' was shared for the bacteria, by inviting local knowledge into the research and bringing different forms of knowledge together. Finally, drawing again on Law, the methodology is mainly discourse analysis of scientific papers, supplemented with interviews with some of the key actors in each of the relevant countries.

Room 144 - Professions

'That little someone in your ear saying you've got to discharge all these patients': community health professional's negotiation of patient self-management and the 'return to scripture'

Hannah Kendrick

(London School of Economics and Political Science)

Health policy in the UK and internationally has increasingly placed focus on patients taking greater responsibility for self-managing their conditions. Sociologists have explored the way in which 'responsiblised' and 'enterprising' identities are constructed for patients, encouraging them to make well informed and self-sufficient decisions about their health, as well as how health professionals, acting as 'pastors', attempt to shape these desirable patient subjectivities. This paper draws on ethnographic data collected within a community based integrated care (CBIC) service in England (see: Kendrick & Mackenzie, 2023), to explore how staff were encouraged to seek out and eliminate 'waste' from the service by discharging patients to self-management. Drawing on Foucault's (2007) notion of 'counter-conduct', I demonstrate how these 'pastors', faced with an increasingly frail and vulnerable elderly population, made a 'return to scripture' by reaffirming their professional values and emphasising the importance of care. Particularly, senior community nurses were found to intervene to guide junior staff away from too stringent enforcement of self-management. This paper contributes by exposing the complex and relational nature of how pastoral subjectivities are constituted within community health teams, as well as ethical dilemmas faced by staff responding to organisational efforts to reduce caseloads under conditions of austerity.

Foucault, M. (2007). Security, territory, population: Lectures at the Collège de France 1977-1978 (G. Burchell, Trans.). London: Palgrave-Macmillan.

Kendrick, H., & Mackenzie, E. (2023). Austerity and the shaping of the 'waste watching' health professional: A governmentality perspective on integrated care policy. SSM - Qualitative Research in Health, 3, 100255. https://doi.org/10.1016/J.SSMQR.2023.100255

15:45-16:15

Room 155 – Citizenship & Health

‘Hold the door open’ – Inviting older adults to shape the dissemination of health research

Taru Silvonen, Hannah Christensen, Carmel Mcgrath

(University of Bristol)

UK has an ageing population which makes it essential to ensure health research activities are inclusive of older adults. Yet, older adults have been shown to shy away from active roles in healthcare due to perceived limited capability for meaningful contribution. Patient and public involvement (PPI) can further the inclusion of older adults by increasing awareness of ways to get involved beyond conventional research participation.

This paper shares reflections from a completed patient and public involvement (PPI) project. The ‘Hold the door open’ -project aimed to expand PPI practices to the dissemination of research findings by inviting people aged 55+ to co-design dissemination activities with researchers. The innovative UK-wide project is examined in this paper through the lens of citizen participation. Encouraged involvement through a range of activities supports moving towards partnership between researchers and older adults instead of tokenistic PPI that focuses on meeting the demands of research funders.

The project combined three approaches: (i) an online questionnaire to scope what activities older adults enjoy; (ii) online planning workshops to support co-designing community events; and (iii) community involvement events to share research findings. These three approaches combined digital and in-person activities and were carried out in four locations across the UK between December 2021 and February 2023. Drawing on Arnstein’s ‘ladder of participation’, the paper shows how the PPI activities gradually encouraged increased involvement, moving from seeking and sharing information to shaping activities with older adults.

Room 135 – Inequalities & Intersectionality

“It's like, if I'm not trans, I'm suicidal. If I am trans, we're not safe. So either way it feels life and death"

Steph Busby, Liz Price, Kay Brady, Paul Whybrow

(Hull York Medical School)

This paper presents some of the emerging key findings from a PhD project on trans peoples experience of homelessness and health. Trans people in the UK have a disproportionate level of homelessness compared to the general population and the reasons for this are complex. Trans studies and homelessness are growing areas of research, cutting across several disciplinary boundaries; with politics, inequalities and health often being front and centre. Health can be widely impacted by homelessness with research demonstrating an increased likelihood of systemic conditions, chronic pain, mental health disorders and infectious disease in people who are experiencing/have experienced homelessness. In addition, global research shows trans homeless people are more likely to have gender dysphoria, chronic mental health conditions, have a disproportionately high risk of HIV and continued detectable viral load. Much of this data is quantitative and there is a paucity of UK based qualitative data.

This research explores the relationship between being trans and experiencing homeless to better understand the health experiences of this marginalised group. Using reflective narrative methodology as a tool for understanding experiences over a life course, the project uses storytelling, timeline mapping and object elicitation to further understand how housing, health and gender interact.

Room 115 - Open

Prostate cancer-literacy through the mass media in Japan, a reading of cultural scripts

Genaro Castro-Vazquez

(Kansai Gaidai University)

In a country where cancer has been dubbed a ‘national disease’ (kokumin bio) that mostly affects Japanese men, this paper presents a reading of the cultural scripts underneath prostate cancer—one of the ‘Western type of cancers’ (ōbeigata no gan). The reading is grounded in an adaptation of the ‘sexual scripting theory’ (Gagnon & Simon, 2005), the construct of cancer-literacy, and the analysis of 3,092 newspaper reports published from 2005 to 2020, in three Japanese newspapers with the largest circulation in the country. The analysis is presented in line with three axes: cancer-self, cancer-biopedagogy and cancer-economics to indicate that a cancer-self largely entails the subjectivity of a Westernised, married, heterosexual man who undergoes andropause, needs to understand what bladder somatics is, and depends on his family and the feminisation of care to cope with cancer. The chances to prevent and/or survive the disease chiefly hinge on adopting a form of cancer-biopedagogy, which entails a composite entanglement of knowledge and health-related practices underpinned by the ethnicisation of cancer through the consumption of ‘traditional food’ (washoku) and the assumption that turning into a ‘healthy self’ is determined by Japanese ethnic traits. Cancer-economics is concerned with costs of testing and treatments, health care insurance policies, and food and dietary supplements that serve to commodify a cancer-self who deals with prostate and urinary-related issues.

Room 118 - Experiences of Health & Illness

The experiences of people living with head and neck cancer.

Anna Rajakumar, Sasha Scambler

(King's College London)

This ethnographic study involves an exploration of the journey from diagnosis through to rehabilitation, for people with Head and Neck Cancer (HNC). Documentary analysis, observations and in-depth interviews were used to explore the experiences of people receiving care from the Southeast London Community Head and Neck Cancer Team (CHANT). To capture the macro view a document analysis of cancer policy documents was carried out, observations of key settings provided a meso level analysis and the individual narrative was captured through in-depth interviews (micro), focussing on cultural schemas and attitudes around mind and body.

The urgency of diagnosis, the effects of radiotherapy and the impact of loss of function on the whole self post-treatment were identified as key themes in the data. Whilst these themes align with existing sociological research around cancer experiences there are elements within HNC which are uniquely traumatic. These include the process and side effects of receiving radiotherapy to the face, extensive pre-treatment dental extractions and the impact of treatment on basic functions such as swallowing, eating, communication and movement.

This study provides a new, and in-depth, insight into the experiences of people receiving care for HNC that is currently lacking in the existing literature. The results capture the noise and urgency of the initial stages of treatment and provides a uniquely contextualised account of the biopsychosocial impacts of treatment and rehabilitation. This patient experience study can be used create and/or reform patient centred practices in this area.

Room 144 - Professions

When the Penny Drops: Understanding Socially Stratified Careers in the UK Medical Profession

Louise Ashley

(Queen Mary University of London)

In the UK, medicine is both socially exclusive and socially stratified as doctors from more advantaged backgrounds are more likely to train for specialities with more competitive entry. Within the profession, a tendency for doctors from less advantaged backgrounds to take-up jobs in underserved specialities and locations has been posited as a useful way to fill related shortages. While pragmatic in one sense this hints at exploitation if people with social identities constructed as 'lower' status are seen as a more obvious 'fit' for less competitive roles. In this article, we consider how social class influences speciality choice, based on a longitudinal study following thirty medical students from working-class backgrounds as they negotiate medical school and early careers. Theoretically, we draw from Bourdieu's 'theory of practice,' which shows how forms of capital informing an individual's socio-cultural outlook and dispositions internalised as habitus contribute to the reproduction of professional (dis)advantage. Bourdieu's work has been accused of structural determinism, though we argue this is likely where analyses draw on his core concepts in isolation, rather than interrelated. We apply his framework in this more inclusive sense, using narrative analysis focusing on two interviewees, to show how classed habitus constraints speciality career, though not in a predictable or deterministic sense. Our analysis confirms the value of habitus as a research tool, offers practical insights to ensure speciality positions are allocated on equitable grounds, and suggests urgent questions for future research, as the UK medical profession continues to diversify while working conditions deteriorate.

WEDNESDAY 13 SEPTEMBER
16:20-16:50

Room 155 – Citizenship & Health

Designing Homes for Healthy Cognitive Ageing: Gaining insights into residents' use of home, changes, and related decisions in ageing through home mapping

Martin Quirke, Sadhana Jagannath, Mary Njoki, Cate Pemble

(University of Stirling)

Designing Homes for Healthy Cognitive Ageing (DesHCA) is a research project based at the University of Stirling, funded by UK Research and Innovation. DesHCA aims to identify how homes can enable people living with cognitive change to live as they wish for longer. It combines the perspectives of older people and a range of housing professionals to investigate what is desirable, practical, affordable and scalable in designing or retrofitting new and existing homes.

This paper presents initial findings from a creative home mapping activity with 50 older people experiencing cognitive change. It explores their likes and dislikes about their homes, what they have changed, would like to change, or would be willing to change. Collage, photography, home tours and semi-structured interviews were used to gain insights into how people think about and use their homes as they get older.

We provide insights into participants' experiences and perspectives concerning changes within the home and in considering moving house. Firstly, we discuss the significance of the different terms of 'adaptation' and 'change' in understanding participants' reflections about their homes. Secondly, we present data on the temporal aspects of participants' reflections, including the influence of past lifecourse experiences and anticipated futures on decision making. We suggest that paying close attention to these dimensions can shed light on 'disconnects' between people's desires as they age and housing and design professionals' assumptions.

Our analysis will improve understanding of how to enable people to live better with cognitive change as they age.

Room 115 - Open

"If you've just been arrested, how compliant are you to being sensible and honest to questions": Police custody healthcare risk assessment as site of detainee resistance

Gethin Rees, Stephanie Mulrine

(Newcastle University)

Against a backdrop of reduced care and social services, it is often the police who are the first providers of healthcare, especially in cases of mental health crises. Given this context, our paper aims to explore the ways that employees in police custody suites (police officers, civilian detention officers and healthcare professionals) collaborate to provide adequate care to persons in custody (potentially in mental health crisis and/or other forms of healthcare needs) even when (as the quotation suggests) they are not convinced they have full healthcare information.

This ESRC funded mixed-methods project is presently in the data collection period. Data is collected from in-custody risk-assessments, ethnography and interviews with healthcare professionals, detention officers, police officers, and from those with lived experience of being detained in police custody. This paper will explore the performance of the police healthcare risk assessment as a detainee arrives in custody. In particular the negotiations between the Custody Officer and detained person as the former attempts to avoid a death in custody during the period of detention. The risk assessment is performed in a largely public space and requires the declaration of any health conditions (including intoxication). In this heavily-charged interaction, how do law enforcement ensure they gather sufficient information to limit risk? While at the same time, the detainee assesses their own risk of discomfort and suffering, and strategise to accelerate a preferable outcome. This paper problematises how healthcare histories can be assembled in criminal justice contexts.

Room 118 - Experiences of Health & Illness

Digital Illness Narratives: Exploring the Illness Experiences of Black Women with Sickle Cell on TikTok

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There is a research gap surrounding the digital illness narratives of Black people in the UK. This paper aimed to understand how illness-related content was created and shared on TikTok by Black women living with Sickle cell disease (SCD) in the UK and how online peer-to-peer connections and support were established with other users .52 TikTok videos from four creators were collected and analysed. Creators presented their illness experiences in a multimodal way which sometimes featured intimate, unedited videos of the physical manifestation of an internal sickle cell crisis to their audiences. Whilst some experiences were presented in a comedic way through how the videos were worded, expressions, body language, and audios used. Black British/African/Caribbean culture-specific expressions and idioms shaped the content of creators' digital illness narratives. The themes found were in line with master narratives found in research on living with chronic illness. Themes of the invisibility of their illness, the challenging of misconceptions, the disruption SCD had in their lives, and how SCD shaped their identities through the identification with war/military metaphors using hashtags such as #sicklecellwarrior and #sicklecellwillnotdefeatme. Although this study only focused on SCD, it illuminates the potential value of TikTok data for health and illness research more broadly.