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Abstract Book

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WEDNESDAY 11 SEPTEMBER

13:25-13:55

Room 0.08 – Experiences of Health and Illness

Delegitimation, stigma and multiple selves: How (perceived) limited understanding of endometriosis amongst significant others shapes women's lived experiences

Caroline Law, Nicky Hudson, Lorraine Culley, Elaine Denny

(Centre for Reproduction Research, De Montfort University)

Sociological scholarship has long attended to the significance of social networks in matters of health and illness. Yet social science research into endometriosis commonly explores individualised experiences. Despite recent enquiries into couples' experiences and the relational impact, explorations of how endometriosis intersects with family, friends and wider social networks have been less thoroughly developed. This paper builds on existing endometriosis literature which highlights the lack of societal understanding, loneliness and isolation those with the condition experience, to provide an in-depth exploration of (perceived) limited understanding of partners, family and friends and the implications of this for interactions with others and for individuals' sense of self. It draws on findings from the ESRC-funded ENDOPART study, in which women with endometriosis and their male partners took part in qualitative in-depth interviews (n=44). It explores women's perceptions of how the enigmatic, unseen and variable nature of endometriosis affects how significant others (partners, family, friends) view the condition, how this shapes their interactions and the implications of this for women's lived experiences. It considers these findings in relation to Goffman's theories on dramaturgy, the self and stigma, as well as ideas regarding threatened bonds and in/authenticity in social bonds (Lewis et al 2023) and the ontological demands that arise regarding the multiplicity of self (Ekendahl et al 2022). It explores how perceived limited understanding amongst significant others can give rise to disbelief and delegitimation of the condition and its impacts, and can call into question self, character and personality of those living with endometriosis.

Room 0.17 – Health Service Delivery

Ward rules, privileges, and cultures of control: The intersections of race, gender, and class in the care of people living with dementia

Shadreck Mwale, Katie Featherstone, Andy Northcott

(University of West London)

Recent sociological research has raised important questions about the need for improving care for people living with dementia (PLWD) in acute hospital settings. Drawing on a 5-year multi-sited NIHR funded hospital ethnography, this paper examines everyday cultures of care in acute hospital wards to interrogate how race, gender and class intersects to shape the care of older PLWD. Drawing on Hill-Collins' concept of intersectionality and the relational nature of power, the analysis reveals that, while cared for by a diverse team of healthcare professionals, a patients' age, race, gender, and class, as interconnected categories appeared to influence the tightening of ward rules for some patients and the granting of significant privileges for others during and across shifts. Focusing on walking within the ward, with a large number of older people and PLWD classified as 'wandering' or displaying 'wandering behaviours', the paper explores ways in which intersectional identities informed who was allowed to leave the bedside, 'wander' the ward, and who was restricted to the bed or bedside. The paper concludes that understandings of behaviour, and how racism and attitudes to gender, class, and ageing,

permeate the routine everyday organisation and delivery of care in acute hospital settings have significant implications for PLWD.

Room 0.13 – Pedagogy and Methods

Improving care and support for survivors of sexual violence: Prospectively applying Ostrom's principles as a methodological innovation to foster sustainable collaboration

Bertil Lindenfolk, Helena Kilander, Glenn Robert, Oli Williams

(School of Health and Welfare, Jönköping University)

This paper explores whether the prospective application of Elinor Ostrom's core design principles within an Experience-based Co-design (EBCD) process facilitated multi-actor collaboration to improve care and support for survivors of sexual violence. Survive was a 12-month project bringing together organisational actors in a Swedish county from a wide range of sectors (health, education, law, social care, third sector, local government). EBCD provided an inclusive and collaborative approach to achieve this aim. However, there were concerns about sustaining the engagement of this disparate collection of actors in a new initiative. To address these concerns, a methodological innovation drawing on Ostrom's 8 core design principles for collaborative group working was applied within the EBCD process. To enhance sustained collaborative working, a design facilitator tailored tools and exercises drawing on the principles and applied these at intentional points during the co-design process. Sixty-two participants from multiple organisations took part in surveys, interviews, focus groups, co-design workshops, and co-design teams. Twenty-eight participants working in three co-design teams met monthly over a 4 month period with full participation - no withdrawals. The co-design teams: (1) created structures to encourage innovation within and between organisations; (2) raised awareness of the importance of recognising survivors of sexual violence; and (3) supported individual professionals to identify and engage with survivors. This paper focuses on the engagement and sustainability of the newly created Survive network to critically reflect on the potential usefulness of applying Ostrom's principles in the context of other multi-actor co-design processes aiming to improve public services.

Room 0.18 – Diagnosis, Screening and Treatment

Evidencing a suicide epidemic: Logics and practices of documenting suicides in Tharparkar, Pakistan

Laila Rajani

(University of Edinburgh)

Public health scholarship on suicides in Pakistan have heavily relied on the myriad sources of data to argue that certain parts of the country have a suicide 'epidemic' or 'crisis'. These proclamations have mobilized aid, monetary and technical, garnered local and international attention, and solidified Tharparkar's image as a destitute hinterland of the country. Yet, little is documented and said about the veracity of the evidence that undergirds these proclamations. A few attempts have taken place by public, development, and media organisations to address the need for evidence to back up the mental health interventions in the country and specifically Sindh. These attempts form an interesting site to examine intersections and engagements between various actors as well as their politics and understandings surrounding mental health.

The paper outlines the practices and logics of such efforts to document suicide-related evidence by public health actors in Tharparkar including a psychological autopsy of suicide cases in 2020, and the newly appointed statistics office at the district level in 2022. This evidence and datafication of suicides

seek to illuminate certain realities and obscures others. Using the concept of data performativity (Tichenor, 2017), I examine the precarity of not only the evidence produced but also its producers and beneficiaries. Against the milieu of the ever-shrinking health budget of Sindh's provincial government, the evidence plays a crucial role in protecting livelihoods of the staff who documents it, and ensuring the survival of the wider health infrastructure that depends heavily on the funding from global health institutions.

Room 0.19 – Open

Self-care and breathlessness: Minimising the threats of self-care in the PrimaryBreathe co-design study

*Sarah Hoare, María Goodall, Lindsey Berends, Cheryl Chapman, Jonathan Mant, Anna Spathis
(University of Cambridge)*

Breathlessness is a pervasive, debilitating and often frightening symptom. The conditions which cause it are typically stigmatised (including lung cancer and COPD) and breathless individuals often experience shame about their breathlessness and the adverse consequences it has on their life. PrimaryBreathe is a non-pharmacological intervention aiming to help people with persistent breathlessness to better manage their symptoms. Underpinned by palliative care principles and developed from an effective secondary care model, PrimaryBreathe is currently being tested in primary care.

In this presentation I will consider how the PrimaryBreathe self-management approach to breathlessness is being successfully used with breathless people and seemingly navigating around expected problems associated with self-care (such as challenges with 'empowerment', the 'responsibilisation' of patients and the displacing of their knowledge for 'approved' alternatives). Drawing on my thematic analysis of interviews I conducted with 40 PrimaryBreathe participants in 2023-24, I will explore how those involved addressed the moral challenges of having breathlessness and learning/teaching approaches to manage it. Participants' narratives of breathlessness were of unhelpful 'natural' bodily responses that a breathless individual could learn to overcome and control with appropriate clinical support. I argue this approach allowed breathless individuals to recognise and distance themselves from self-taught breathlessness management attempts that they described as 'bad habits', and to adopt 'good' alternatives in a way that limited (but did not entirely preclude) moral judgement of themselves. I hope to explore whether and how PrimaryBreathe's palliative care foundations enabled it to minimise the threats of self-care to breathless individuals.

WEDNESDAY 11 SEPTEMBER

14:00-14:30

Room 0.08 – Experiences of Health and Illness

Researching post-mastectomy narratives

Jacqueline Cochrane

(Faculty of Arts and Social Sciences, Open University)

Clinicians have a growing interest in qualitative research on women's experience of health, illness, and recovery, as it supplements physiological and functional perspectives. Such research can provide vital information on the impact of medical treatments, such as mastectomy, on women's lives during physiological recovery and beyond.

Mastectomy following breast cancer is an area of importance not only within medical and scientific fields, but also for sociologists and social psychologists because of its relevance to body image, and self-identity.

Research conducted in social, health, medical, and nursing research has tended to focus on inpatient experience, and the immediate aftermath of surgery. The project presented in this paper, supported by the Grand Union Doctoral Training Programme, investigates the impact of mastectomy on women's lives beyond physiological recovery. The research explores lived post-mastectomy experiences with a focus on narrative and meaning making. Mastectomy is approached as a 'narrative disruption' potentially troubling narratives of the body and self, and therefore requiring women to engage in a process of narrative re-negotiation.

Data were collected in UK interviews with twenty-six women aged between 25 and 55 years old. All participants had undergone a mastectomy as treatment for breast cancer, and were a minimum of six months post-mastectomy, and no longer requiring any further treatment. Data from the interviews and additional found data are analysed following a critical discursive approach from social psychology. The paper will present an initial analysis of findings to show the complex impacts of mastectomy that persist beyond physiological recovery.

Room 0.17 – Health Service Delivery

The rhythms of the ward: Using rhythm analysis to understand the experiences of care for people living with dementia across an acute hospital admission

Andy Northcott, Paula Boddington, Katie Featherstone

(Geller Institute of Ageing and Memory, the University of West London)

This presentation posits Henri Lefebvre's concept of Rhythm analysis as a novel methodology for observing and understanding the everyday life of the hospital ward. To do so we draw on observational data taken by the authors across three NIHR funded multi-site studies of acute NHS hospital wards in England and Wales (25 wards across 14 hospitals) between 2015 and 2024, exploring resistance to care, continence care and the everyday use of restrictive practice.

This data demonstrates how analysis of the rhythms of the ward, and the arrhythmias that manifest around patients, allow us to develop a detailed and embodied perspective of how the ward is experienced by the many different actors within it. We focus on one particular group, people living with dementia, considering how they fit both within and outside the rhythms of the ward, and the dressage

required by staff to maintain those rhythms, and how these actions create new arrhythmias across everyday care.

We conclude by discussing rhythm analysis as a means to observe underseen aspects of hospital care and pressures on both patients and staff within them. We discuss the value of rhythm analysis for researchers when exploring hard to define concepts such as power, personhood and dignity within the ward setting.

Room 0.11 – Lifecourse

Knowing you, knowing me? Egg donation, ‘medical need’ and the limits of donor anonymity

Christina Weis, Jessica Turner, Sara Lafuente, Veerle Provoost, Lara Jacxsens, Nicky Hudson, Lei Decappelle

(De Montfort University)

The use of donated egg, sperm and embryos in fertility treatment has grown exponentially in recent years and has been accompanied by a continued debate about the circumstances under which donation should take place, including whether donors should be anonymous or identifiable. Within Europe, a patchwork of regulatory approaches exist, with some countries outlawing anonymity entirely (including the UK) whilst others insist donors’ identities be concealed. Part of the rationale for making donors identifiable is that donor-conceived people have a right to knowledge about their ‘medical history’ and even in countries where donors are anonymous, there are often requirements that donors become de-anonymised in the case of ‘medical need’. However, there is an absence of research which explores how differing donation regimes manage the complexities of identifiability in relation to health information, and the impact of differing approaches on the experience and perceptions of donors.

This paper reports on data from the ‘EDNA’ study which explored the social, political and economic context of egg donation in Europe. We interviewed 75 egg donors from three European country cases: the UK, Spain and Belgium, where anonymity is regulated in differing ways. We describe how donors in these countries framed their reproductive and medical responsibilities to people conceived via their eggs, ranging from the possibility of becoming a living tissue donor, to one of medical information provider. Our research demonstrates the ways in which constructions of ‘medical history’, ‘medical need’ and ‘reproductive responsibility’ are shaped and situated in specific national and sociotechnical contexts.

Room 0.13 – Pedagogy and Methods

Researcher, mediator, mother, advocate or activist? Exploring shifting researcher identities and positionalities in rare disease research

Catherine Coveney

(Loughborough University)

There has been much written regarding how researcher positionality and identity shapes the research process and researchers’ relationships with research participants. However, much less attention has been given to how the research process, and in particular, collaborations between academic and non-academic communities in the pursuit of generating impact from one’s research, reshapes researcher identity and positionality. This becomes more pertinent amidst continued calls for academics to demonstrate the societal relevance and practical applications of their work.

I analyse three different collaborations I curated to generate non-academic ‘impact’ from my sociological research on family’s experiences of living with rare genetic disease with:

i) a patient organisation (with murky connections to big pharma)

- ii) public relations team and media
- iii) artists

I reflect on the complex entanglements of identities and subject positions each collaboration engendered. As different expectations, interpretations, motivations, and interests merge – sometimes aligning and at other times conflicting - important questions emerge about power and control, ownership and accountability, liminality and whose interests are being served in the quest for impact.

Room 0.18 – Diagnosis, Screening and Treatment

Futures with Cancer: Exploring Risk and Help-seeking Narratives Following an ‘all-clear’ Cancer Diagnosis

Chloe Phillips

(University of Oxford)

While the development of new cancer diagnostic pathways is motivated by a desire to identify more cancer sooner, understanding of their unintended consequences remains limited, particularly for patients who are found not to have cancer. Andersen highlights that the national and international policy focus on cancer control has both prolonged life with cancer and altered the temporality of life at risk of cancer.

This paper draws from the experiences of patients who used the Oxford SCAN pathway, meant for patients who present to their GP with vague symptoms, who are then offered the opportunity to have multiple, non-invasive tests to assess the likelihood of cancer.

While there is established sociological literature exploring how experiences of cancer screening impacts perception of risk, there is limited work on diagnostic pathways which aim to rule out cancer from numerous other diagnostic possibilities for symptomatic patients – and the impact of this on newly imagined futures of cancer following referral to these pathways.

Addressing this gap, I examine the impacts of an ‘all-clear’ cancer diagnosis and subsequent safety netting advice in 25 patient interviews. I analyse their help-seeking narratives and their understanding of cancer risk to focus on how an ‘all-clear’ cancer diagnosis shaped imagination and anticipation of futures with cancer.

This work illuminates the unintended consequences of a rapidly changing cancer diagnostic landscape, particularly how this relates to the concept of ‘chronic living’ proposed by Heinsen and colleagues. Through this sociological lens, valuable insights can be provided to inform an NHS priority issue.

Room 0.19 – Open

“I think you get, not brainwashed ... but I think something changes in you ... God knows why to be honest, some magic hormonal thing”: Mothers’ perceptions of the relationships between post-partum hormonal shifts their parenting behaviours, beliefs, and wellbeing.

Hilllary Collins, Daniel Wight, Shona Hilton

(University of Glasgow)

Medical literature details the dynamic levels of various hormones perinatally and makes associations between these endocrine shifts and maternal behaviour and affect (Mileva-Seitz and Flemming, 2011; Thul et al, 2020). Recently, sociological analyses of understandings of hormones (Roberts and McWade, 2020 and Ford et al, 2024), have referenced key STS concepts of Actor Network Theory and

Harraway's Cyborg Theory. This paper aligns with these sociological analyses but takes an emic approach with the aim of gathering personal and cultural insights into perceptions of how hormones influence perinatal experiences.

The presentation is based on semi-structured interviews with 23 mothers of young children about their parenting beliefs and practices and how they perceived these impacted on their wellbeing. Transcripts were analysed using thematic (Braun and Clarke, 2006) and framework (Gale et al, 2013) analysis. The mothers were not asked directly about hormones, but the subject was raised by several of them and developed inductively as a theme during analysis.

In the comments of some mothers, hormones are cited as an explanation for deviations from their expected rational thinking or behaviours, for not feeling like 'themselves'. However, if these hormones are not of the self, how should they be understood? One possibility is to view the body as distinct from the self, that hormones act as non-human agents on interpersonal and intrapersonal relationships. Alternatively, hormones could be seen as chemical remnants of experiences such as pregnancy and childbirth, or even as something belonging more to their child than to mothers themselves.

Room 0.20 - Inequalities and Intersectionality

Older people's accounts of racism in UK healthcare settings: Initial findings from the Frailty & Ethnicity study

Victoria Cluley

(University of Nottingham)

The Frailty & Ethnicity study aims to explore the intersection between old age and ethnicity as an alternative entry point to understanding health inequality in the UK. There is relatively little sociological research to address this intersection. Combined with the realities of a diverse ageing population in the UK, more research is required to work towards the improved healthcare of frail older people. In response to this, the findings of the Frailty & Ethnicity study will be used to co-produce a frailty screening tool and a training module for NHS staff involved in the care of older people. In this presentation I will share initial findings from the photovoice element of the study. Following the participatory action research ethos of photovoice, this element of the study aimed to capture older people's experiences of health and ageing in order to develop a training module grounded in lived experience. This work involved 73 older people across six different ethnicities. Over 1000 photographs were shared and over 200 hours of talk recorded. Myriad topics were shared and discussed, resulting in a holistic yet nuanced depiction of health and illness experience. The everyday experience of racism in healthcare provision is one such topic that was initiated by participants and discussed in depth. Here I will provide examples from the study, using the concept of intersectionality to think through the participants' accounts.

WEDNESDAY 11 SEPTEMBER

14:35-15:05

Room 0.08 – Experiences of Health and Illness

The gap between political fertility narratives and women’s lived experiences: An example from India

Alankrita Anand

(University of York)

India’s fertility rate has recently been found to have fallen below the replacement level of 2.1 children per woman. Although regional variations remain, the drop marks a significant milestone in the country’s post-independence population growth history. Fertility in India, and in other global south contexts, has historically been entangled with anxieties around women’s sexuality and status, and culture and tradition, sustained by the lasting logics of population control and stratified reproduction, which are promoted by both national governments and transnational agencies. Most recently, Prime Minister Narendra Modi has alluded to India’s Muslim population as ‘those who have many children’, re-amplifying the majoritarian rhetoric that the Muslim minority of 14.2 percent will outnumber the 79.8 percent Hindu population. The fertility rate among Muslims in India is the highest among all religious communities but it has also registered the steepest decline among all religions in recent decades.

My qualitative study on household dynamics and young married women’s access to care in India shows how women negotiate fertility and family planning at the level of marriage and the marital household, and in this paper, I use my findings to illustrate the gap between the rhetoric that certain social groups deliberately maintaining high fertility rates and women’s lived experience of navigating gendered relations, social norms, and sexual consent. The paper is based on my doctoral study comprising 38 in-depth interviews and 7 focus group discussions with women aged 16-28 in Bihar, the state with the country’s highest fertility rate of 3.1 children per woman.

Room 0.17 – Health Service Delivery

Conceptualising Preparation for Surgery: Experiences from a co-design study into preparation of patients undergoing amputations

Esmee Hanna, Sasha Loyal

(De Montfort University)

In this paper we seek to advance the notion of preparedness in the context of healthcare, extending its current usage in relation to disaster and emergency planning in healthcare, into its potential value for patient centred approaches to care. This paper draws on recently completed ethnographic observations of ward rounds, as well as 48 semi-structured interviews with a broad range of healthcare professionals (n=29) and vascular patients undergoing amputations (n=19) conducted in two hospital sites in England. Through utilising vascular surgery as a case study, we examine what good preparation for surgery may entail, proposing that preparedness can be conceptualised through a model of the “three C’s”- Context, Communication and Collaboration. We argue that through assessing preparation of patients in this way, it could help healthcare services to better identify potential gaps in care, empower staff to support patients in meaningful ways, and improve the experiences and, potentially the outcomes, for patients themselves. We argue that the concept of preparedness as detailed in relation to macro events, through its focus on resilience, recovery and response capability, has much to offer for advancing quality improvement within healthcare settings. Whilst our findings speak of how this model could be used to

assess and improve care in relation to surgery, it offers broader potential for how preparedness could be integrated into patient centred approaches to care in the future.

Room 0.11 – Lifecourse

Frozen not thawed: Why are so few women returning to use their previously frozen eggs in fertility treatment?

Kylie Baldwin

(De Montfort University)

Despite being expensive, not risk free, and a somewhat controversial reproductive technology which offers no guarantee of a live birth, social egg freezing has seen a vast increase in the number users in the UK and other western countries over the past decade. Sociological research has provided valuable insights in to the motivations and experiences of users who use this technology in a bid to secure their reproductive futures. However, whilst growing numbers of women are 'banking' their fertility for future use, current evidence shows only a very small number ever return to their eggs in an attempt to conceive. Furthermore, a legal change in 2022 means that, in the UK, these eggs can now be held in 'suspended animation' for up to 55 years. Currently very little is known about why such small numbers are returning to use their eggs to conceive, how women view their frozen reserve or what they would do with their eggs should they not need, or use, them in fertility treatment. Drawing on qualitative interview data with users of social egg freezing and using sociological theories from family and parenting culture studies, this presentation will seek to address these currently unanswered questions and will consider the extent to which social egg freezing may not be, as is sometimes assumed, 'buying' women more time to pursue normative expectations of motherhood, but instead providing them time to pursue alternative visions of (non)motherhood.

Room 0.13 – Pedagogy and Methods

Navigating the complexity of peerness: Examples and reflections from participatory research into minoritised experiences of MS care

Sharifa Battashi, Alison Thomson

(Queen Mary University of London)

People from ethnically minoritised backgrounds in the United Kingdom continue to be disproportionately impacted by health inequalities and under-representation in research. In Multiple Sclerosis (MS) research, the voices of people with MS from Black British and South Asian backgrounds remain under-represented despite forming a significant proportion of MS patients. Our participatory study uses a peer research approach to develop a deeper understanding of the needs, preferences and challenges to care faced by ethnically minoritised people by engaging their experiential knowledge in the research process. Peer research has the potential to empower these people to take part in research and attempt to reduce power imbalances between researchers and participants. Conceptually, research shows that peer researchers use their 'peerness' or relatable experiences to generate rich, contextual understanding through the power of shared characteristics. However, working with peerness in practice does not come without challenges. While it seems a key advantage to develop a nuanced understanding of participants' experiences, the intersectionality, and situatedness of peerness in practice add layers of complexity to the research process. In this paper, we reflect on the empirical and epistemological messiness of peerness when working with 5 peer researchers, who share similar ethnic and health related backgrounds, in our study. We argue that working with peer researchers and asking them to contribute their experiential knowledge involves messy and power-infused relationships which are not easy to navigate due to further intersecting categories of gender, disability, professional expertise and education.

Room 0.18 – Diagnosis, Screening and Treatment

Escaping liminality: A qualitative exploration of the journey to heart failure diagnosis

*Clare Goyder, Clare Taylor, Nikki Newhouse, Catherine Pope, Richard Hobbs, Lisa Hinton
(Nuffield Department of Primary Care Health Sciences, University of Oxford)*

Studies show missed opportunities for heart failure (HF) diagnosis in primary care, but the impact of these on patient experience is poorly understood. This study explores the experience of HF diagnosis and aims to develop recommendations for clinical practice. We conducted remote, semi-structured interviews with 24 people. Data were analysed thematically and informed by theories of liminality (Gennep 1960), biographical disruption (Bury 1982) and the sociology of diagnosis (Jutel 2009). We developed three themes: liminality and suffering at the threshold of diagnosis; meaning and framing in the diagnostic moment, and truth-telling and sense-making in the escape from liminality. Participants described a liminal existence at the threshold of diagnosis: they were unwell but not diagnosed or not aware of the diagnosis. Although receiving the diagnosis brought relief, it also came as a shock due to the meanings associated with the term 'heart failure'. Some thought HF meant imminent death and was incompatible with living. Participants also described not being properly informed about the diagnosis (e.g. hearing of the diagnosis indirectly or via a letter). Life was disrupted by a HF diagnosis, but the diagnosis did not facilitate a transition from liminality. Truth telling, in combination with careful explanation enabled the escape from diagnostic liminality. Through sense-making, participants were able to build an understanding of what HF diagnosis actually means for them and their future. General Practitioners and cardiologists have a vitally important role in helping patients to escape from diagnostic liminality through prompt HF diagnosis and patient-centred communication.

Room 0.19 – Open

A new era: Changes to informal caring relationships with people with dementia- a qualitative interview study

*Sasha Lewis-Jackson, Suzanne Li, Sue Ziebland
(University of Oxford)*

Current shifts in familial relationships due to social circumstances such as not having a spouse and children, caregiver's health and living geographically far from family have all caused gaps in the provision of informal caregiving.

This paper aims to explore how caregiver relationships are established and navigated when pre-existing relationships with the person living with dementia (PLWD) or other family members are strained, geographically distant and repurposed to deliver care.

We conducted a narrative interview study that aimed to explore caregivers' experiences of caring for a PLWD. Throughout these interviews, it emerged that a number of our participants were in unconventional caregiving relationships whereby they became caregivers because there was not an appropriate or willing caregiver available. We began to refer to these participants as 'default carers'.

We found that how default relationships emerged varied, with participants being an only child or having siblings not involved in caregiving to be the most common factors. These default carers often had to renegotiate relationships with the PLWD or other family members to help facilitate effective care. For many, this was difficult, as they lacked closeness within these relationships due to being estranged from

family or having strained pre-existing relationships. We further found being a default carer impacted decision-making around seeking support and the availability of individuals to share responsibilities with.

Despite these default caring relationships filling a gap within informal care provision, they create significant future challenges around their rights and ability to navigate formal legal and medical networks.

Room 0.20 - Inequalities and Intersectionality

Surviving stomach bugs in UK ethnic groups

*Iram Zahair, Stephen Clayton, Oyinlola Oyebode, Tanith Rose, Ben Barr
(University of Liverpool)*

Stomach bugs exert a significant public health burden on healthcare services in the UK. The few studies of differences in stomach bugs between UK ethnic groups have reported conflicting findings on ethnicity. This study investigates the nature of ethnic inequalities through a qualitative study exploring the lived experiences of UK ethnic minorities, their beliefs and interactions with their environment relevant to stomach bugs. Thirty-nine semi-structured interviews were undertaken to privilege the lived experiences of UK ethnic minorities, eliciting in-depth insights into the experiences, perceptions and practices related to stomach bugs and whether these experiences differ between generational status, gender and age. Preliminary qualitative analyses extrapolate that there are more similarities than divergences in managing stomach bugs across ethnic groups, like the consequences (mental, physical, financial, work or school-related) and exposure beliefs, i.e. managing food preparation, travel and personal cleanliness. Behavioural change practices such as the increased importance of handwashing, handling food in the household and seeking immediate medical attention to prevent transmission were also explored. These findings make an empirical contribution to insights into the association between stomach bugs and ethnicity and can help address policy actions to reduce ethnic health inequalities. The evidence from this scholarship infers the need to adapt control measures to these specific risks in ethnic minority communities and understand the mechanisms that predispose them more to risk. Future research should consider how ethnic inequalities exacerbate exposure to stomach bugs and can be tackled through upstream, population-based interventions.

WEDNESDAY 11 SEPTEMBER

15:10-15:40

Room 0.08 – Experiences of Health and Illness

Dyscluded mothers: The experiential and embodied stories of women mothering autistic children

Juliet Hall

(University of Plymouth)

My PhD research uses auto/biography to share the experiential and embodied knowledge of women mothering autistic children. Borne out of my own personal experiences, it uses our interwoven biographies to raise awareness of a significantly misunderstood experience and ‘voice what might otherwise remain invisible’ (Mauthner & Doucet, 1998, p.141). 30 women participated in lightly structured, research conversations to share the reality of their every-day lived experiences. We connected experientially and emotionally.

Women shared the realities of their experience. Their maternal identity and motherhood defined, and shattered, by normalising socio-cultural ideologies. They described a perpetual uncertainty. They experience complex emotions. Women find their mothering undermined and devalued because they were unable to produce a perfect child. They face discrimination, marginalisation and othering by professionals, friends, family and society. They become dyscluded.

To be dyscluded is neither included nor excluded. The prefix dys-, destroying the good sense of inclusion (Liddell & Scott, 1878); it becomes impaired/defective. Whilst mothers may try to join, or create new communities, they often feel isolated, describing it “like being in a club you don’t want to be in”. They become located in a position of dis-belonging. They feel like the persistent outsider, because other people “don’t have that to deal with, so they don’t know what it feels like”. They question whether they are good-enough mothers because of their (in)ability to live up to mothering expectations. Their mothering feels flawed, difficult to negotiate, complex, and risky. Worse, they feel that their children “get written off” straightaway.

Room 0.17 – Health Service Delivery

Using normalisation process theory to evaluate the implementation of a digital health intervention in community and secondary care long COVID clinics

Fiona Stevenson

(University College London)

Background: The potential and expected benefits of digital health interventions (DHIs) have long been discussed, however substantial challenges to implementation at scale have been highlighted. We report on the implementation of a DHI providing supported self-management for long COVID.

Methods: Data comprised 55.5 hours of zoom recordings of meetings between (i) clinicians and members of the research team, (ii) meetings about study set up with two major trusts and (iii) meetings with the core team relating to problem solving and technical issues. Following reflexive thematic analysis, data were mapped on to the constructs of Normalisation Process Theory.

Findings: The DHI fitted the contextual circumstances, namely a pandemic in which physical contact needed to be limited. The design supported flexibility to suit circumstances in different trusts. Healthcare

professionals worked to support the implementation of the DHI, requiring flexibility to take account of local circumstances. DHIs were reported to have the potential to complement care but were not perceived to be a replacement for face-to-face clinical input. The DHI demonstrated the potential to affect long-established structures of engagement between healthcare professionals and patients in relation to access to care.

Conclusions: NPT provided a framework for considering both individual agency as well as organisation context. The discipline of considering first the context, then the work and finally the practical effects helped place order on the 'mess' involved in the rapid cycle of developing, refining, and implementing a DHI in an atypical environment.

Room 0.11 – Lifecourse

'Just a data problem'?: The role of contested data in saving babies lives

Julie Roberts, Natalie Armstrong, Elaine Boyle, Beth Mccleverty, Penny Mcparland, Thomas Padden, Carolyn Tarrant, Nicola Mackintosh

(University of Leicester)

This paper explores the role of quantified data in quality improvement in healthcare. The PremPath study (2023-2025) is a qualitative study of the 9-element care bundle for the optimisation and stabilisation of preterm infants currently implemented in the NHS (Saving Babies Lives version 3, 2023). We draw on interviews with 40 staff with strategic roles in the Maternal and Neonatal Safety Improvement Programme and in implementing Saving Babies Lives version 3 and ethnographic fieldwork in two hospitals in England. We show how data about what percentage of babies receive each element of the bundle is mobilised in quality improvement to motivate frontline, healthcare staff to implement the bundle. Data is used to direct attention to areas of low performance, track progress, stimulate competition between hospitals, and reward good performance. However, the power of the data to achieve these functions is limited by a lack of trust in the data. Staff draw on experiential knowledge and 'soft intelligence' (Martin et al., 2015) to argue that the data does not reflect the reality of clinical practice. They explain this by reference to problems in data infrastructure, data flows and the priorities of clinical care. In other words, apparently low rates of implementation are 'just a data problem.' We ask questions, drawing on sociological theory on the logics of accounting and performativity, about how to interpret this soft intelligence and to what extent quality improvement risks becoming 'data work' (Bonde et al., 2019), focused on producing and curating data rather than improving care.

Room 0.18 – Diagnosis, Screening and Treatment

Exploring perceptions and experiences of NHS Breast Screening for socio-economically disadvantaged women in Yorkshire

Emily Lunn, Jo Cairns, Una Macleod

(Hull York Medical School)

The NHS breast screening programme detects breast cancer in the earlier stages and improves the chances of survival. Women from less affluent areas are less likely to attend breast screening than those from more affluent areas. Uptake remains low despite a wealth of knowledge about the barriers to breast screening. This study aimed to explore the perceptions and experiences of breast screening for women living in socio-economically disadvantaged areas.

This research, conducted via community and third-sector organisations, adopted a qualitative research design. Twelve interviews and five focus groups were conducted with 35 women eligible for breast screening from diverse ethnic groups in Yorkshire. Twenty-six women had attended breast screening, and nine had not. Thematic analysis of the data was conducted.

To understand the complexities of gaining access to breast screening, these findings are underpinned by the concepts of Candidacy, Concordance and Recursivity. Low levels of health literacy, cancer myths and cultural practices impact the perceived level of risk of breast cancer and, therefore, attending screening. Additionally, previous negative healthcare encounters and feeling stigmatised or not listened to in healthcare are barriers to accessing breast screening. However, where women have a strong social network, barriers such as caring responsibilities, transportation, literacy and language are significantly reduced.

These findings contribute to the development of interventions that can enhance breast screening attendance. Given that the majority of the participants already undergo breast screening, there are promising opportunities to collaborate with them in devising strategies to motivate others from similar socio-economic backgrounds to participate.

Room 0.19 – Open

The unspoken truth in disability talk

Clare Butler

(Newcastle University)

This paper considers how women who stammer respond to a question commonly posed by employers: do you have a disability? This seemingly simple question, cloaked in the warm fuzziness of inclusion, wellbeing and reasonable adjustments, offers up quite the challenge for the nineteen women who were interviewed as part of this research project. The challenges they discussed moved beyond the sharing of their difficulties, needs and/or vulnerabilities and instead shone a light on the interdependence that is inherent in communication – something they described as an unspoken truth within much disability talk. Funded by the Dominic Barker Trust and drawing on Judith Butler's work around interdependence and vulnerability, this paper shares a truth which is often unspoken, and maybe not even considered, in disability talk.

Room 0.20 - Inequalities and Intersectionality

Exploring Perceptions of British South Asians and barriers faced on accessing Drug and Alcohol Treatment Services

Zeb Sattar, William Mc Govern, Lydia Lochhead, Hayley Alderson, Michael Cave, Rachael Hope, Monique Lhussier, Ruth MCGovern

(Northumbria University)

Societal stigma from the South Asian/Muslim community often plays a vital role in preventing those in the community accessing drug and alcohol treatment when needed. There is very limited research regarding this area and barriers faced when accessing treatment. This qualitative study aimed to understand the challenges of why this population group were not accessing recovery treatment.

Snowball sampling was utilised to recruit participants to take part in one-to-one semi-structured interviews. Participants comprised of one practitioner and ten members of the South Asian Muslim community. Qualitative data analysis followed Braun and Clarke's (2019) reflexive thematic analysis approach, and generated the following four themes, (1) Drug and alcohol use as a taboo topic (2) Barriers to treatment (3) Awareness of treatment and (4) Accessibility of treatment.

There was a perceived generational difference when it came to willingness to discuss drug and alcohol use, with the younger generation more open to discussing the topic and perceived as consuming drugs and alcohol more, in comparison to the older generation. Hiding drug and alcohol use was highlighted as a barrier to accessing treatment and seeking recovery, as it created a space for the individual to use drugs secretly with limited-service intervention. Further work on the need for outreach in the community and for existing services and groups to connect with community leaders to create familiarity and awareness is suggested.

WEDNESDAY 11 SEPTEMBER

15:45-16:15

Room 0.08 – Experiences of Health and Illness

Understanding the lived experiences of women managing problematic menstruation in the Nigerian banking profession

Juliet Nwafor, Kate Sang, Rania Kamla, Katerina Strani

(School of Social Sciences, Heriot-watt University)

The banking sector has been associated with putting bank workers under enormous pressure to perform and maximise profit; women in this sector experience pressure from work coupled with mandatory familial and bodily responsibilities like maternity, menstruation and menopause (Mordi, Mmieh et al. 2013). Different studies have found that gynaecological/menstrual issues intersect with other structural challenges that women face in the workplace (Sang, Remnant et al. 2021).

This study explores in-depth women's experiences of blood work, which is an additional form of labour to conceal menstruation and gynaecological health conditions to avoid leakiness or stains in a bid to fit into professional settings and maintain menstrual etiquette.

Drawing from the theory of gender performativity, this study focuses on how women perform wellness within the banking sector in Nigeria.

Early findings from the scoping study suggest that women managing menstruation while navigating a career in the Nigerian banking sector face a wide range of challenges, such as prolonged/unregulated work hours, weekend shifts and extra commute hours due to traffic congestion. Findings also point to how other chronic health conditions, such as sickle cell anaemia, and women's reproductive health concerns, such as birth control, and how they intersect with symptoms of gynaecological health conditions like heavy bleeding, leakiness and even the cessation of menstruation.

Room 0.17 – Health Service Delivery

Improving the involvement of people with learning disabilities, people living with dementia and stroke survivors in nursing care decisions on acute hospital wards: Why is it so difficult?

Jo Hope, Teresa Corbett, Syd Anstee, Cindy Brooks, Emily Jones, Tula Brannelly, Jackie Bridges

(University of Southampton)

People with learning disabilities, people living with dementia and stroke survivors are often excluded from hospital care decisions, leading to inappropriate or poor care. This has resulted in poorer health outcomes, including avoidable deaths.

We carried out a systematic literature review to evaluate interventions to engage the above groups in nursing care decisions in hospitals, identifying 11 relevant studies. Our findings show quantitatively significant impact is mostly limited to staff confidence in communication and understanding needs following training. While the use of tools or other evidence of involvement of patients in decisions in practice sometimes reached significance, findings were inconsistent or limited. This was mirrored in qualitative findings with staff reporting increased knowledge and understanding of communication and inclusive practices but limited implementation in practice. Reasons given included perceived time constraints, a lack of awareness of specialist support, a task-focused approach prioritising physical

care, inconsistent use of patient information passports and distress recognition tools, staff not released to attend training, and staffing shortages.

We interpret these findings in relation to our own and wider sociological work on missed care in acute hospital wards, which disproportionately affects the care outcomes of these patient groups. This includes the persistence of a Total Institution task focus, reducing time with 'difficult' patients, and how different care tasks are prioritised. We argue that these groups also experience care inequalities due to implicit and (during COVID-19) explicit care rationalisation, connecting this to social and historical ideas about stigma and belonging in general acute wards.

Room 0.11 – Lifecourse

The enduring impact of COVID-19 lockdown restrictions on adverse birth and pregnancy outcomes, and associated inequalities: A qualitative study in England

Iona Hindes, Stamatina Iliodromiti, Dominik Zenner, Fiona Samuels

(Queen Mary University London)

Aim: To explore the impact of COVID-19 lockdown restrictions on the lived experience of birth and pregnancy; identify lasting impacts of the pandemic on new mothers; and explore socioenvironmental determinants of pregnancy and birth outcomes in England.

Methods: This study recruited individuals who gave birth in England during lockdown restrictions in 2020-2021. Semi-structured interviews were conducted via video-conferencing software. Interviews were recorded, transcribed, and underwent Grounded Theory Analysis using the constant comparative method in NVivo. A combination of Feminist and Inter-phenomenological theoretical lenses was applied to develop themes.

Results: Thirty-eight participants from a variety of socio-economic backgrounds and ethnicities took part. Emerging themes include 1) experiences of neglect and fear in hospitals due to partner restrictions and overstretched services; 2) high reporting of poor maternal mental health due to loneliness and unaddressed trauma; 3) racialization of bodies and discrimination in maternity care settings, coupled with the stigmatization of vulnerability within racialized communities, as key contributors to pregnancy and birth outcome inequalities; 4) the benefits and drawbacks of navigating motherhood in the context of digital workplace environments and social isolation.

Conclusion: Our findings outline the substantial and enduring negative consequences of lockdowns on maternity care experiences and maternal mental health. Maternity services were unable to provide adequate care due to compounding pressures on the NHS and limitations on vital partner support. While work-from-home measures have provided valuable flexibility for some new mothers, restrictions also resulted in loneliness and isolated vulnerable, recovering women from vital support structures.

Room 0.13 – Pedagogy and Methods

Being an immigrant ethnographer in a contemporary NHS setting: Shifting constantly along the insider-outsider continuum

Tanvi Rai

(University of Oxford)

Ethnographic methods are increasingly used to interrogate the organisational, interactional and cultural aspects of context which influence the adoption and embedding of new technologies. To achieve this, ethnographers are encouraged to employ "techniques of estrangement" (Gobo and Molle, 2017, p. 152) to help them de-construct and de-naturalise what is considered normal/abnormal. One such technique

is what Schwartz and Jacobs (1979) called 'the cultural stranger device'; and scholars have noted how the immigrant is a salient example of a stranger – immigrants seek to learn the conventions of the group they wish to enter and become skilled at noticing details that may be considered unremarkable or irrelevant to group members.

This paper is based on ongoing ethnographic research evaluating the introduction of a new way to manage postpartum haemorrhage in NHS maternity units. I examine the methodological significance of being a non-white immigrant researcher in a contemporary NHS setting, where almost two-fifths of doctors, a third of midwives and a quarter of patients are from racially minoritised and/or immigrant backgrounds (IFS 2024). Using observations and interview data from seven case studies, I explore how my positionality with respect to the diverse maternity staff I encountered (in terms of roles and racialisation) affected both how I was received by them, and my own research approach and analysis, and in doing so, revealed shifting contours of new kinds of knowledge it is possible to generate.

Room 0.18 – Diagnosis, Screening and Treatment

Diagnostic ambivalence and conflicted biomedical selves: Clinician perspectives on navigating meanings of diagnosis when supporting people with possible endometriosis

Sharon Dixon, Katy Vincent, Emma Evans, Abi Mcniven, Francine Toye, Lisa Hinton

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

Endometriosis affects approximately 10% of female at birth individuals, and can be associated with symptoms including pelvic pain and subfertility. Delays in diagnosis are pivotal in endometriosis discourse; the average interval between symptoms and diagnosis is 8 years. Achieving a diagnosis is positioned as the goal of care, often portrayed as an oppositional process where clinicians represent obstacles (or foes) to be overcome.

We report a secondary analysis of 42 GP interviews about possible endometriosis, and 46 interviews with primary care clinicians about supporting women's health. We utilise sociological theories of diagnosis (Jutel) and ambivalence (Merton) to present our findings, illuminating perspectives on meanings of diagnosis to clinicians, an area previously sparsely documented.

Diagnosis is valued by clinicians as desirable in a biomedical model of care, including enabling evidence-based treatment and advocacy. Clinicians recognised and valued potential meanings of diagnosis for patients. They also valued diagnosis as a means to afford them some protection from risk. However, clinicians hold these considerations alongside uncertainty about how, when, and whether diagnoses help in endometriosis and pelvic pain, including that diagnosis may not change treatment or inform prognostication about or influence outcomes. Recognising that care remains with them, whatever the outcome of tests, they actively work to ensure they enable ongoing care whether a diagnosis is identified – or not.

Together, these tensions contribute to diagnostic ambivalence, and complex considerations. Reductive awareness-raising education which does not account for these personal tensions will not likely alone change practice or reduce delays in diagnostic journeys.

Room 0.19 – Open

Post-diagnostic ambivalence: Exploring the lived experiences of women diagnosed in adulthood with Autism and ADHD in the UK

Emma Craddock

(Birmingham City University)

This paper explores the post-diagnostic narratives of women navigating combined diagnoses of autism and ADHD in adulthood. Through interpretative phenomenological analysis of in-depth email interviews with six late-diagnosed women, it uncovers the pervasive ambivalence characterising their experiences of living with and comprehending both conditions. These findings highlight the complex process of reconciling individual identities within the context of prevailing medicalised and neurodiversity paradigms. The analysis reveals a nuanced interplay between individual sense-making and the overarching societal and scientific narratives concerning autism and ADHD. As the first study to investigate the lived experiences of late-diagnosed women with both autism and ADHD, this paper offers original insights into the complexities of managing such ambivalence. By amplifying the voices of late-diagnosed women, whose perspectives have historically been marginalised in research, this study contributes to a more comprehensive understanding of the lived realities of autism and ADHD and how women make sense of these realities. The recognition of ambivalence as a central theme underscores the need for nuanced approaches to post-diagnostic support. This paper not only enhances understanding for post-diagnostic support but also contributes to a deeper comprehension of the dynamic interplay between individual experiences and societal narratives of health and illness.

Room 0.20 - Inequalities and Intersectionality

An intersectional study of family carers: Examining the interaction between ethnicity and young adulthood to develop appropriate support

Chandini Subramanyam

(University of Leicester & LOROS Hospice)

Approximately 10.6 million family members provide care to someone with a serious illness or disability across the United Kingdom. Ethnically diverse (ED) carers report greater care burdens and marginalisation in comparison to White British carers. Young adult carers (YACs) also face an array of challenges due to juggling multiple life domains such as, social, education and personal growth. At present, the ways in which ethnicity and age may overlap to influence experiences of caring are not well understood.

This project aims to analyse the experiences and support needs of ED YACs from the theoretical perspective of intersectionality (Crenshaw, 1989). Data collection and analysis is occurring via three workstreams: A survey of ED young people (analysed quantitatively); semi-structured interviews with ED YACs (analysed via interpretive phenomenological analysis, IPA); and semi-structured interviews with a range of professionals who support carers (analysed thematically). This abstract reports some preliminary findings from the ED YAC interviews.

Preliminary results suggests that caring is viewed from a bifurcated perspective due to conflict between age and ethnicity. ED YACs state that young adulthood is a crucial developmental period which impacts their cultural identity as well as their transition into older adulthood. Furthermore, ED YACs report experiencing exclusion by healthcare professionals which is reflective of wider systemic issues. Marginalisation such as this ultimately has impacts on wellbeing and quality-of-life. In summary, ED YACs negotiate multiple identities which distinguishes their experiences from White British YACs. Understanding how these layers intersect, and differ, is essential to understanding the support they need.

WEDNESDAY 11 SEPTEMBER

16:20-16:50

Room 0.08 – Experiences of Health and Illness

How paediatric patients and their families emotionally respond to, understand and value seeing images of injuries, diseases and conditions from medical imaging: A qualitative systematic review

*Natalie Tyldesley-Marshall, Sue Neilson, Albert Farre, Sheila Greenfield, Andrew Peet
(University of Birmingham)*

Background: Medical imaging, such as MRI, CT scans, endoscopy, ultrasound, and x-ray, is essential to the diagnosis and management of many conditions and chronic illnesses. With advances in technology allowing a patient's images to be easily shown, accessed and transmitted, it has become common practice for healthcare professionals to share these images with patients and their families. However, there seems a paucity of research exploring patient views, understandings, and perspectives surrounding viewing their own medical images, or images of significant others, and the best way to share these images with the family.

Methods: CINAHL, Cochrane, MEDLINE, PsycInfo and Web of Science were systematically searched for qualitative research that explored the experiences of how patients, and their family members, understand, value, and emotionally respond to seeing images of injury, disease and conditions from medical imaging, within a medical context.

Results: The search was run in 2016, and re-run in June 2023. In 2016, after de-duplication, 3,576 results were retrieved, and 123 full texts screened. In 2023, 3,576 results were retrieved, and 103 full texts screened. 7 studies met the inclusion criteria from database searches and reference checking. Coding of the data and conceptualisation of themes, following Thomas and Harden (2008), is due to start in April and complete in July.

Implications: The systematic review will synthesise the research exploring the value, (mis)understanding, and emotional responses of, paediatric patient families viewing medical images, and aid practitioner best practices for sharing medical imaging.

Room 0.17 – Health Service Delivery

Decision-making about broad spectrum antibiotic prescribing for suspected maternal sepsis during childbirth: A qualitative study

*Carol Kingdon, Alison Holmes, Abi Merriel
(University of Liverpool)*

Maternity care is where the UK government's standalone ambitions to tackle sepsis, antimicrobial resistance, reduce preventable stillbirths, maternal and neonatal deaths, coalesce. Sepsis is a rare, but life-threatening condition, which originates from an infection. Women and pregnant people admitted to hospital for childbirth are vulnerable to infections because of immunosuppression, physiological labour processes and exposure to invasive medical interventions. Whilst early identification of emerging maternal sepsis and treatment with broad-spectrum antibiotics is key to reducing deaths, over-prescribing for suspected sepsis may increase antimicrobial resistance threatening medicine's ability to treat maternal and neonatal sepsis effectively. The aim of this study is to explore clinicians' decision-

making about prescribing broad-spectrum antibiotics for suspected sepsis in women admitted to hospital for childbirth, to identify if, how, and why, over-prescribing may occur. This is a qualitative study, using semi-structured interviews. The study draws on Gabbay and Le May's concept of mindlines to advance understanding about how clinicians navigate different kinds of knowledge in their every-day decision-making processes. This is current research funded by the UK Health Security Agency to provide lived experience evidence of the complexity of clinical decision-making in context. Purposive sampling has ensured diverse representation from clinicians working in NHS maternity units across England, Scotland, and Wales. Nineteen interviews have been conducted using Microsoft Teams. Interviews are recorded, transcribed, and uploaded into MAXQDA qualitative data analysis software for analysis using the thematic Framework Approach. The framework matrix has been developed with analysis ongoing. Final data interpretation and results will be available summer 2024.

Room 0.11 – Lifecourse

How families affected by Turner syndrome challenge and reframe reproductive timing stigma

Kriss Fearon

(Centre for Reproduction Research, De Montfort University)

Turner Syndrome (TS) is a female chromosome condition usually causing infertility and delayed physical or emotional development. Often diagnosed in childhood, it disrupts the timing of puberty, menarche, childbearing and menopause. Based on qualitative interviews with 30 UK-based women with TS and mothers of girls with TS, this paper explores how women with TS and mothers of girls with TS resist and reframe the stigmatisation associated with missing socially-expected timing milestones.

The social expectation that women will become mothers (Suppes, 2020) means mothers of girls and women with TS often fear infertility will be traumatic for their daughter. As a result, they do 'anticipatory labor' (Wu, 2023) to ease her transition through key life stages and plan for her reproductive future. In turn, women with TS strategise around managing the stigma associated with infertility, the anticipated relationship impacts of disclosure, and their complex reproductive options.

This paper shows how Kafer's concepts of 'crip time' (Kafer, 2013), which critiques the normativity of social timing expectations, and the 'curative imaginary', the expectation to work to a future cure, can be fruitfully applied to temporal misfitting around infertility related to chronic illness. These concepts illuminate the dimensions of timing and anticipation, showing how they are applied to mothers as well as to women and girls with TS. This improves our understanding of the lived experience and reproductive decisions of women with this under-researched condition.

Room 0.13 – Pedagogy and Methods

Reflections on conducting longitudinal qualitative research: a Long Covid project

Sarah Akhtar Baz, Chao Fang, JD Carpentieri, Laura Sheard

(University of York)

This presentation will reflect on conducting qualitative longitudinal health research. As part of the CONVALESCENCE Long Covid project, we interviewed parents from the Born in Bradford cohort and wider Bradford community over 4 points in time (Nov 2021 to Oct 2023) about the multi-dimensional impacts of Long Covid on their health and wellbeing. 145 interviews were conducted in total. We had a very low attrition rate (40 at sweep 1, 33 at sweep 4). There was an overrepresentation of ethnic minority participants (75%), particularly as they were disproportionately impacted by Covid-19 (Meghji et al, 2022) but underrepresented in Long Covid research at the time. The presentation will provide insights into the different stages of the project, including strategies to recruitment, reengagement and maintenance of participants over time, conducting interviews over time, engaging with people who are

traditionally unheard in research (like ethnic minorities), and analysis challenges and opportunities, e.g, capturing change over time (Saldaña, 2002). How can we do longitudinal research in a meaningful way and what does this approach offer to advancing sociological health research?

Room 0.20 - Inequalities and Intersectionality

Hansen's Illness and sociocultural epidemiology in the Brazilian Amazon: A case study at Vila Santo Antonio do Prata

Maria Beldi Alcantara, Carlos. E Cobertt, Marilia Brasil

(University of Sao Paulo)

This study utilizes an interdisciplinary and epidemiological lens to explore Hansen's disease, commonly known as leprosy, from the perspective of interculturality. It highlights the crucial role of cultural and social dimensions in comprehending and managing the disease/illness. Health/illness is portrayed as a complex entity that extends beyond mere biological interactions, necessitating a comprehensive approach that synthesizes insights from various disciplines. The research delves into the stigmatization and cultural narratives surrounding Hansen's disease/leprosy, illustrating how stigma and the concealment of the condition serve as significant barriers to treatment adherence. Despite advancements in medical treatment, a persistent negative cultural stigma continues to influence patient experiences negatively, emphasizing the importance of incorporating psychological, social, and cultural considerations into treatment strategies. The study underscores the negative impact of cultural perceptions on patients' therapeutic paths and argues for the necessity of surmounting these perceptions for effective and empathetic care. It calls for a paradigm shift in health practices to encompass these wider dimensions, asserting that such an inclusive approach is indispensable for the holistic and humane treatment of leprosy. This paper encourages a critical reassessment of existing health practices, advocating for the integration of cultural and social factors into the healthcare framework to improve treatment outcomes and patient experiences.

THURSDAY 12 SEPTEMBER

09:00-09:30

Room 0.17 – Mental Health

"Boy's don't cry"?: Men's mental health in the music industry

Emma Williams, Dr Christopher Elsey

(De Montfort University)

This presentation explores the sociological foundations of music-making within the music industry. We examine (1) music as a workplace, and (2) music's volatile relationship with mental health and well-being. Music and work make incredibly odd bedfellows in which the creative process and the emotional foundations of the music and lyrical content are 'sold' for the benefit of the record industry. The well-documented potential for harm and risk associated with pursuing a musical career is most starkly exhibited in the disturbing statistics that they have a disproportionate risk of death by suicide compared with wider society. Furthermore, this paper considers how men's mental health issues are "hidden in plain sight" in the music industry.

This study uses Discourse Analysis to explore how male musicians describe, conceptualise and respond to mental health issues and crises, and analyses song lyrics and music videos to understand how male artists express their mental health struggles through their compositions. Artists like Citizen Soldier, The Collection, and others use audio visual platforms to disclose personal mental health challenges through music. Analysis of these musical outputs are paired with media interviews featuring the artists (e.g. online videos, written articles, and podcasts) to unpack the intersection of music and mental health. This will offer insights into how male musicians convey emotional/mental health experiences within and about their 'work' situations.

The hope is that this research could lead to the establishment of a duty of care to cover the 'vulnerable' people working in music-making and creative spaces.

Room 0.11 – Embodiment and Emotion

Young people's sexual wellbeing: A life-history study

Raquel Boso Perez, Ruth Lewis, Kirstin Mitchell

(University of Glasgow)

Sexual wellbeing is integral to consensual, healthy and pleasurable sexual experiences and relationships. We define sexual wellbeing as feeling safe, secure, respected, comfortable, and confident in relation to sexuality, and able to work through changes, challenges, and negative past experiences. Sexual wellbeing stems from the accumulation of advantageous and disadvantageous experiences within socio-structural contexts. Our conceptualisation is one of multiple, in a field that draws on varied theorisations (and where often studies fail to provide a definition).

Despite the importance of sexual wellbeing to a person's overall wellbeing, we lack knowledge on how the components of sexual wellbeing shape—and are shaped by—different sexual histories. In this paper we draw on primary qualitative data to explore the lived sexuality-related experiences of 25 young people (aged 17-23). The sample included participants from a range of gender identities, sexual orientations, ethnicities, socio-economic backgrounds, degrees of sexual experience, and religious identifications.

Participants were recruited through Natsal-4, a probability sample survey about the sexual health, behaviour, and attitudes Britain's general population. Natsal-4 participants consenting to recontact were invited to take part in a life history interview (in person or online). The interviews focused on participants' recollection of moments that have shaped how they felt and thought about sex and sexuality. Our findings report qualitative insights into the developmental experiences that strengthen, sustain, or detract from sexual wellbeing. This paper will be useful to those seeking to support young people to experience wellbeing in their early sexual lives.

Room 0.18 – Open

Jokes, talk and support in men's hair loss journeys

Paul Hodkinson, Matt Hall

(University of Surrey)

Qualitative research on men's experiences of going bald is limited, but some studies suggest the process can be a turbulent and distressing one (DeMuro-Mercon et al 2000; Ricciardelli 2011; Jankowski et al 2021). The Journeys of Hair Loss project has explored men's experiences of hair loss through in-depth interviews and photo elicitation with 34 men between 18 and 49. The project took a life course perspective focused on experience of hair loss as a developing journey.

This paper explores how men interacted with others about hair loss, as part of journeys that often featured periods of emotional struggle. Jokes and humour often were central to communication about baldness but, while some welcomed humorous interactions as a means to bring their hair loss into the open, others found jokes intensely hurtful. Either way, participation in jokes often acted as a way to convey comfort with baldness, whether sincerely or not. In contrast, serious forms of talk that conveyed or sought support for the emotional challenges of going bald were unusual. We explore how the prevalence of humorous communication and absence of serious emotional talk connect to broader discourses of acceptance and authenticity in the men's narratives. Such discourses, draw, in part, on enduring forms of masculine stoicism, and reflect longstanding barriers to male emotional disclosure and support-seeking (Seidler et al 2016; Hodkinson and Das 2021). Yet they also reflect the societal trivialisation of male hair loss, rendering it well-suited to humour, but illegitimate subject-matter for emotional, supportive forms of talk.

Room 0.19 – Professions / Health Care Organisations

What role can internationally educated health professionals play in shaping vaccine attitudes in their communities?

Krithika Subbiah, Elena Neiterman, Farimah Hakemzadeh, Elizabeth Beggs, Melanie Lyn Bedard

(University of Waterloo and York University, Canada)

Background: Vaccine hesitancy among healthcare providers, particularly in primary care settings, has been understudied. The COVID-19 pandemic has highlighted the importance of understanding the role healthcare professionals play in promoting vaccines. Internationally Educated Health Professionals (IEHPs) practicing in Canada can influence patients' attitudes towards vaccinations, but there is limited knowledge about their views on vaccines and their potential role in promoting vaccinations in their communities.

Aims: We explore how the intersection of professional, gender, and ethnic/racial identities of IEHPs practicing in Canada shape their views on vaccinations. Specifically, we examine how IEHPs' views on vaccines are influenced by the intersection of their professional and personal identities.

Methods: We conducted 20 open-ended interviews with IEHPs practicing in Canada as physicians, nurses, dentists, or pharmacists. Using NVIVO 12, we applied an intersectional lens to inductively analyze the interviews.

Results: The vast majority of IEHPs held positive attitudes towards vaccines and had a strong sense of trust in public health officials. Some participants viewed access to vaccines as a privilege of practicing in the global north and vaccine hesitancy as a "first-world problem." However, employment precarity combined with gender, racial, ethnic, and professional identity may hinder their ability to freely communicate their opinions about vaccines to their patients.

Conclusions: Despite challenges related to employment precarity and workplace discrimination, IEHPs can be effective ambassadors of health-related information, especially when there is alignment between IEHPs' and their patients' ethnic and cultural identities. Supporting IEHPs in this role and empowering them as agents of change is crucial.

SPECIAL EVENT

THURSDAY 12 SEPTEMBER

09:35-11:15

Room 0.08 – Experiences of Health and Illness

New dialogues between medical sociology and disability studies

Janice McLaughlin, Gareth Thomas, Sasha Scambler

(Newcastle University)

This special event brings together papers from a Special Issue of *Sociology of Health and Illness* (Vol 45, Issue 6, July 2023), which explores the intersections, boundaries, and collaborative opportunities between medical sociology and disability studies. Our aim is to work past (while still acknowledging) the legacy of dispute and tension between medical sociology and disability studies to find new points of convergence and collaboration. The problem remains that disability is frequently cast aside, or at least overlooked, as a serious and critical topic in sociology. Medical sociology and disability studies working together is one aspect of challenging that recurrent marginalisation. By pursuing a critical yet open and collegial dialogue with one another, we can explore the complexity of living with disability from multiple vantage points. The work emerging across medical sociology and disability studies show that it is possible to think through earlier areas of disagreement – such as engagement with medicine, structure and agency, politics, embodiment and impairment, research practice, and the distinction between ‘illness’ and ‘disability’. The special event recognises past disagreements, whilst also working across current fields of inquiry, to engage with the challenges faced by chronically ill and disabled people in different contexts. More specifically, contributors to the special event will prompt discussion on how we can: produce new ways of theorise disability; bring together analyses of chronic illness and disability; think through the utility of particular concepts (e.g. ‘stigma’); and reflect on the opportunities to develop new methodological practices and partnerships.

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, Sushila Chowdhry, James Richards

(Strathclyde University, Herriot-Watt University, University of Edinburgh, Dundee University)

This paper focuses on the workplace as a significant site of convergence between the disciplines of medical sociology and disability studies. Both disability and employment seem to exist only on the margins of medical sociological exploration and theorising, mirroring how disabled workers remain on the margins of the workforce, subject to disproportionate rates of unemployment, under employment and workplace mistreatment.

The paper focuses on employees who experience troubling menstruation and/or have gynaecological health conditions – ‘leaky’ bodies. It brings together data from three studies conducted between 2017 and 2020: interviews with disabled academics (n=75), university staff with gynaecological health conditions (n=23), and key decision-makers in universities (n=36) (including university executives, line managers and human resources staff). These studies had separate, but linked foci: 1) the inaccessibility of workplaces, 2) managing (gynaecological) health conditions at work and 3) supporting disabled people at work. Drawing on the Social Relational Model of disability and theories of embodiment, we explore the experiences and management of workers with leaky bodies in UK university workplaces.

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

“I am more than just my label” – Rights, fights, validation, negotiation: Exploring theoretical debates on childhood disability with disabled young people

*Geraldine Brady, Anita Franklin, RIP: STARS Collective
(Nottingham Trent University, University of Portsmouth)*

Through the creation of safe spaces in which to explore and challenge dominant negative views of disabled children and young people, this co-written paper presents unique insight into the meaning and impact upon disabled young people's lives of medical lenses and deficit models of disability. Bodies of work and dominant debates in medical sociology, disability studies and childhood studies have so far largely overlooked the experiences and positioning of disabled children and young people and have rarely involved them in the development or discussion of theory. Drawing on empirical data, and through a series of creative, reflective workshops with a UK-based disabled young researchers' collective (RIP:STARS), this paper discusses areas of theoretical importance identified by the disabled young researcher collective - the validation of their lives, negotiation of their identity and acceptance in society. The implications, and possibilities, of platforming disabled children and young people's voices in theoretical debates are deliberated and are achieved through the yielding of privileged academic voice and the development of a symbiotic, genuine partnership which resonates with disabled young people and recognises them as experts in their own lives.

THURSDAY 12 SEPTEMBER

09:35-10:05

Room 0.09 – Politics and Ethics / Theory

Capitalism and the ‘commercial determinants of health’: A more-than-human analysis of ‘unhealthy’ food consumption

Nick Fox

(University of Huddersfield)

Public health and social science scholars have described a range of phenomena described as the ‘commercial’ or ‘corporate’ determinants of health (CDoH). This paper argues that CDoH scholarship needs to acknowledge fully the part that the capitalist mode of commodity production and exchange plays in producing negative health outcomes. As such, it seeks a synthesis between CDoH perspectives and the critical political economy of health and health inequalities.

This objective is achieved by recourse to a recent development in political economy that has established a more-than-human, relational and monist (or ‘flat’) ontology of capitalism, in place of the more conventional neo-Marxist perspective. Based on recent research, this ontology reveals a dynamic to capitalism that operates beyond human intentionality, driven by the supply of, and demand for the capacities of commodities. This dynamic determines the production and consumption of all commodities, some among which (such as tobacco, alcohol and processed foods) contribute to ill-health.

This analysis is illustrated by a case study of one of the areas that has been identified in the CDoH literature: the consumption of ‘unhealthy’ processed foods often high in sugar, salt or fat. Using data from a study of food choices, the more-than-human political economic approach outlined in this paper demonstrates how unhealthy food consumption is driven by capitalist supply and demand affects. Ways to undermine this more-than-human dynamic are offered as an innovative approach to addressing the effects of commerce and capitalism upon health.

Room 0.17 – Mental Health

Talking mental health? Exploration of gendered assumptions within sport-based health promotion initiatives

Christopher Elsey, Emma Williams

(De Montfort University)

This presentation will explore a series of gendered assumptions about mental health as they appear in sporting contexts, examining how mental health disclosure practices are conceptualised and applied in health promotion initiatives. In particular, the paper will examine how the numerous assumptions about mental health and gender in sport are repeatedly referred to and re-produced in public health discourses.

Examples of these assumptions include: Men don’t/can’t talk about their mental health, are not able to formulate their concerns and delay seeking help from healthcare services. These ‘facts’ are then used as explanatory devices to account for why men are more at risk of taking their own lives.

From a health promotion perspective, these assumptions (men have poor mental health literacy/vocabulary AND they follow/participate in sport) are often re-produced to furnish the rationale for football-based mental health initiatives.

Informed by Discourse Analysis this research explores two public awareness campaigns: (1) 'Heads Up' (co-ordinated by the Football Association, Heads Together and Public Health England), (2) Campaign Against Living Miserably's 'Tackle it Together' and 'Unseen Signals' campaigns with specific focus on key video content developed for distribution via social media platforms. The analysis will explore how gendered assumptions are embedded in the rationale and design of the interventions to instigate mental health 'conversations', as well as critically assessing how cultural and social change can be evaluated and measured.

In conclusion, the paper will highlight examples from sports-related podcasts that exhibit how to talk about mental health issues and thereby normalise mental health conversations.

Room 0.11 – Embodiment and Emotion

'We are not witches!': Commercial surrogacy and the construction of the moral reproductive subject in India

Aishwarya Chandran
(University of Sussex)

The paper draws from my doctoral project which engages with ethnographic fieldwork among surrogate mothers, repetitive egg donors, medical practitioners and clinical agencies in India. The normative reproductive subject or the aspirational reproductive subject in south Asian politics has always been part of the vision of the modernised postcolonial state – with smaller nuclear families – where working class reproduction has been met with anti-natalist policies. How then do surrogate mothers navigate the conflicting interests of the anti-natalist state that vilifies them as hyper-fertile and reckless mothers, along with the demands of the waged market for visceral forms of labour where their reproductive labour becomes a sought-after commodity? Their reproductive subjectivity then is nestled within struggles for recognition as legitimate citizens and productive workers, and is a site for negotiating affective intimacies between the realms of the embodied and the economic. The presentation hopes to be able to think of reproductive subjectivity as an ethical and political project where the realms of the jurisprudential and the affective, the legal and the intimate come together in complex ways. The paper argues that the intersections of the precarious market for waged labour and the increasingly pervasive incursion of reproductive technologies into everyday life materialise the bodies of marginalised working-class women as both 'bioavailable' (Cohen 2007), but also as ignoble feminine figures whose bodies and reproduction must be policed.

Room 0.18 – Open

Men's sheds and participant capital, capability and structurally transformative health-relevant agency

Steven Markham
(University of Oxford)

Men's sheds are community places where older men engage in creative pursuits, mending and adapting wood and other materials. There are over 900 UK men's sheds, reaching more than 13,000 regular participants. At these venues, men work 'shoulder-to-shoulder' with other men. This leads to men talking and partaking in supportive conversations.

Primary research was undertaken across three research sites to explore what participants bring to, and share within, men's sheds, so as to explain how sharing resources influence health and well-being.

Amartya Sen (1993) argues that a primary human right is the freedom to achieve wellbeing. This can be understood in terms of people's real opportunities to be, do or function in line with their values. Our health capability, is the ability to hold alternative combinations of functionings from which we can choose, and our ability to achieve valued functionings. Health capability helps us understand and explain differences in the health and wellbeing of individuals or groups, based on their ability to exercise agency within the context of the social structures they negotiate. Through health-relevant agency, men at men's sheds transform structures that influence their health and wellbeing.

This theory could support understanding of why reductions in social inequalities and/or negative consequences on health have occurred. Men's sheds, and their membership, implicitly support action to reduce social inequalities and enhance positive assets and resources that enable capacities for health and wellbeing. When investigating social programmes, it is logical to aim for understanding of the 'capability sets' upon which people draw.

Room 0.19 – Professions / Health Care Organisations

Disparate perspectives on quality between healthcare providers and management in home care nursing: An ethnographic study

Jörg W. Kirchhoff, Catharina Bjørkquist, Hanna Marie Ihlebæk
(*Østfold University College*)

The regulations of home care nursing in Norway aim to ensure that both healthcare providers and management provide services with professional integrity, emphasizing patient safety. However, there are also regulations that emphasize patients' needs, dignity, and self-respect, thereby highlighting their perspectives on the quality of healthcare. As a result, employees and managers of home care nursing are required to balance these two disparate perspectives in the provision of health care services.

This paper explores the perspectives of employees and management on quality and how these perspectives influence the provision of healthcare services to patients and the organization of home care nursing. The findings are based on participant observations, in-depth interviews, and focus group interviews with employees, first-line managers, and management's advisory staff.

The study reveals that although both perspectives exist among employees, the perspective that emphasizes patient safety was predominant and expressed by professionals, ie. employees with healthcare education, and their managers. Unskilled employees, on the other hand, identified the interrelationship with patients as the main indicator of quality in the provision of healthcare services. However, their perspective was invisible because the organization favoured the perspective of patient safety and reinforced it through management's efforts to establish a system that underlines professional integrity.

Room 0.20 – Inequalities and Intersectionality

Crafting a good life on the margins

Eleanor Kashouris
(*Newcastle University*)

Globally, the emergence of antimicrobial resistance (AMR) in clinically important microbes threatens routine medical work, from treating common infections to prophylaxis for surgery.

In the UK, responses to AMR have primarily understood it as a problem of excess, and often reflect a depression about what else might be done to care aside from antibiotics. This leaves a fundamental question surrounding antibiotic use and antimicrobial resistance: what is to be done for symptomatic patients once antibiotics have been identified as inappropriate?

I take the important case of urinary tract infection and, drawing on Jeanette Pols' theorisation of patient knowledge, and Mallery and Strengers' social practice theory, I find an inventiveness and creativity about care beyond antibiotic treatment in the practices of people poorly served by current clinical approaches and living with persistently poor bladder health.

Drawing on Black feminist bell hooks' concept of the 'radical openness of the margins', the contribution of this paper is in noticing that the precarious and unequal circumstances people live within are productive of different ways of caring, without celebrating or fetishising precarity and inequality in themselves.

I offer an object-interview methodology used with patients with persistent symptoms after treatment for UTI to elicit mundane but innovative and creative ways of crafting a good life on the margins of care amidst inequality. Sociological methods can elicit what is already being done to care beyond antibiotic treatment as we collectively attempt to reduce our reliance on antibiotic care practices.

THURSDAY 12 SEPTEMBER

10:10-10:40

Room 0.09 – Politics and Ethics / Theory

How professionals and policy construct self-neglect in health, social care and beyond: A qualitative study in England

David Orr, May Nasrawy, Cindy Morrison

(University of Sussex)

Following national policy changes in 2014, health, social care, housing and allied services in England have been required to place greater priority on responding to cases of self-neglect. English statutory guidance provides the definition that self-neglect 'covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings.' The breadth of this category has created challenges for services and practitioners, at the same time as it has enabled them to recognise and negotiate key aspects of situations including, but not limited to, medical non-compliance, hoarding, deteriorating home conditions, fire risk, 'Diogenes syndrome,' and street homelessness. At the same time, people labelled as 'self-neglecting' may contest its appropriateness, seeing in it a strategy to disempower and/or 'responsibilise' them.

This paper draws on (a) a review of 273 publicly-available safeguarding case reviews, and the policies and procedures found on English Safeguarding Adults Board websites, and (b) data from interviews with 69 practitioners from Health, Housing, Social Care and Fire & Rescue, and with 18 people with lived experience of self-neglect, to explore the meanings and uses of self-neglect in current health and social care practice. As responses to self-neglect continue to evolve in response to changing professional perceptions of risks and responsibility, practitioners find themselves navigating ethical and political concerns and conflicts over agency, safety and well-being. A critical reading asks what social dimensions of people's lives are foregrounded, and which are obscured, by classification under the concept of self-neglect.

Room 0.17 – Mental Health

Community competencies and young people's mental health in Colombia: Examining the case of a human capital building programme through a 'capabilities approach' lens

Sara Donetto, Shari Baddan, Maria Camila Garcia Duran, Philipp Hessel, Annie Zimmerman, Ricardo Araya Baltra, Fabio Idrobo

(Brighton and Sussex Medical School)

Colombia, a Latin-American country troubled by decades of armed internal conflict, has a high prevalence of mental health difficulties among its young people. Mental health stigma and fragmented, often inadequate service provision contribute to amplifying the problem. The 'Jovenes en Acción' (JeA) programme is a state-funded initiative based on conditional cash transfers and aimed at building social capital via supporting young people's education and wellbeing. In this paper, we draw upon data from one-to-one interviews and group discussions with staff from the JeA programme and young people registered as its beneficiaries. This data is part of a larger, ongoing mixed-methods study aimed at developing and testing a mental health intervention for Colombian youths. Here, we use analytical tools from stigma scholarship and Amartya Sen's 'capabilities approach' to explore how participants talked about stigma, mental health services and the programme itself. We suggest that the insights from this analysis point to ways in which existing support interventions for young people may be enhanced. In

particular, we draw attention to the possibility of strengthening the sociocritical approach of programmes such as JeA by adding emphasis on 'community competencies' to their existing, predominant focus on individual competencies. We argue that incorporating a collective focus in social interventions aimed at supporting human capital has the potential to strengthen young people's resourcefulness and to draw more attention to the structural dimensions of stigma.

Room 0.11 – Embodiment and Emotion

How people treat discomfort through affects? Reconceptualising therapy, care, and healing

Taoyi Yang

(The Free University of Berlin)

This presentation aims to discuss and distinguish three terms – therapy, care, healing – based on my digital ethnography of people's lay treatment practices and affective experiences in non-clinical settings. Rather than fully adhering to conventional sociological understandings of 'therapy', 'care', and 'healing', I have re-conceptualised the three terms based on the ethnographical material. By following persons from different countries and regions and their treatment practices online and offline, my digital ethnography reveals that lay treatment practices are primarily produced from and enacted through affective relations (i.e., affects) between humans and non-humans in socio-material settings, such as doing physiotherapy by following an instructor on PhysioApp, watching the 'Together at Home' online concert during the Covid-19 pandemic, or listening to rain sounds before sleeping. The reconceptualisation of the three terms reveals specific mechanisms of affects in forming people's ordinary perceptions and practices of treatment, and manifests the conceptual and practical plurality of treatment. 'Therapy' refers to affective treatment that is interwoven with popular therapeutic knowledge, and this knowledge is not directly learned from therapeutic discourses but is enacted in practices of affective treatment. 'Care' means that in some affective treatments, the affective relationality between digital content and situated engagement conjures up imaginaries of the self and others that move persons to care and feel cared for. 'Healing' corresponds to a 'healing boom' from East Asia, that is, to feel at ease by focusing on sensations induced by digital technologies and media that are mostly devoid of linguistic meaning and semantics.

Room 0.13 – Citizenship and Health

Immigrant experiences of mistreatment in sexual and reproductive healthcare in Spain

Simon Fern

(Rice University)

Medical spaces represent sites where patients come for healing but may encounter harm. Sexual and reproductive medicine exemplifies this dynamic. This mistreatment reveals insights into structural and cultural failings within healthcare. A growing literature discusses Spain's concerning relationship with obstetric violence; however, immigrant experiences are under addressed. Immigrant patients face additional challenges, driven by xenophobia, racism, and bordering. This study explores immigrant experiences of harm in sexual and reproductive healthcare, with the aim of developing evidence of this underrepresented issue. Informed by feminist scholarship, this study considers the intersecting identities, relations, and practices which produce and intensify this harm. In May-August 2023, semi-structured interviews were conducted with 121 respondents concerning health experiences since immigrating to Spain, reflecting diverse racial, ethnic, and national backgrounds. This paper draws from 69 respondents, primarily from the Philippines, the Americas, and Europe. Overarching themes including: 1) doctors expressing dismissive attitudes; 2) doctors behaving inappropriately and with prejudice; 3) doctors failing to respect patient autonomy and consent; 4) doctors mistreating patients during procedures. Respondents connected experiences of harm to prevailing issues with xenophobia,

racism, and misogyny in Spanish medical culture. Consequences include delayed and missed care, physical and psychological harm, and considerations regarding future migratory, medical, and reproductive decisions. Respondents provide insights into harms at interpersonal and structural levels. Results suggest failures in the care of immigrant patients, reflecting need for improved training, and integrating immigrant patients' perspectives into improving medical practice.

Room 0.18 – Open

Prostate cancer and banal nationalisms in medicine: A Japanese urological gaze

Genaro Castro-Vazquez

(Kansai Gaidai University)

Cancer encompasses the highest mortality and morbidity rates, and affects more men than women in Japan. Prostate-cancer has been clinically, structurally and culturally constructed as a 'lifestyle-related-disease', whose incidence is allegedly the result of population ageing and Westernised-eating-habits. Yet, advocacy of routine testing for prostate-cancer remains elusive. Grounded in an adaptation of the 'sexual scripts' theorising (Gagnon and Simon 2005), a sample of 21 Japanese urologists residing in Osaka, Kobe and Tokyo, was acquired through snowball-sampling and interviewed from 2021 to 2022, to unpack the impact of banal nationalisms in medicine—daily medical practice underpinned by cultural scripts related to the Japanese ethnic-self, rather than by clinical 'biological causation to explain illness' (Barry and Yuill 2008, 20), on their onco-practice. 'Systemic networks' (Bliss, Monk, and Ogborn 1983) guided interview-analysis, which indicates that the medics often (re)produce banal nationalisms in medicine via their view of an onco-self who embodies an 'essentialised' version of the Japanese-self involving rational-thinking, clinical-conformity, and reliance on familialism and the feminisation of care to grapple with cancer. In dealing with prostate-cancer, onco-biopedagogy emanating from the consumption of traditional Japanese food entangles banal nationalisms in medicine ingrained in prostate onco-practice. Lastly, officially endorsed and subsidised Traditional Japanese Medicine mirrors an element of onco-economics that is concerned with banal nationalisms in medicine. Nevertheless, emotionality underneath decision-making processes, and an onco-self asking for the use robotic surgeries casts a critical light on the validity of banal nationalisms in medicine when comprehending onco-practice.

Room 0.19 – Professions / Health Care Organisations

The organisation of policing occupational health charities

Helena King

(The Open University)

It is increasingly recognised that police officers experience mental and physical health impacts related to their occupation. In the UK, policing employer-led healthcare programmes are supplemented by the third sector, with police chiefs advised by the government to signpost employees to charities as part of a package of care. However, little research has been conducted on this hybrid approach to the organisation of policing occupational healthcare.

This paper presents findings from an exploratory mixed-methods study on charity sector healthcare provision for UK police. Through exhaustive searches of charity regulator databases, 54 charities delivering health-related services to policing employees were identified. Analysis of secondary data and focus groups with senior charity representatives reveal a complex mosaic of charitable organisations connected to police forces, funded predominantly by membership schemes.

Charitable activities are seen through the lens of medical pluralism, combining conventional clinical treatments with respite, complementary therapies, and services addressing social determinants of health. Distinct institutional logics create opportunities for police to disclose vulnerabilities, bridging gaps in healthcare provision caused by in-force health stigma and public stigma against police which hinder access to statutory health programs.

The study highlights resourcing challenges and uneven geographical distribution of policing occupational health charities across the UK, resulting in unequal availability of services for officers. These findings raise important questions for police leaders and health policymakers regarding the appropriateness of reliance on the third sector for healthcare support and whether lessons can be gleaned from their operational models to improve statutory healthcare services for police.

Room 0.20 – Inequalities and Intersectionality

Everyday life conditions and healthcare inequality for individuals with lung cancer not participating in rehabilitation

Mikala Erlik, Helle Timm, Anette Hinhede, Malene Missel
(UCSF)

Lung cancer is commonly associated with socioeconomic disparities, particularly in terms of access to rehabilitation services. There is limited research exploring the everyday life of individuals with lung cancer who do not participate in rehabilitation and how their everyday life conditions contribute to healthcare inequality.

This paper reports findings from an ongoing ethnographic study conducted among 12 individuals with lung cancer living in Denmark's capital city. Analysis of the empirical data reveals that individuals with lung cancer who do not participate in rehabilitation come from diverse socioeconomic backgrounds. Regardless of their backgrounds, they share similar daily challenges imposed by the illness, primarily through 1) physical limitations, 2) uncertainty about others' reactions, and 3) hospital appointments and treatments. Among these factors, the latter is considered the most disruptive. Notably, the participants do not perceive lung cancer as a transformative disruption but rather as a temporary obstacle amidst the ups and downs of life.

The findings point to novel perspectives for understanding the needs and available resources of individuals with lung cancer in relation to perceived inequality in rehabilitation. They also prompt a critical examination of the rationale behind participating in cancer-specific programs, especially when the individuals do not consider cancer itself as a significant disruption, particularly if the rehabilitation programs are related to hospital treatments that create the most substantial disturbances in the everyday lives of individuals with lung cancer.

THURSDAY 12 SEPTEMBER

10:45-11:15

Room 0.09 – Politics and Ethics / Theory

Investigating contracepting and its dimensions

Marie Larsson

(Usher Institute, The University of Edinburgh)

Contraception is often considered the purview of the fields of medicine and public health, less so sociology and critical social sciences. This has meant that a large majority of academic research into contraception has focused on the perspectives of healthcare providers, and individuals primarily when they enter the healthcare system as patients. While an individual's contraceptive journey can, and often does, include healthcare institutions, the journey seldom starts or ends there (Larsson, 2023). In fact, there are far more dimensions that people often must navigate and that make up their experience with contraception. As such, important wider questions are raised regarding how contraception is made possible or challenging, done or carried out, by whom, under what circumstances, and with what associated meanings and consequences.

To explore such issues, however, I suggest that a more holistic conceptualisation of contraception and contraceptive use is necessary. In this presentation, I am going to introduce such a conceptualisation, namely that of contracepting as an ongoing relational practice and doing, and outline its multifaceted dimensions. Namely, epistemic, emotional, identity, interpersonal, economic, physical/embodied, practical, and biographical dimensions. My aim with this paper is to provide a roadmap to investigating contraceptive experiences for researchers, practitioners and policy makers, to ultimately produce knowledge around sexual and reproductive health that is more responsive and reflective of people's actual everyday experiences, practices, needs, desires, and challenges.

Room 0.17 – Mental Health

“What's the point?": Epistemic injustice and young people's reported speech in their mental health case notes

Tessa Morgan, Jack Smith, Francesca Crozier-Roche, Taliah Drayak, David Graham, Robbie Duschinsky

(University of Cambridge)

Despite the long-standing policy push to include young people's perspectives in their mental health care, research about young people with social work involvement has consistently shown that they feel they are not listened to.

Drawing on Fricker's concept of epistemic injustice we examine the notes of 70 young people with a social worker (comprising 16,566 unique case notes) accessing one Child and Adolescent Mental Health Service (CAMHS) .

Our team of five researchers, including three experts-by-experiences, applied discourse analyses to the notes to examine how these young people's knowledge of their lives and needs was situated.

Recognising that case notes reflect the expectations of a system rather than what young people actually said, we consider how system-level priorities resulted in CAMHS professionals listening for risk, compliance and narrow mental health symptomologies. As a result of service resource limitations young

people's speech was included as proof of the authenticity of their words/actions. It was only if young people said the right risky things that they were deemed serious enough to receive care.

This decontextualised, risk-orientated approach to young people's speech resulted in testimonial invalidation whereby young people's stated preferences often did not align with what care they received. Younger children and those living in residential care were disproportionately viewed as lacking credibility. Epistemic justice, we contend, relies on professionals taking seriously young people's unique knowledge about their own emotional lives. Listening to young people requires better resourcing of mental health services to ensure young people's preferences can be actioned.

Room 0.11 – Embodiment and Emotion

Misoprostol and mifepristone in Argentina: The changing affective lives of the two abortion drugs after legalisation

Lea Happ

(King's College London)

In March 2023, Argentina's Ministry of Health announced that mifepristone had been approved for national production and distribution. Alongside misoprostol, mifepristone is the most effective abortion drug and generally considered the 'gold standard' of pharmaceutical abortion. Developed specifically for abortion, it is generally difficult to access in contexts with restrictive abortion laws. Meanwhile, the more generic misoprostol has long been widely available in pharmacies across Latin America, leading feminist activists to develop effective strategies for self-managed, misoprostol-only abortion. As others have pointed out, misoprostol has developed distinctive affective lives in the context of this activism, at times taking on personified identities within wider activist constellations.

With the legalisation of abortion in 2020, and more recently the domestic production of mifepristone, abortion in Argentina has been changing. In this paper, I trace how misoprostol and mifepristone have developed new affective lives alongside and in response to shifting abortion realities since legalisation. This work is grounded in interviews conducted between October 2022 and June 2023 as part of my ongoing PhD research, as well as an analysis of relevant activist publications and public health protocols. Drawing on literature from science and technology studies, reproductive sociology and feminist theory, I argue that the changing affective lives of the two abortion drugs since legalisation and over the course of the implementation process on the one hand reflect and other hand enable changing understandings of the relationship between pharmaceuticals, the body and reproductive freedom.

Room 0.13 – Citizenship and Health

Impact of Local self-governments through community members during COVID-19: An Ex Post Facto Analysis on the Panchayats in Rural Kerala

Kiran Prakash V

(Indian Institute of Technology Kharagpur (IIT Kharagpur))

The outbreak of COVID-19 was identified in Wuhan, China, in December 2019. Coronavirus, officially named Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), was declared a pandemic by the World Health Organization due to rapid and widespread transmission. This contagious and communicable disease became one of the significant public health challenges in the world. In India, the first coronavirus case was reported in the Thrissur district of Kerala on January 30, 2020. The government set up rigorous rules and regulations to safeguard the community from disease transmission. Several key strategies like surveillance, quarantine, good quality testing strategies, uninterrupted treatment services, community participation, proactive care for the elderly and people with comorbidities, and educational and social mobilization for behavioural change, contributed to

effective pandemic management. The WHO acknowledged the state's strategic planning and disease control, and social security methods, which came to be known as the Kerala model. The research aims to assess the challenges and response actions of local self-governments during COVID-19 and to assess the community perceptions of their impact. It uses the Social-Ecological Model (SEM) to understand the complex interplay of different societal systems which impacted the pandemic responses. The paper presents findings from the field study conducted in the research locale which highlights the emergency plans and policies, service delivery, communication and empowerment strategies of the local government during COVID-19. The paper also explains the perceptions of the community members regarding the impact of local government in the COVID-19.

Room 0.18 – Open

Privileges, unbearable lightness of masculinity and middle age crisis of ageing men

Iva Smidova

(Masaryk University)

An ongoing qualitative study on institutions of ageing men targets power and self-care relations of men as they age. The fieldwork in several social environments (marginalised and privileged) in the Czech Republic and work-in-progress analysis of in-depth face-to-face interviews with men provides an insight into men's conceptualisations of their relations, everyday performance and impact on health as they age.

This paper targets a more privileged group among our research participants and addresses their unreflected status presented as aspects of "ease". The analytical focus is on such a "lightness of being" as well as their accounts of the middle age crisis when reflecting on mental health, performance and bodily limits of their everyday achievement-oriented lifestyles. The outputs are based on interpretations of transcripts of interviews with men competing in veteran sports categories, managers passing on their businesses, and men participating in men's groups reviewing their own lives. The analysis addresses ageing men as a gendered category (Hearn and Parkin 2021) and is informed by CSMM (Critical studies on men and masculinities) approach. We target how „social privilege and the ways in which men in later life with accumulated social, cultural and economic capital experience social relations" (Willis et al. I, 2023: 223) and their mental health.

Room 0.19 – Professions / Health Care Organisations

Risk negotiation in emergency medical services: A model for multidisciplinary research

Shawnea Sum Pok Ting, Jo Angouri, Matthew Booker, David Rawlinson, Lauren Williams, David Lockey, Lyba Nadeem, Nigel Rees

(University of Warwick)

Risk negotiation in emergency medical services (EMS) dispatch is under-researched despite its significance for patient safety and cost-effective use of the services. Our project is the first in the UK addressing this gap through capturing risk negotiation holistically among various stakeholders along the dispatch decision-making pathway. We adopt an Interactional Sociolinguistics approach to study emergency calls and textual communication among the stakeholders alongside policy documents regulating EMS. Our design integrates ethnographic fieldwork and microanalytic analysis of emergency calls.

Our data show that risk indicators may be lost in the decision making pathway when call-takers need to balance completing scripted questions following a strict sequence; adding extra textual remarks when a caller's response does not directly address the particular scripted question asked; and allowing space for the caller to describe the situation in their own way.

Call-takers play an important role in risk negotiation and dispatch decision making. Under the current organisational structure, they have little power but to be expected to complete scripted questions. Our findings support healthcare organisations to re-evaluate the value of call-takers in strengthening EMS dispatch and delivery. Additional to focusing on completing scripted questions, sociolinguistic-informed training could be provided to call-takers to facilitate and empower this under-appreciated but essential group of stakeholders to co-create conversations with callers that maximise accurate expression, uptake, and transfer of risk, which is vital for EMS dispatch and delivery.

Room 0.20 – Inequalities and Intersectionality

Is pregnancy work?: An institutional ethnography of invisibilized maternal work and Dalit motherhood(s) in urban India

Pragya Roy

(The University of Sheffield)

Social organisation of maternity entails many activities. These include but are not limited to—maintaining health of foetus and pregnant woman, management of social relationships in the household, with health workers and surrounding society, managing mental stress, bodily discomforts and sensations, and receiving timely healthcare. Conventionally, these activities during pregnancy and related maternal health conditions have been devalued and/or rendered invisible through gender essentialist ideas of motherhood. They are also predominantly unpaid, unless women are paid surrogates, or they live in countries where pregnancies are incentivised. The nature and amount of activities also vary across social groups. Women from marginalised communities lack social and kin support, and themselves perform these activities in their maternal health journeys, along with regular housework, childcare and formal/informal work with limited resources.

In India, the maternal health of Dalit women, who are at the bottom of the caste hierarchy, and are further marginalised by gender and economic class, is of particular concern. With increased medicalisation of pregnancy, they find themselves managing demands from both familial and professional actors who exert authority over their bodies. Against this background, I introduce the concept of 'maternal work' to create an analytical framework that will enable to 'see' these previously invisible forms of work and its workers. Using observations, and interviews with Dalit women living in caste-based segregated urban slums in Kolkata, I explore these 'hidden' forms of work. I draw from the methodology of institutional ethnography, centering Dalit women's actualities—everyday doings—which might not have been traditionally deemed as 'work'.

THURSDAY 12 SEPTEMBER

11:20-11:50

Room 0.09 – Politics and Ethics / Theory

An account of structuralist institutional insulation in contested pharmaceutical spending governance

Ben Main, Dr Piotr Ozieranski

(Durham University)

Government pharmaceutical spending policy is an arena of capitalism in which state and external actors negotiate or compete for command over social equity, regulation, prices and the patterning of the socio-economic fiscal compact. Across the globe capital is ascendent in this relationship. This paper seeks to illuminate the sources of state and social power in this relationship from a negative case in liberal-democratic capitalist governance of pharmaceutical spending, that of New Zealand. In re-posing the classic, vexed dilemma in state theory of how state actors' decision making can be independent of those of external actors and the capitalist economy it draws together qualitative data sets from state-bureaucratic, legislative and judicial sub-arenas of the New Zealand state. A theoretical case of 'structuralist' institutional insulation is built through a reconstructive disposition to competing instrumentalist and structuralist concepts in the weberian-skocpolian institutionalist tradition and the strategic relational approach to state power. The explanation describes a structuralist insulation form. This explanation holds that the state agency's pricing strategies demonstrate an institutional source of a societal surplus to the state elite. Structuralist insulation in this understanding is thus simultaneously a 'demonstrable' substance, an activated nesting by higher state actors and a concomitant involution of 'instrumentalist' pressure space around the policy. The paper makes three sets of theoretical contributions. First the paper extends Jessops SRA with an empirically grounded argument. Second it introduces a form of insulation that bridges structuralist and instrumentalist emphases in state theory. Third for the political sociology of pharmaceuticals it problematizes John Abrahams Neo-liberal Corporate bias theory through the claim of a meso-organizational to macro-societal direction in contrast to NLCB's cultural-ideological premises and an account of actor acculturation whereby 'socially democratic' actors are made in the neo-liberal state in a process which has a source, potentially, in societal value.

Room 0.08 – Experiences of Health and Illness

Growing up with disability and chronic illness: The significance of institutional responses and intersectional inequalities in shaping living with difference

Janice McLaughlin, Jane Cullingworth, Edmund Coleman-Fountain, Charlotte Pearson, Katie Salmon, Tracy Shildrick, Nick Watson

(Newcastle University)

An important area for bringing disability studies and medical sociology together is examining the experiences of people whose mind-body differences involve both impairment and chronic illness. This presentation, based on an ESRC project, explores what disabled young people in the North East of England and Central Scotland are experiencing as they move towards adulthood. Within our participants, the mind-body differences, including mental health issues, discussed do not always sit clearly within categorisations of impairment or illness. The project involves a range of methods, including interviews and creative activities with disabled young people, as well as interviews with people

who have a disabled young person within the family and actors in organisations who support disabled young people. The presentation will report on the first wave of interviews with disabled young people. We explore the material, social and political conditions in which stories are being shared with us to understand how living with varied mind-body differences is influenced by the world around our participants. For example, how childhoods marked by long drawn-out diagnostic investigations affect the levels of support provided in places such as education. How limitations in service provision in education and social care contribute to the difficulties disabled young people can experience. How the socio-economic contexts within which disabled young people grow up, including poverty, can make living with mind-body differences more difficult. Our overall argument is that growing up with varied mind-body differences is influenced by limitations in support and unwelcoming mainstream spaces in areas such as education.

Room 0.17 – Mental Health

The role of guilt and shame in forensic psychiatric assessment and treatment

Piyush Pushkar

(University of Manchester)

This paper examines how clinical and legal professionals understand, interpret and mobilise guilt and shame during legal proceedings for mentally unwell offenders. An initial hypothesis was that highly educated professionals are simply policing people from more deprived backgrounds, using a moral language of care in which guilt and shame play a key role, the function of which is to individualise responsibility for social deviance. However, my research – based on interviews with the professionals that write and make use of medicolegal reports - nuances this picture, illuminating the ethical labour that bridges the gaping inequality between doctors and lawyers on one side, and prisoners or patients on the other.

Feelings of guilt and shame play an important role in the assessment of mentally unwell offenders. Clinicians consider these emotions while forming clinical judgements regarding diagnosis, personality, and risk. Clinicians then make decisions based on these assessments, not just for treatment plans but also for medicolegal reports that influence court processes.

Sociologists and philosophers have drawn links not just with trauma, adverse childhood experiences and offences, but also with class, gender and ethnicity. Shame has been described as a key technology of responsabilisation, contributing to the production and maintenance of socioeconomic inequality. Recent anthropological studies have enriched the study of responsibility, demonstrating the overlapping, multidirectional push and pull of competing responsibilities. This paper advances the literature on responsibility and responsabilisation by investigating how and why particular emotions are pathologised, and who benefits or loses out from such pathologisation.

Room 0.11 – Embodiment and Emotion

The impact of work on children's health, who engaged in the informal weaving sector in Addis Ababa, Ethiopia

Garedew Desta

(The Organization for Social Science Research in Eastern and Southern Africa (OSSREA))

Child labor is a significant issue in developing countries like Ethiopia, with detrimental effects on both the children involved and society as a whole. This study aimed to explore the health impacts of child labor in the informal weaving sector in Addis Ababa. Utilizing a qualitative research approach, data was gathered through interviews, focus groups, and observations.

The findings revealed that children in this sector face numerous health challenges, including communicable diseases such as scabies, headaches, stomach-aches, coughs, typhoid, typhus, and musculoskeletal pain. Additionally, skin diseases like scabies, dandruff, and trachoma were prevalent due to poor personal hygiene, substandard working conditions, and inadequate nutrition.

Poverty was identified as a key driver of child labor, emphasizing the importance of addressing socio-economic issues through education and awareness campaigns targeting parents, employers, and the community. By addressing these underlying factors, efforts can be made to safeguard the health and well-being of child weavers in Addis Ababa and mitigate the negative impacts of child labor on both individual children and society at large.

In conclusion, the study sheds light on the urgent need to address the root causes of child labor in Ethiopia and implement targeted interventions to protect the health and rights of vulnerable children engaged in the informal weaving sector. Through collaborative efforts at various levels, progress can be made towards creating a safer and healthier environment for these young workers.

Room 0.13 – Citizenship and Health

A study on online local community design to improve health literacy of the elderly - The case of Minami-Alps City: Utilizing a decentralized personal data application and online survey for communities desired by elderly

*Kenichi Shibata, Ikuko Tsumura, Koiti Hasida
(RIKEN, Tamagawa University)*

As the world's birthrate declines and the population ages, loneliness among the elderly due to social isolation is an issue. Research conducted by the Japanese government has shown that the existence of a community that promotes human connections is an effective measure to combat social isolation among the elderly. The number of studies on online communities for the elderly has been increasing recently. However, few studies have empirically investigated the impact of online communities on the health and well-being of the elderly. Therefore, we took the following two steps. First, we conducted a questionnaire on the community design the elderly desires. Second, we developed and tested an application to promote interaction among the elderly. By assessing the participants' health literacy in the experiment, we investigated the impact of community participation on healthy living.

In the first survey, we surveyed 1,000 older adults in Japan aged 60 and older. The results showed that the willingness to participate in the community increases with age.

The second demonstration experiment used a communication support application developed using a PLR library based on decentralized management technology that enables safe and secure management of personal information. It was conducted on 29 elderly people with the cooperation of Minami-Alps City, Yamanashi Prefecture. The results showed that the app users' communicative and critical health literacy was significantly higher than that of the general elderly population.

The analysis suggests that the proposed app could further assist elderly people with self-reliance and good health and empower community coexistence.

Room 0.18 – Open

Therapy embedded in local support system: Autism-related therapy in Japan's 'Ryoiku'

*Sawako Shinomiya
(University of Exeter)*

[Research question and objective] This paper aims to reveal how internationally known therapy such as applied behaviour analysis (ABA) is embedded in Japanese care systems for autism, especially in a scheme called 'ryoiku'. This research will depict the way that international medico-psychological knowledge is locally situated in non-Western contexts, which has been underexamined.

[Background] In Japan, children with autism take ryoiku in a regional ryoiku centre. Ryoiku might include internationally known therapy, but playing, eating, doing homework, etc. are also conducted as ryoiku. 'What is ryoiku?' and 'How is it different from therapy?' are the questions of this research, but workers in ryoiku centres also hold the same questions and there are public discussions on what is ryoiku, what it should be, and whether it should be more 'scientific' by incorporating internationally known therapy more.

[Method] I interviewed workers in ryoiku centres in Japan to reveal how they define ryoiku, what practices are conducted as ryoiku, and how they think of internationally known therapy.

[Findings] Japanese ryoiku workers think ryoiku is a holistic practice; Ryoiku approaches not just children's autistic traits but their daily life and their parents' well-being, and thus simply letting children play is meaningful if it works as respite care. Some interviewees were cautious about internationally known therapy while they think ryoiku should be more 'evidence-based' and 'based on expertise'. They viewed therapy as one component of ryoiku, in other words, a mere option for supporting daily life that should be examined from the holistic perspective.

Room 0.19 – Professions / Health Care Organisations

NICE ideology and reality: 25 years of pharmaceutical cost-effectiveness regulation in the UK

John Abraham, Gowree Balendran
(King's College London)

2024 marks a quarter-of-a-century since the National Institute for Health and Care Excellence (NICE) was established in 1999. NICE regulates the cost-effectiveness of pharmaceuticals (among other things), that is, it assesses whether or not (new) drugs already approved on to the market as safe and efficacious are good value-for-money for the NHS to purchase/prescribe. Drawing on data from our eight-year (2015-2023) empirical investigation of NICE, the most extensive such social scientific inquiry to date, involving far-reaching documentary research and ethically approved non-random interviews with relevant informants and sampled observations of meetings, this paper focuses on how NICE, as a meso-level organization, relates to the stakeholder interests it regulates, such as the pharmaceutical industry, the NHS, patient groups, and wider public health. By reference to (medical) sociology theories of corporate bias, neo-liberal ideology, pluralist polycentricity, and regulatory capture, we aim to characterize NICE's twenty-five years of pharmaceutical cost-effectiveness regulation, and to consider the implications for stakeholders, public health, and for understanding public perceptions/representations of NICE throughout the period. We argue that the ideology of 'the fourth hurdle', in which NICE is predominantly portrayed as withholding access to expensive drugs on the NHS - perpetuated by a few high-profile regulatory decisions and court cases involving NICE and patients/patient groups - is inconsistent with the reality of NICE's decision-making at the meso-organisational level. In fact, after NICE was established, NHS expenditure on pharmaceuticals grew by about £1 billion annually. This paper suggests that sociological understanding of NICE can help to explain why.

Room 0.20 – Inequalities and Intersectionality

Candidacy and the 'ED logic': An ethnographic study of physical illness diagnosis in emergency departments, for patients with a concurrent mental health condition

Archana Jayaprakash, Elisa Liberati, Graham Martin, John Gibson

(University of Cambridge)

Emergency Departments (EDs) are commonly considered to have porous boundaries: access is typically afforded to everyone who presents. However, our multi-site ethnography reveals that asserting 'candidacy' (Dixon-Woods et al., 2006) for physical health diagnosis in EDs is not always straightforward for patients with co-occurring mental health conditions. We explore the tensions experienced by patients and staff across the diagnostic process, offering implications for practice, the theory of candidacy, and wider literatures on access and diagnostic disparities. Analysis draws on 276 hours of observation and 42 interviews across three English EDs.

We demonstrate how the presence of mental health conditions creates additional challenges for patients and staff throughout the diagnostic process. For example, patients with mental health conditions at times struggle to identify their symptoms as worthy of attention in a timely fashion, accessing the ED as a 'last resort'. Some required more time to communicate their concerns than ED staff could provide; others struggle with diagnostic testing due to traumas or phobias. Staff's 'adjudications' are shaped by the presence of mental health conditions: while some doctors seek to mitigate stigma and 'diagnostic overshadowing', others conflate mental health difficulties with challenging behaviours, aggression and deceit - with consequences for diagnostic decisions.

We propose the concept of 'ED logic' to describe an operational mode that prioritises acute, life-threatening conditions, and fast, decisive actions. ED logic may systematically disadvantage mental health patients presenting for physical health care, who often struggle to present their needs as urgent and legitimate according to dominant criteria.

THURSDAY 12 SEPTEMBER

11:55-12:25

Room 0.09 – Politics and Ethics / Theory

Barriers to health services for residents in underserved wards in East and West Birmingham

Alexis Paton, Celine Benoit

(Centre for Health and Society, Aston University)

Access to health services is experienced unequally throughout Birmingham. Following the principles of the inverse care law, residents of the most deprived wards of Birmingham often have the least health services available to them, precluding them from living as healthily as possible. In this presentation we discuss the development and findings from a collaboration between Aston University, Birmingham Community Healthcare NHS Foundation Trust, and Citizens UK, which aimed to better understand health inequalities in the most deprived wards of East and West Birmingham. Using an innovative methodology of health listening, we held five listening events with these underserved communities to understand local challenges to accessing health services. The biggest barriers that residents identified included:

GP accessibility

Language barriers and lack of suitable translation/interpretation services

Lack of continuity of care

Inadequate support and provision for children and young people services

A community sandpit event was held to co-produce solutions to respond to these challenges. With that information, a series of co-produced initiatives were launched, funded by the project partners, to help tackle barriers that lead to poor health outcomes in these areas. Five follow-up projects were funded to support health and wellbeing among local residents. We end this presentation with a discussion of these projects and three recommendations to health and social care providers to improve provision and access of services. The project serves as an example of how using our innovative health listening approach can provide targeted solutions to issues of health and social care access in different communities.

Room 0.08 – Experiences of Health and Illness

Flexible bodies, rigid boxes: The construction, classification, and diagnosis of hypermobility disorders

Melissa Martin

(Cardiff University)

Joint hypermobility, or double-jointedness, is often experienced as benign and can prove beneficial to athletes or performers. However, in some people, it is associated with pain, fatigue, and/or frequent injury, or is indicative of an underlying condition affecting the connective tissue. Following longstanding ambiguity around how such cases should be diagnosed, a group of specialised researchers and clinicians designated a new classification and diagnostic criteria in 2017. Although this change was intended to reduce overlap between diagnostic labels and provide clear guidelines for how these conditions should be diagnosed, it resulted in widespread confusion among patients and professionals, and reenergised debates about how hypermobility disorders can best be defined and classified.

In this presentation, I examine the social implications of the ongoing construction and reclassification of disorders related to joint hypermobility. Drawing upon my PhD study – specifically my observations of community and professional conferences, and interviews with patients, clinicians, and researchers – I consider the consequences of changes to the definition, appellation, and categorisation of hypermobility disorders. Throughout my analysis, I illustrate the complex interplay between diagnosis as category and diagnosis as process. I reflect on how this interplay provides means for making sense of illness but also how it generates tensions where there are conflicting drivers behind the theoretical classification and practical application of diagnosis. Exploring how such tensions generate uncertainty and prompt reclassificatory work, I conclude with consideration of how diagnostic work demands compromise between competing pressures and allowances for how flexible bodies resist rigid classification.

Room 0.13 – Citizenship and Health

Alignment, liminality and disruption in social media visuals of BRCA hereditary cancer syndromes

Stefania Vicari, Hannah Ditchfield, Yu-Ning (Nock) Chuang

(The University of Sheffield)

Sociologists have pointed at the role of public visuals in offering “anchoring potential” (Radley and Bell 2007: 369) for shifts in “disease regimes” (Klawiter, 2004), namely, in providing the cultural fabric for changes in dominant practices, discourses, actions and policies through which diseases are experienced and socially constructed. However, while some attention has been drawn to social media visuals of illness as enhancing information sharing, peer support and patient advocacy (e.g., Mazanderani et al., 2013), the role that digital platforms play in shaping these visuals has been mostly overlooked. In other words, we do not know how the techno-commercial contexts where social media visuals originate play with reinforcing or hindering dominant practices of illness and medicine.

We present an investigation of popular public visuals relevant to BREast CAncer (BRCA) hereditary cancer syndromes posted on Instagram, Twitter (now X) or Facebook over the course of twelve months. By combining cultural analytics, visual network analysis and interpretive techniques (Rose, 2023) of the 10 most engaged with monthly posts containing still visuals (10 top visuals * 12 months * 3 platforms = 360), we identified commonalities and differences across platforms and within the overall social media ecosystem. Our analysis suggests that BRCA visuals gaining traction on mainstream social media polarise in two directions, with the condition being discursively constructed as either an embodied matter or an issue of cancer and genetics. Our conclusions elaborate on how this plays with existing societal practices along three dimensions: of alignment, liminality and disruption.

Room 0.18 – Open

Community power, charity and healthcare at the edge of a National Health Service

Ellen Stewart, Francesca Vaghi

(University of Glasgow)

People in remote and rural parts of Scotland often experience lengthy and arduous journeys to access basic diagnostic equipment. This paper explores community responses to this in Shetland, an archipelago of islands at the far North of Scotland where, in the last twenty years, two successful fundraising appeals have purchased expensive scanners (a CT scanner and an MRI scanner). Rather than dwell on the lack (of healthcare funding, or of equipment which is widely available in mainland Scotland), fundraisers planned engaging and celebratory activities. Awareness of longstanding inequalities in access to services was tempered by a keen understanding of the inevitability of material

challenges of living on what one interviewee described as “a windy rock in the middle of the sea”. We characterise this as ‘pragmatic ambivalence’, a sphere of community participation guided by a sense that the public need to ‘take matters into their own hands’ in the face of service scarcity, and argue that pragmatic ambivalence is a defining affective characteristic of public fundraising in the National Health Service. We trace the ways that pragmatic ambivalence challenges, yet also enables, institutional systems of resource allocation. Appeals subverted institutional systems of resource allocation: there was a shared understanding that, once purchased, the scanner would become part of the NHS estate, and therefore ‘Edinburgh’ would meet its running costs including its eventual replacement. However appeals also sustain institutional systems: enabling state-provided healthcare to continue without overt challenge to metrics which disadvantage remote populations.

Room 0.19 – Professions / Health Care Organisations

Teaching patients pain management: Examining e-learning practices

*Anette Lykke Hindhede, Christina Andersen, Tom Moeller, Karsten Lassen, Bitten Dybdal
(UCSF Center for Health Research/University of Copenhagen)*

The growing trend of shifting procedures from hospital care to ambulatory surgery in Denmark and elsewhere necessitates patients to take greater responsibility for their recovery. Our study focuses on how healthcare professionals teach post-surgery pain management through an app. We analyze 10 instructional videos and conduct 20 telephone interviews with patients one week after surgery. Our investigation explores the app’s modes of communication and draws on the conceptual toolkit offered by the Semantics dimension of Legitimation Code Theory (Maton 2013, 2019; Walton & Rusznyak 2020) to better understand the context-dependence and complexity in meaning in these teaching practices and the potential for cumulative knowledge building. We analyze semantic profiles in the videos and relate them to patients’ experiences and pain management approaches. Our findings indicate that the accompanying videos’ expressive communication styles require specific patient resources, such as digital and health literacy. Moreover, the effectiveness of the app in conveying medical knowledge about pain were contingent on the patients’ resources. The familiarity of examples and presentation style also influenced knowledge building, necessitating diverse skills like linguistic proficiency. Consequently, the instructions provided may not adequately empower patients to address specific pain-related post-surgery situations. In conclusion, when educating patients to take an active role in their medical care, it is essential to create equitable learning opportunities that accommodate patient diversity. This means that the educational materials must be responsive to individual contexts and build upon patients’ previous knowledge, integrating with knowledge acquired in other contexts and at different points of time.

Room 0.20 – Inequalities and Intersectionality

Experts by experience: Working with Travellers in Lincolnshire to improve access to healthcare

*Laura Way
(University of Roehampton)*

Travellers are among the UK’s most socially excluded groups and have the worst health outcomes of any ethnic minority (Women and Equalities Committee, 2019). At policy level, attempts to tackle such health inequalities have been criticised for their limited success (Holman et al, 2021), particularly concerning the health status of Travellers, further underscoring the value of local charities/organisations who work with Traveller communities ‘on the ground’. Lincolnshire Traveller Initiative (LTI) is one such

organisation, who have been exploring a number of ways to positively raise health outcomes for those they engage with; including 'Well Woman' groups and 'Health Champions'. Various factors can contribute to the barriers obstructing adequate healthcare access for such communities, making outreach increasingly important (Keat et al, 2020). This paper will share findings from a recent collaborative research project with LTI in which Travellers, trained as peer researchers, co-developed a set of recommendations for local healthcare providers concerning how to better engage Travellers in their services and develop inclusive outreach with a view to increase healthcare access, raise health outcomes and go some way to tackling the health inequalities of these particular communities.

SPECIAL EVENT

THURSDAY 12 SEPTEMBER

14:00-15:40

Room 0.18 – Critical Public Health

Power, public health and the sociological imagination

Katie Powell, Rebecca Mead, Nick Fox

(University of Sheffield)

There are increasing calls in UK policy and guidance to enhance the use of sociology in public health practice. However, social theories of power, which are multiple and contested, can seem abstract and inaccessible to practitioners and policy-makers concerned with the immediate practical challenges of health and social inequalities. UK sociologists have identified a need to explore how sociological concepts, tools, and methods are used in practice, and how these can be developed to better meet the particular needs of public health practitioners. This special event is designed to generate discussion and action planning among sociologists who influence public health research and practice.

We present two case studies of sociological frameworks used in practice in England. First, we present an application of McCartney et al.'s (2020) place-based power framework to participatory systems mapping with local government officers and second, an adaptation of Popay et al.'s (2020) community power framework for use by community groups to better understand how power operates in their setting and inform action on their aims.

We reflect on the opportunities and challenges of working with academic frameworks in a practice-based context. We will ask a) what can we learn from these examples; b) where and how can we extend collective learning on such examples and c) what opportunities are there for action research to enhance the use of power frameworks in public health practice?

THURSDAY 12 SEPTEMBER

14:00-14:30

Room 0.09 – Patient-Professional Interaction

“I want to get out... I've got a child at home”: intersubjectivity and reality disjunctures in the care of people living with dementia

Alison Pilnick, Rebecca O'brien, Suzanne Beeke, Isabel Windeatt-Harrison, Lauren Bridgstock, Rowan Harwood

(Manchester Metropolitan University)

Intersubjectivity (the shared understanding of thoughts, meanings or feelings between two people) is a phenomenon which has long exercised philosophers (see e.g. Husserl, 1960). However, it is also a practical social problem; as Schutz (1966) argues, the intersubjectivity of the lifeworld is the basis on which all social relationships are founded. The pivotal role of language in achieving intersubjectivity can create particular problems in contexts where medical conditions affect the use of language. Dementia is one such condition (Dooley et al, 2015). In this paper we present data from two UK-based NIHR funded projects, collected from acute healthcare of the elderly wards in two general hospitals.

We collected 94 video and audio recordings of interactions between healthcare professionals (HCPs) and people with dementia (PWD). For our second project, patient participants were identified by their healthcare team as being prone to showing distressed behaviours, and data collection was targeted accordingly. Data were analysed using conversation analysis.

Using Pollner's (1975) concept of reality disjunctures, and drawing on previous work by Lindholm (2015) and Hyder and Samuelsson (2019), we explore how HCPs respond to the challenge of competing experiences of the world. We analyse the ways in which the lack of a common reality becomes apparent, the approaches staff use to manage or avert the distress which can occur as a result, and the consequences of these approaches. Our analysis shows some of the ways in which PWD can be supported to maintain a social rather than a subjective self.

Room 0.17 – Health Service Delivery

The geopolitics of Covid-19 variants: genetic sequencing and technology governance during the pandemic

Edison Bicudo

(Aston University)

The role played by vaccines, healthcare services, and healthcare providers during the Covid-19 pandemic (2020-23) has been studied in social sciences. However, another aspect deserves more detailed analysis: genetic sequencing. Initially used in Covid diagnosis, sequencing subsequently proved fundamental for the identification of new Variants of Concern (VOCs), which, in its turn, was essential for designing pandemic response measures and vaccination programmes.

The genetic monitoring of Covid VOCs revealed key features of the global biomedical landscape. Some VOCs emerged and were identified in the same country – such as the Alpha variant in the UK – whereas other VOCs had an international trajectory – such as the Gamma variant, which emerged in Brazil and was initially sequenced in Japan. Whereas some countries – such as the USA – built up high-throughput sequencing facilities and developed artificial intelligence-based algorithms for VOC detection, other,

low-income countries – such as Zimbabwe – exported biological samples for VOC monitoring. At the same time, some non-hegemonic countries could play key sequencing roles – such as South Africa and Botswana, both involved in the detection of the Omicron variant. Furthermore, the pandemic intensified a global market for next generation sequencers, reagents, and associated hardware.

This presentation focuses on this political economy of Covid-19 genetic sequencing. Based on a literature review and interviews with laboratories and companies of various countries, this study scrutinises the old biomedical patterns which were consolidated by the pandemic, as well as the new scientific and governance avenues opened up during the outbreak.

Room 0.11 – Lifecourse

“It’s really easy to fall under the radar and get lost”: Being unseen in postpartum care pathways after hypertensive pregnancy

Lisa Hinton

(University of Oxford)

Hypertensive disorders of pregnancy are experienced by around 10% of women and are among the most severe health problems affecting people during, and in some cases, following pregnancy. Symptoms can persist in the weeks and months following birth, with potential to impact on longer-term health. Postnatal care is critical but provision has been described as not fit for purpose and haphazard. To understand what care women receive, how it gets done, and additional barriers for minority or socially deprived groups, we undertook remote and face-to-face semi-structured interviews and focus groups with 44 women with a hypertensive pregnancy in the past 3 years and interviews with 35 health professionals providing postnatal care in NHS trusts and primary care and community services in England. Additional efforts were made to recruit seldom heard groups. Interviews explored experiences of high blood pressure during pregnancy, postnatal care, what works well, and perceived gaps in care. Thematic analysis revealed that, despite the first 6 weeks being an important period for managing blood pressure, women often fall through the cracks between secondary and primary care; discharged from maternity services after 2 weeks but not picked up by their GP until the 6-week check. Invisible to these siloed specialities, they are faced with new self-management/surveillance responsibilities alongside the work of new motherhood. Analysis was informed by the theory of responsabilisation and draws on Scott’s ‘sociology of nothing’, in particular her writing on invisibility and gaps to explore these responsibilities and the consequences of being ‘unseen’ between services.

Room 0.13 – Professions

Choosing to study medicine: How minority ethnic 6th Form students make that choice

Ashok Patnaik, Etyln Kenny, Christian Darko, Joanne Duberley, Dulini Fernando

(University of Birmingham)

Theory: Sociological theories of ‘careership’ and Bourdieu’s concepts of ‘capital’ and ‘habitus’, including an intersectional approach, were employed to explain how minority ethnic students make the choice of whether to study medicine and how social context influences this choice.

Research Aims and Methodology: Focus groups with minority ethnic Year 13 science students were used to understand how they decided on a career in medicine and to explore motivators, enablers and perceived barriers. We conducted 12 focus groups across 7 schools and 1 Further Education college - nine focus groups with medical school applicants and three with a comparison group of science students not pursuing medicine. 47 girls and 38 boys, from various minority ethnic groups, from selective and non-selective schools and colleges, participated.

Findings: The principal enablers of a medical career were an interest in science; perceptions of medicine as a 'caring' and highly 'rewarding' profession and a safe, stable career; and aspects of doctors' jobs (e.g. variety, patient-doctor interaction). Social institutions such as family, schools, universities, and communities, along with students' social identities (e.g. minority ethnicity, religion) and work experience, played important enabling roles by shaping students' motivations and offering practical support. The main barriers were the challenges of working in medicine (e.g. work-life balance) and low pay. Disadvantages associated with minority ethnicity (e.g. racism) and its intersection with female gender and low socio-economic status made medicine less attractive. The findings revealed how students exercised their agency in relation to structural factors in choosing to enter medicine or not.

THURSDAY 12 SEPTEMBER

14:35-15:05

Room 0.09 – Patient-Professional Interaction

Moral evaluation in the age of liberal individualism: Revisiting Parsons' sick role in four English emergency departments

Bella Wheeler

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

Parsons (1951) notion of the sick role proved a seminal moment in medical sociology exposing the underpinning ideological frameworks that shape everyday healthcare interactions. Sociologists including Hughes (1988), Jeffrey (1979), Silverman (1989) and Strong & Dingwall (2001) have explored how healthcare staff legitimise patient access to the sick role, and how encounters shape access healthcare. In this presentation we explore the idea that since the 1970s an ideological shift has taken place within society and healthcare institutions and this has altered these legitimisation processes. This has moved from civic republicanism underpinning the foundation of UK public health provision in 1948, and towards liberal individualism in the 1970s and increasing marketization. This has altered the moral evaluation of patients. Drawing on an ongoing NIHR funded ethnographic study of inequalities in waiting times in four English emergency departments, and an analytical framework informed by narrative analysis (Andrews et al 2013, Bamberg & Andrews 2004, Bruner 1991, Georgakopolou 2006), we explore how these shifts and the potential construction of the patient as consumer, with associated concepts of patient rights, might have disrupted emergency care work and ideas of worthiness and the subsequent moral evaluation of patients. We explore whether the determining of entry into the sick role is still a feature of contemporary English emergency departments and if so, what the consequences might be for patient and professional interactions, health and healthcare more widely.

Room 0.08 – Mental Health

Migrant Chinese women's online social support in the UK and its impact on their postnatal mental wellbeing

Siyi Wang

(University of Sheffield)

Social support has been shown to be an effective factor in improving women's postnatal mental wellbeing. Medical sociologists unpack social support as informational support, emotional support, and tangible support (Lin et al., 1999). For migrant population, seeking social support from digital spaces is popular because they lack adequate offline social networks to provide social support in host countries.

In order to understand migrant women's experience of developing peer relationships to obtain social support in digital spaces and how the social support affects their postnatal mental wellbeing, my project focuses on migrant Chinese mothers living in the UK as an example. Twenty semi-structured interviews and three focus groups were employed to collect data. In my presentation, I will outline how my participants characterise supportive peer relationships in online groups. I will then address the types of social support that emerged from the groups and show how the social support affects migrant Chinese mothers' postnatal mental wellbeing. The research shows that informational support actually functions as emotional support to mitigate migrant mothers' negative feelings during the postnatal period. Mitigating educational anxiety is particularly a prominent characteristic of a supportive peer relationship for migrant Chinese mothers.

Currently, sociological scholarship's understanding of how people perceive and process social support is mostly determined by Western perspectives. My research contributes to the concept of social support by exploring the lived experience from the perspective of migrant Chinese mothers. This could therefore increase the cultural sensitivity of the current theoretical framework of social support.

Room 0.17 – Health Service Delivery

Powerless or powerful? Contested narratives surrounding organisations' engagement with those affected by safety incidents

Polina Mesinioti, Sarah Hampton, Gemma Louch, Jane O'hara, Laura Sheard
(University of York)

In 2022, the largest change in patient safety incident governance, structures, and processes in several decades took place, with the introduction of the Patient Safety Incident Response Framework (PSIRF) across all NHS Trusts in the UK. We conducted qualitative interviews with 50 NHS staff to understand the landscape of standard practice in relation to patient safety incident management, monitoring, and investigation before PSIRF implementation. Interactional Sociolinguistics, an established discourse analytic approach, was employed for the co-examination of the micro- (here-and-now interactions) and macro-level (broader social context within which actors operate). We focus here on staff's narratives surrounding the Trusts' engagement with patients and families affected by safety incidents.

Findings illustrated two contested narratives: the first one is organisations' lack of engagement with patients and their families, which is largely attributed to external forces with interviewees appearing powerless (e.g., centrally mandated timelines, rigidity of the Serious Incident Framework). The second, less frequently employed, is the consistent engagement with patients/families, attributed to local factors, with interviewees foregrounding their role in this process (e.g., capable staff in strategic positions, strong team relationships). We discuss how these narratives are constructed through certain linguistic strategies, including othering processes and emphatic speech, as well as how they are situated in the broader organisational context (professional roles, organisational priorities).

Nuanced perspectives delving into the intricacies of staff narratives in the context of patient safety frameworks, as the one taken here, have the potential to unravel the complexities of health service delivery and inform policy implementation.

Room 0.11 – Lifecourse

Successful" ageing in later older age: A sociology of class and ageing in place?

Kate Gibson
(Newcastle University)

Supporting people to 'age in place' – to live independently at home and remain connected to the community – is an international policy priority. But the process of ageing in place is mediated in a socio-cultural context where neoliberal tropes of successful ageing reproduce a pervasive model about 'ageing well' by elevating ideals of individualised choice and self-governance.

Based on two waves of qualitative interviews and interim observations, we employ a Bourdieusian conceptual framework to explore the ramifications of this context on the experiences of 46 longer-living older adults (80+) ageing in place in North East England. All participants enacted everyday improvisory practices to render their homes habitable. But our participants – most of whom were located in middle-class social positions – supplemented such improvisations with a strategic disposition to plan for and actively shape their ageing-in-place futures. Our participants conveyed a distinct sense of agency over

their ageing futures and underpinning their orientations to practice was an awareness of the value attached to individually 'ageing well'.

Our analysis demonstrates the role of capital, accrued throughout the life course, in bringing such future trajectories into effect. The central argument of this paper therefore is that the embodiment of (neoliberal) ideals of successful ageing in place requires the deployment of classed capital. In sum, contrary to the individualising narratives ubiquitous in policy pertaining to ageing well, we show the importance of classed structural moorings in this process.

Room 0.13 – Professions

How far can you go? Ethnic minority doctors' choice of specialty in medicine

Christian Darko, Etlyn Kenny, Joanne Duberley, Dulini Fernando, Ashok Patnaik, Richmond Egyei
(University of Birmingham)

There is ongoing interest in ensuring that the medical profession is representative of the society that it serves. But despite being well-represented in medicine, ethnic minority doctors fall behind their white counterparts in pay and career progression. To understand the underlying mechanisms, this ongoing study analyses how doctors' characteristics, namely ethnicity, and other factors such as gender, socio-economic status, and academic performance affect choice of specialty.

The study uses individual-level data from the UK Medical Education Database for a cohort of medical doctors that started medical school between 2007 and 2013 and had already applied to and started specialty training. Econometrics techniques including OLS are used in the first instance to analyse the effect of ethnicity and other factors on the number of applications made, number of offers received and accepted. Multinomial regressions are then used to examine the likelihood of an individual allocating to a specific specialty. Potential individual-level heterogeneities in specialty allocations will also be addressed using Propensity Score Matching technique to construct samples of ethnic minority individuals comparable to samples of White individuals.

Preliminary findings indicate that despite no significant differences in 'point of entry' test scores, ethnic minority doctors make, on average, more specialty applications than white doctors but are also associated with reduced offer rates. In terms of specialty allocation, initial descriptive overview illustrates that ethnic minority doctors apply in higher proportions than white doctors to higher income and surgical specialties. This finding is consistent with results from multinomial regressions when other factors are controlled.

Room 0.19 – STS and Medicine

The hidden algorithms in Molecular Tumor Boards and the widening gap between research and care

Dominik Hofmann, Elena Esposito
(Bielefeld University)

The presentation explores the role of algorithmic procedures in the implementation of Precision Medicine (PM), guided by the exemplary case of Molecular Tumor Boards (MTBs). Having emerged from the confluence of traditional Tumor Boards and the increasing molecularization of medicine, these interdisciplinary expert panels issue treatment recommendations for cancer patients for whom baseline therapy has failed. Almost all their tasks implicitly rely on a range of advanced algorithmic tools. Yet the crucial contribution of algorithms in all stages of the processing of molecular data is neither acknowledged nor mentioned. Drawing on our empirical observation of the deliberations in MTBs, combined with interviews conducted with MTB participants and administrators, it is argued that creating

this relative invisibility is precisely a function these institutions fulfill. Instead of being the open negotiation between various fields of expertise as which it is commonly presented, the MTB session is highly streamlined and geared to confirming a pre-prepared recommendation. The mediation through MTBs provides algorithmically processed data with the legitimacy required to be implemented in medical decisions. By arguing thus, a contribution is also made to the debate about the changing relationship between research and clinical in the realm of PM. Contrary to the widespread assumption of a blurring boundary between both fields, the claim is made that the intensification of contacts and exchanges among research endeavors and clinical operations makes the separation between the two fields increasingly sharp. As a consequence, there is a need for new forms of translation, which are accomplished by MTBs.

Room 0.20 – Theory

Theorising stigma emergence and mutation over time

Hannah Farrimond, Mike Michael

(University of Exeter)

How and why do new stigmas emerge? How do they relate to existing stigma? How can we understand their change over time? Moving away from understanding stigma as fixed and linear, we offer a new processual approach to theorising stigma change over time; 'stigma mutation'. Stigma change can be conceptualized along three dimensions, 'lineage' (in relation to its history), 'variation' (in relation to its context) and 'strength' (in relation to its amplification or weakening over time) (Farrimond, 2021). Furthermore, we draw on STS theories (e.g. Deluze & Guattari, 1987) to suggest these dimensions are inter-connected; creating multiple non-linear networks or 'assemblages' of stigma. Stigma is thus both predictable ('territorialized'), forming around existing disadvantage and marginalization, but also unpredictable ('de-territorialized') through new associations, actors and events. From this theorization, stigma can be understood as the product of competing forces; stigmatization and destigmatization are possible simultaneously.

This theorization is illustrated through the case study of Long Covid stigma. We show how the lineage of existing stigmas, coupled with the symbolic need to 'forget' the pandemic has created the perfect environment for the amplification of Long Covid stigma; and make some tentative suggestions on how we might interrupt this process. It is our goal that by better articulating how stigma emerges and mutates, we are better positioned to actively disrupt and challenge stigma where it occurs.

THURSDAY 12 SEPTEMBER

15:10-15:40

Room 0.09 – Patient-Professional Interaction

Goblins and bugbears in the waiting room: Updating Arber and Sawyer's classic study of GP reception work using ethnography in eight English general practices

Catherine Pope, Annelieke Dreissen, Abi Eccles, Bella Wheeler, Carol Bryce, Jacob Heath, Chloe Phillips, Toto Gronland, Helen Atherton

(University of Oxford)

In 1985 Arber and Sawyer published their seminal 'dragon behind the desk' paper describing the discretionary rationing power of GP receptionists. This revealed deep hostility by patients and the public to receptionists' 'officious' filtering and inquisitive questioning of the legitimacy of requests to see the doctor. Our paper revisits this territory, reporting data from an NIHR funded study about how people make and get appointments with their GP.

In the intervening years much has changed. Online digital triage has been introduced to assess and prioritise patients. Telephony has been digitised and many practices have automated menu systems to filter and order demand. Where once a solo GP or small partnership and limited reception role existed, there are now myriad practitioners and services. The problem of access persists, exacerbated by increasing multi-morbidity, chronic physical and mental illness, and pressures on other health services. Media, politicians and surveys regularly warn of the crisis in general practice, and point to the 'unacceptable' delays patients experience when trying to get a GP appointment.

Our ethnography in eight English general practices explores everyday interactions between receptionists and patients/the public. We observed waiting and reception areas (front and back stage), interviewed staff and patients and examined practice documents pertaining to access. Our analysis highlights an important redistribution of frustration and anger associated with getting an appointment. Rationing, legitimising and advocacy remains core to access interactions, but the dragon has changed, and patients and receptionists appear embroiled in managing rather different 'creatures' and challenges.

Room 0.08 – Mental Health

Depression, anxiety and their major risk factors among the Ukrainian female refugee population in Czechia and Ireland

Iryna Mazhak

(RCSI University of Mercian and Health Sciences)

Female war-forced migrants from Ukraine have experienced a wide range of stressful and traumatic events. Depression and anxiety as comorbid illnesses are mental health conditions that can seriously impair a person's functioning and general well-being. It is critical to comprehend how prevalent depression and anxiety symptoms are among Ukrainian female refugees in the Czech Republic (N=919, 2022) and the Republic of Ireland (N=656, 2023) as well as the risk factors that contribute to them. This cross-sectional study was conducted as part of a bigger mixed-method research project with Ukrainian female refugees over 18 years old via an online survey.

Depression symptoms were measured by using PHQ-9. As a result, more than half of females have moderate to severe symptoms of depression. In Ireland, female refugees experienced more severe levels of depression. Additionally, more than 50% of Ukrainian female refugees in both host countries have moderate to concerning anxiety measured by BAI.

Linear logistic regression analysis showed that there are some similar factors associated with depression and anxiety increase (limitations in activities due to illnesses, low SES and decreased financial status during migration, lack of necessary psychological help, relationships with relatives, colleagues, neighbours, and locals deteriorated, applying avoidant coping strategies) or decrease (participating in Ukrainian community meetings, applying problem-focused coping strategies). However, there are different (experienced cultural difficulties in Ireland and discrimination in Czechia) and even opposite (having children under 18) factors too which could be partially explained by differences in social policy. These findings could have important public health implications.

Room 0.17 – Health Service Delivery

Modern general practice access: Digital, efficient and equitable?

Sara Shaw, Natassia Brenman, Sophie Spitters, Sara Papani, Michael Gill, Sharon Spooner, Deborah Swinglehurst, Joseph Wherton

(University of Oxford)

In this paper, we focus on the triage systems that many general practices use as a means of managing demand for care. These systems are typically supported by digital platforms, which filter patient requests (for anything from a repeat prescription through to an urgent appointment) through online forms, to be assessed by practice staff before appointments are booked. The vision is one of digital triage seamlessly organising patient requests and ensuring regulated flow through practices. This vision is encapsulated in recent policy on Modern General Practice Access, which envisions a way of organising work in general practice that enables practices to (amongst other things) provide inclusive, straightforward online and telephone access; prioritise and allocate patient requests safely and equitably; and improve the efficiency of their processes. But what does that mean in practice? We draw on ethnographic research in three general practices in England to explore the organisation of triage work in more depth. Inspired by Deborah Stone's writing on values in health policy, we explore how "efficiency papers over a lot of conflicts", and examine who's perspective is foregrounded in the quest to improve efficiency and manage demand through digital triage systems. We conclude by reflecting on how issues of equity, continuity and care might come to the fore in policy.

Room 0.11 – Lifecourse

Theorising perceptions and experiences of multiple long-term conditions: Insights from a study with the Mass Observation Project

Sue Bellass, Victoria Bartle, Avan A Sayer, Rachel Cooper, Thomas Scharf

(Manchester Metropolitan University)

The experience of living with multiple long-term conditions (MLTC) - the co-occurrence of two or more health conditions lasting over 12 months – is becoming increasingly common, with far-reaching consequences for individuals and healthcare systems. Increasing recognition of the challenges of MLTC has led to substantial investment in research; however, how people's biographical and temporal landscapes are shaped by MLTC as they progress through the life course remains poorly understood.

In offering new insights into the effects of MLTC on people's lives, this presentation draws on a novel approach. We present an analysis of 142 written accounts from members of the general public who contribute to the Mass Observation Project. This is a unique social history archive which captures and

preserves perceptions and experiences of everyday life in Britain. The writers were provided with a series of prompts (known as directives) comprising topics related to MLTC, including awareness and understanding, everyday living, health and social care, and experiences of ageing with MLTC.

The presentation will describe collaborative research undertaken by a team comprising academics from different disciplines and a public contributor to develop the directive and analyse the data. Bringing the data into conversation with theories developed from sociological research on single chronic conditions – such as biographical disruption - provides an opportunity to consider the applicability of these theoretical positions to the context of MLTC, and to develop theoretically informed insights into the interplay between the entwined trajectories of MLTC and self, identity, relationships and biography.

Room 0.13 – Professions

Dilemmas encountered by village doctors in rural China: A trust crisis?

Yichen Cheng

(University of Cambridge)

The profession of village doctors in China has navigated a tumultuous trajectory throughout history. From being highly esteemed between the 1950s and 1970s to experiencing patient attrition post the market reform in 1978, the life of village doctors has traced a narrative of prosperity giving way to decline. This article aims to comprehend why the challenges faced by village doctors, particularly patient attrition, do not solely stem from a trust crisis caused by a lack of medical expertise, as proposed by Parsons in his theory of doctor-patient relationships. While it is true that the expertise of village doctors may be lacking, the trust they garner from patients in rural areas is primarily built on familiarity and longstanding interpersonal relationships developed over the years. The trust bestowed upon village doctors by their patients is evident, challenging the exclusivity of expertise as the sole determinant in the professional trust theory. Through interviews with 13 village doctors and a senior feature in Inner Mongolia, it becomes clear that the challenges faced by village doctors arise from various factors, including the consequences of modernisation, market reforms, urbanisation, increasing wealth, and infrastructural development. These factors induce out-migration from villages, leading to a decline in the potential patient population, coupled with governmental negligence in compensating and supporting village doctors. This study also highlights a broader consideration within healthcare professions. Current medical sociological theories predominantly revolve around doctors focused on treating and saving lives, overlooking another subset of healthcare professionals responsible for crucial public health duties.

Room 0.19 – STS and Medicine

You are what (bugs) you eat: Metabolising microbes, meaning and modernity

Katherine Kenny, Gianni Tien, Roberta Pala

(The University of Sydney)

Once the exclusive domain of biomedical scholarship, the microbiome has become an increasingly common object of scientific study, popular fascination, and health intervention. Implicated in everything from periodontal disease, obesity, mood and mental health to inflammation and immunity, the microbiome is now widely recognised as fundamentally constitutive of our embodied humanity as well as our current – and future – health.

Increasingly, biomedical scholarship has highlighted various entanglements between one's microbiome and their environment, diet, lifestyle and socioeconomic status. Concurrently, rising public interest in 'gut health' has positioned cultivating an optimal gut microbiome as a key component of 'living well'. As such, the microbiome presents a fruitful site for advancing a politics of metabolism (e.g. Hatch et al,

2019). Metabolism is, most familiarly, a fundamental life-sustaining process that converts food into the energy that fuels us. But it may also feature as an analytic lens, blurring the boundaries between our embodied biological systems and the external, historical, material, and socio-political environments that are increasingly both threatening to human life and compromised by the way we exist within them. Drawing on data from a broader program of research on human-microbial relations in everyday life, this analysis attends to the politics of metabolism to explore some of the paradoxes emerging around the microbiome as a modern technology of the self and site of (self)care with both liberatory potential and enduring legacies of disciplinary self-governance.

Room 0.20 – Theory

Theorising models of ‘care’ from a disability politics perspective

Ioana Cerasella Chis

(University of Birmingham)

This talk engages with Feminist and Disability Studies literatures to explore differing accounts of social reproduction and ‘care’ in the context in which ‘care’ continues to have an ‘unclear epistemological status’ in academic literature (Thomas, 1993:668). Taking an anti-productivist stance to socially reproductive work and informed by Disability Politics scholarship, I critique the mainstream feminist assumptions regarding the care relation that obscure the agency and participation of those subjected to disablement oppression and exploitation, whose approach I call ‘the service model of care’. In short, feminists often construct and centre the agency of non-disabled women as caregivers through a dyadic and hierarchical relationship that also reduces other participants in the care relation to the role of care receivers. It follows that the ‘receivers’ of care are deemed to be unproductive, agency-less, and passive consumers of a service (care). By approaching this work through a moralising perspective, such accounts of care work also obscure the role of social reproduction in reproducing disabling capitalist social relations of oppression and exploitation. By contrast, I argue that social reproduction scholarship ought to centre an anti-productivist politics that seeks to move towards an ‘organising model of care’ and prefigure alternatives against-and-beyond disabling capitalism.

THURSDAY 12 SEPTEMBER

16:00-16:30

Room 0.09 – Patient-Professional Interaction

Multi-layered uncertainties in the interactions between healthcare professionals, patients and caregivers in the context of palliative care: The role of general nurses

Eliska Vokralova

(Faculty of Social Sciences, Charles University)

This paper discusses the ongoing PhD research. The research focuses on the interaction between healthcare professionals, patients and caregivers. The aim of the dissertation study is to find out and describe the multi-layered of uncertainty in the context of palliative care, focusing more specifically on the role of general nurses and how they deal with uncertainty and what mechanisms and strategies they use. The topic is investigated using a qualitative, ethnographic approach. A combination of participant observation and semi-structured interviews is used for data collection. The plan is to make at least 50 hours of observation and about 20 of semi-structured interviews during seven month period from February to August 2024. The second part of the research will be held for at least another four months from September to December 2024. Participant observations will be recorded in a note sheet and supplemented by keeping a diary of the researcher, which also allowed to reflexively engage with the hybrid researcher's/nurse position. Open, thematic and selective coding techniques will be used to analyse the data. The study aims to describe the diversity of uncertainty in interactions related to serious incurable disease in a gynaecological oncology department and the specific role of the general nurses. In addition to sociological and theoretical outcomes, the research will have applied outcomes in the form of a workshop for non-medical staff. The study has been approved by two Ethical Committees.

Room 0.17 – Health Service Delivery

An idle mind is devil's workshop: Transactional sex and adverse sexual and reproductive health outcomes among young women in urban slums during the COVID-19 pandemic lockdown in KwaZulu-Natal, South Africa

Obasanjo Bolarinwa

(York St. John University)

The COVID-19 pandemic and subsequent lockdowns have disproportionately affected vulnerable populations, particularly young individuals in urban slums. In South Africa, this has manifested in adverse sexual and reproductive health outcomes among young females and remains inadequately addressed. This study aims to explore the association between transactional sex and these adverse health outcomes among young women in South African urban slums during the COVID-19 pandemic.

A quantitative cross-sectional survey was conducted in four urban slums during the COVID-19 lockdown, involving 800 young women aged 18 to 24 years. Adverse sexual and reproductive health outcomes, such as STIs and unintended pregnancies, were the outcome variables, while transactional sex served as the key explanatory variable.

The prevalence of adverse sexual and reproductive health outcomes among young women in the included urban slum areas was 13.5%. The prevalence of transactional sex was 7.1%. Young women engaged in transactional sex exhibited higher odds of reporting STIs (aOR=3.3; 95% CI=1.6-6.7) and unintended pregnancies (aOR=2.3; 95% CI=1.1-4.7) compared to those not involved. Additionally,

those with 3-5 and 6 or more sexual partners were more likely to report adverse sexual and reproductive health outcomes compared to those with fewer partners.

These findings underscore the association between transactional sex and adverse sexual and reproductive health outcomes among young women in South African urban slums during the COVID-19 lockdown. Multifaceted interventions, including community engagement in sexual health education within urban slums, are imperative to mitigate these adverse health outcomes in future pandemics.

Room 0.11 – Lifecourse

Beyond autonomy vs. paternalism: An exploration of the moral politics of assisted dying eligibility criteria in Canada

Janna Bryson

(University of Cambridge)

Medical assistance in dying (MAID) was legalised in Canada in 2016 as end-of-life care for terminally ill patients and expanded in 2021 to become available to individuals facing “irredeemable suffering” from non-terminal physical illnesses and disabilities. Proponents of the 2021 eligibility expansion tend to frame it as an issue of patient autonomy: it had been a paternalistic moral imposition for the state to restrict the ‘right to die’ exclusively to patients with imminently fatal illnesses. However, the expanded MAID program still relies on the state to impose eligibility criteria as to what kind of non-fatal suffering is bad enough that life is no longer worth living – MAID is not available to individuals deemed ‘healthy enough’. This paper thus contends that the 2021 eligibility expansion was not in fact a removal of moral values from MAID policy, but rather a change in which values are dominant.

To support this argument, the paper presents preliminary findings of a component of my ongoing doctoral research: a series of elite semi-structured interviews with Canadian pro- and anti-MAID policymakers, clinicians, lobbyists, and activists who influenced the 2021 expansion. A thematic analysis of these interviews identifies values related to dignity, autonomy, productivity, and disability as key sites of conflict in the development of MAID eligibility criteria. The paper highlights that the definition of suffering is socially contingent, and points to resulting challenges for policymakers tasked with operationalising such a definition in a standardised manner.

Room 0.13 – Professions

Professional identity and moral distress in nursing and midwifery leadership

Claire Leader

(Northumbria University)

Background: Nursing and midwifery leaders are faced with decisions on a daily basis that require them to uphold their professional values and act for the benefit of others as well as meeting performance indicators and upholding organisational reputation. Moral distress is defined as the disequilibrium that can result when leaders recognise that they are unable to balance these competing priorities ethically (Jameton 1984, Morley et al 2019). This study explores the perspectives of senior healthcare leadership in undertaking their role; the moral distress they encounter and the ways in which they balance the needs of the service, the wellbeing of staff and their own professional values.

Methods: A qualitative interview study of 19 senior leaders working in the National Health Service. Using Grounded Theory, the interviews have been conducted and analysed with the themes generated providing a unique perspective of the challenges faced by nursing and midwifery leadership.

Findings to date: The themes constructed demonstrate that leaders navigate decision making in alignment with their personal and professional values. Where this is challenged, moral distress occurs. The participants discuss the tactics they deploy to navigate these complex situations and the toll this can take on their own well-being as well as the impact on teams and patient safety.

Room 0.18 – Critical Public Health

Navigating tensions: Boundary work in interdisciplinary post-abortion contraception research collaboration

Nicola Boydell, Marie Larsson, Jeni Harden

(University of Edinburgh)

Access to contraception, including post-abortion contraception (PAC), was disrupted during the COVID-19 pandemic (Scot Gov, 2021), and challenges in accessing PAC persist in Scotland and beyond (Reynolds-Wright et al., 2021). Following abortion, many people experience challenges in identifying, accessing, and initiating their preferred contraceptive method (Kilander et al., 2019). Recognising these challenges, PAC was defined as a 'priority area' in the Scottish Government's 2023-2026 Sexual Health and Blood Borne Virus Action Plan. Our ongoing interdisciplinary, engaged research, explores issues and challenges around PAC, applying co-design principles to develop adaptable PAC models to enhance services and people's choice of, and access to, contraception. Working across the abortion and contraceptive 'ecosystem', the project engages with abortion providers, clinicians, people with abortion experience, community health organisations, abortion advocates, policymakers, and governmental actors. Researching at the nexus of these diverse actors surfaces tensions, including divergent understandings of the "problem" with abortion and contraception in Scotland. While healthcare policies primarily centre "bringing down rates" of abortion and "increasing contraceptive use", healthcare practitioners/practices often focus on improving the care experiences of those seeking abortion (Beynon-Jones, 2013). In this paper, we explore these tensions, and our approach to navigating them, through the lens of boundary work. In so doing, we seek to articulate the ways tensions manifest at the boundaries of disciplines, practices, and policies, which are simultaneously generative, productive, and stymieing, and consider implications for research that seeks to address the diverse needs of people with abortion experiences and researchers and practitioners within the abortion ecosystem.

Room 0.19 – STS and Medicine

Understanding DIY health

Kate Weiner

(University of Sheffield)

- An online community of people with Type 1 Diabetes develop and share knowledge about how to make an open-source artificial pancreas system.
- People in the UK buy an over-the-counter statin and foods containing plant sterols to manage their cholesterol levels.
- Trans people in the US source their own hormone replacement therapy through sharing, purchasing online, or making their own medications.
- Across the globe, makerspace/hacklab communities shift attention during the Covid pandemic to design, make and share knowledge about healthcare equipment.

These diverse practices have all been described by scholars through the lens of Do-It-Yourself or DIY. As these examples suggest, DIY health is a broad and amorphous field of social science study associated with diverse social implications. It is sometimes equated with self-care, aligned with a healthist, consumerist, neoliberal project of the self. Other scholarship proposes it has more egalitarian or critical potential, associated with a broader movement of participation in medicine, equitable access to healthcare, openness, and innovation beyond institutional and corporate science.

This paper aims to map social science scholarship on DIY health and provide a conceptual framework for understanding this. It asks: What does DIY health mean? What substantive topics/cases are discussed and how are they studied? What are the politics of DIY health? What theories or organising ideas are employed? What, if anything, is missing from this scholarship? Drawing this together, I will suggest a typology of DIY health which categorises DIY technologies/practices and links these with their broader social implications.

Room 0.20 – Theory

Materializing privilege: Weaving to withdraw from aesthetic preoccupation in the mind-body industry

Elizabeth Mckibben

(Te Herenga Waka - Victoria University of Wellington)

Mind-body practices such as yoga may seem like a progressive alternative to mainstream medicine. Yet, medicalized interpretations of yoga remain committed to individualistic and moral prerogatives to pursue health that disregard social factors. White, affluent, able-bodied women clad in branded clothing re-produce colonial, neoliberal imperatives through a yoga aesthetic. This aesthetic contradicts a core philosophical intention of yoga: withdrawal of the senses (pratyahara). Paradoxically, pratyahara is only possible in direct contact with the material world. By drawing upon theory which privileges the agency of the material world, I explore pratyahara as a conceptual tool in order to question conformity to the yoga industry's aesthetic status-quo. In this project, I re-configure privileged identities with diffractive auto/ethnography. Drawing upon Barad's "cutting together-apart," reflections, observations, interview transcripts and objects collected from 230 site visits are literally and figuratively woven together into three narratives and a make-shift yoga mat. These creative processes materialize an interplay of whiteness, body-centricity, and neoliberal feminism that otherwise operate invisibly in day-to-day experiences in spaces of yoga practice. In making these power structures visible and tangible, this process of self-study prompts a shift in my scholarly and yoga teaching practices. By engaging with the more-than-human world, power takes a different form, one that can begin to be withdrawn from. Pratyahara thus enables a framework for critical praxis from positions of power. This research challenges the grip of medical ontologies over understandings of yoga, meanwhile prompting the yoga industry towards social change.

THURSDAY 12 SEPTEMBER

16:35-17:05

Room 0.09 – Patient-Professional Interaction

“Change made” from Care Opinion stories: Defining improvement and how it is enabled through care experiences posted online

Emma Berry, Zoe Skea, Marion K Campbell, Louise Locock

(University of Aberdeen)

Care Opinion (CO) is a social enterprise which facilitates patients and carers to share experiences of healthcare online anonymously. Before publication, these stories are moderated by CO staff. Healthcare staff are invited to respond to this feedback and encouraged to use it for improvement. However, previous research highlighted feedback is often not used for improvement. Research into CO highlighted story responses from NHS staff rarely use the “change made” or “change planned” function. This study explored what improvements authors (those who wrote CO stories) want to see and whether CO can facilitate this.

This research formed part of a PhD project and was based in Scotland. A sample of CO stories were purposively selected. Case study research was carried out with 2 NHS boards, involving interviews with 10 NHS staff, 10 authors, and 6 CO staff who moderated stories. One example story per participant was used to facilitate interview discussions (e.g. NHS Staff responded to story). An inductive thematic analysis was undertaken on transcripts.

This presentation will explore how healthcare improvement can arise from CO stories. We will discuss the various ways in which stories contributed to improvement, both directly and indirectly, and note that although changes were made this was not always reported back onto CO. Participants described considerable emotional impact from writing, moderating and working with stories. Together, these findings offer an opportunity to reflect on what care improvement means, and the unseen work making this happen.

Room 0.17 – Health Service Delivery

Complicating candidacy: Navigating inequities to dental access for individuals with severe mental illness

Louise Laverty, Fiona Lobban, Christopher Lodge, Jasper Palmier-Claus, Neil Caton, Rebecca Harris

(The University of Manchester)

Lack of access to NHS dentists in the UK is dominating headlines, with some areas of the country experiencing deserts of provision as patients are increasingly driven to desperate measures to seek help for dental pain and care. Many dentists are abandoning NHS provision due to government contracts that are unable to adequately reimburse practices, with those that remain overwhelmed by demand. This landscape presents challenges for the general population: having to jostle for limited availability, go private, go abroad, or resort to self-treatment. However, for some vulnerable groups, this landscape can make existing barriers to care almost insurmountable. This presentation draws on qualitative interviews conducted as part of a study on the implementation of a link work intervention to support people with severe mental illness to access dental care. Using theories on candidacy that argue that eligibility for care is constructed through interactions between people, health systems and environments, this presentation will explore the experience of participants and link workers as they

attempt to navigate these relationships. Previous studies on candidacy often assume that there are healthcare services available but some struggle to access it appropriately. In the current dental landscape with limited services for people to access, this presentation will argue that people's candidacy is complicated. This will be discussed alongside new power imbalances as providers find themselves able to dictate the rules knowing there are limited opportunities to go elsewhere. For vulnerable groups experiencing higher levels of need, this has implications for how inequalities are managed.

Room 0.11 – Lifecourse

A sociological eye at the development of 'palliative care' in Denmark

Helle Timm

(UCSF - Centre for Health Research)

This paper concerns how the logics of medicine and governance overruled the logic of care in the development of the sub-specialty of palliative care in DK.

The medical sub-specialty of palliative care developed within the last 30 – 40 years in Denmark, a bit later than in the UK, but with great inspiration from here. Even though UK and DK differ according to welfare and healthcare, many of the challenges described and explored by English sociologists in relation to the development of palliative care, seem familiar in a Danish context. Based on data from research literature, policy documents, home pages and interviews, as well as personal experience from working in this field in DK for many years, I demonstrate how the public interest and professional interdisciplinary interest in care for the dying and their relatives, was turned into a medical specialty. And I invite you in to discuss the consequences and perspectives of this development.

Room 0.13 – Professions

The golden ticket? Widening participation in UK medicine and the making of an emotional proletariat

Louise Ashley

(Queen Mary University, London)

Over two decades, the 'Widening Participation' agenda has sought to open access to the UK medical profession, including on the basis of socio-economic background (SEB), motivated in part as doctors from less advantaged backgrounds are more likely to take-up roles that have been difficult to fill. These patterns have been welcomed as access to healthcare is an important determinant of health, and as doctors from less advantaged backgrounds are considered well placed to empathise with diverse communities, thus improving service delivery. However, qualitative research has rarely explored the causes of socially stratified careers or considered potentially less positive effects. Based on interviews with students and doctors from less advantaged SEBs (N=38), this article takes up these themes, finding that while participants value empathy and compassionate care, they believe these traits and skills are less valuable to secure more competitive careers and may even signal less skill. This mismatch helps account for socially stratified careers while highlighting a related tension, as doctors from less advantaged backgrounds may be positioned as the profession's 'emotional proletariat,' with higher representation in roles that do not enjoy the most status or respect. The article concludes by considering the consequences for practitioners, patients, and the profession.

Room 0.18 – Critical Public Health

The strive for normalcy in the contested space of birth

Nicole Thualagant, Katja Schröder
(University of Roskilde)

Taking a theoretical departure in the term of 'space' fueled by Foucauldian readings of the power/knowledge nexus, this paper explores how childbirth and birth care are entangled in political, societal, and professional negotiations and contestations based on different épistémès or aprioris on what determines good birth care. The paper explores birth as a contested space by extrapolating the last decades' political and professional strive for keeping the birth 'normal'. In an era where medical and technological promises are believed to foster a technocratic approach to birth, the term of 'normal birth' was originally applied as an attempt to counteract on a medicalization of birth. However, despite the aim of promoting standards of good care, the term has not only set strict contours for care work but also created standards for what can be experienced as a normal/good birth. Moreover, labelling birth as 'normal' as a counteract on the rise in medical interventions reveals the relevance of approaching birth as a contested space. Through discursive analytical lenses, the paper unfolds birth care policy development in the UK and in Denmark to explore how the term of 'normal', also replaced by terms as 'physiological', 'spontaneous vaginal', or 'without complications' disclose an ongoing dichotomous and hierarchical view on care. In this dichotomous approach to care, birth care can either be legitimised within a midwifery or a medical care model, leading birth to be either pathological or normal and thus leaving little space for more nuanced understandings of actual care needs.

Room 0.19 – STS and Medicine

Smart pharmakon and the softwarization of drugs: Reimagining therapy

Katerina Sideri, Niels Van Dijk
(Panteion University)

When the pharmaceutical company Pfizer expressed their intention in 2023 to release an oncology drug that works with machine learning (ML) they did not just invent another new drug; they introduced a new concept into the world: the individualized digital pharmakon. Their highly toxic oncology drug is deemed life-saving when a mobile application (app) on a patient's phone turns green, but if it turns red the patient knows it is life threatening and they should postpone taking the drug. Another research team (Galway and MIT) has invented an implantable AI robot that delivers and adjusts dosage of drugs as it can sense when and how much medicine it is required to deliver. Such technologies work with AI and require real time, constant and unobstructed inputs from wearable and healthcare applications so that an algorithm makes decisions tailored to an individual's physiology. This is a very new field of technology that can develop towards diverse directions. We ask, who wants the smart pharmakon of the future and why? To answer this question, we use the theoretical tools of the sociology of expectations, an area within sociology and Science and Technology Studies (STS) which addresses the constitutive role of future visions, to explore the interconnections between sociotechnical vanguard groups and visions/imaginaries empirically, as they seek to change the meaning of therapy. We present our initial findings with regard to discourse coalitions, the sociotechnical imaginaries and any competing visions of future development, deployment and use of the smart pharmakon.

Room 0.20 – Theory

State withdrawal, health capital and emerging forms of inequalities among Danish patients: A mixed method Bourdieuan and Buryan analysis

Kristian Larsen, Mette Rørth, Anette Lykke Hindhede
(University Hospitals Centre for Health Research (UCSF))

The transformation and withdrawal of the state and its institutions and professions (Bourdieu, Wacquant & Farage 1994) contribute to new forms of inequality in health and accompanying increased vulnerability and social and health exposure for patients with little or no capital.

Inspired by health capital (Larsen et al. 2021), habitus, capital, and field (Bourdieu 1984) and disrupted biographies (Bury 1991), we examine how own body, health and healthcare are experienced among a heterogeneous sample (social class, diagnosis, acute/chronic, somatic/psychiatric) of patients at Danish hospitals.

Empirical data material consists of current qualitative (30+ individual interviews) and quantitative (Multiple Correspondence Analysis (MCA) (Le Roux & Rouanet 2004) based on 500 questionnaire surveys) studies of Danish hospitalized patients.

Results: We find that illness as a social event has great significance on the way capitals are put into play in relation to treatment, care, and rehabilitation processes. However, the social implications of disease can be compensated by the right amount and composition of capitals, depending on the diagnosis, degree of morbidity/disability. Patients have unequal resources in terms of being able to read the 'healthcare game'; mastering short-term hospitalizations, sector transitions, and investing in health capital. Cultural and social capital are vital. In addition, economic capital is essential, for example, in relation to financial support in case of prolonged illness, risk of unemployment, health insurance, goodwill from the employer, etc.

Discussion: We would like to present empirical examples and discuss the use and interplay of capitals like health capital, cultural health-capital, cultural capital, body-capital.

THURSDAY 12 SEPTEMBER

17:10-17:40

Room 0.09 – Patient-Professional Interaction

Exploring the role of risk and uncertainty in women's childbirth choices

Georgia Clancy

(University of Nottingham)

Aim: To explore how discourses of risk and uncertainty influence women's, and maternity care professionals', perceptions of, and experiences with, childbirth.

Background: Choice has been central to NHS England's maternity policy since 1993 and the latest iteration, Better Births (2016), makes a renewed commitment to 'genuine choice' for women. However, similarity in the rhetoric and goals of the last three maternity care policies, as well as recent Government inquiries, demonstrates the difficulty of putting policy into practice.

Methods: Policy analysis of NHS England's Better Births report (2016) and in-depth interviews with women (n=14) and maternity care professionals (n=13).

Findings: Discourses of risk and uncertainty constrain choice in three main ways: (i) the promise of 'genuine choice' was in tension with the notion of 'increasingly complex cases' in Better Births, with no explanation as to how genuine choice could be provided to all women, including those with complex needs. (ii) Despite a discourse of agentic service-users some professionals struggle to care for this type of woman in practice, raising questions about control and expertise in birth; (iii) presenting choice/information through a lens of risk makes childbirth choices morally-loaded and disciplines women into docile subjects acquiescent to (bio)medical care.

Conclusion: Women have to navigate and negotiate the complex realm of choice in childbirth with maternity care professionals. As different discourses converge, competing ideologies and power struggles between women and professionals are exposed. Understanding these forces enables greater possibility to address the constraints on women's choice and how it can be better supported.

Room 0.17 – Health Service Delivery

Informal caregivers' perceptions of changing behaviours that challenge dementia care in the home setting: A qualitative study

Suzanne Li, Sasha Lewis-Jackson, Sue Ziebland

(University of Oxford)

Background: Research on behaviours that challenge dementia care has focused on institutional settings, with formal caregivers and medical professionals. There is a lack of research on informal caregiving and behaviours that challenge care in the home setting.

Purpose: This paper examines informal caregivers' perceptions and responses to behaviours that challenge dementia care and support at home. We focus on the circumstances around the behaviour, how informal caregivers responded and coordinated care and their strategies to accommodate care and support.

Methods: Narrative interview methods were used to enquire about people's experiences of supporting someone living with dementia. 'Behaviours that challenge care' emerged as a major theme. Out of twenty-four interviews, a subset of thirteen interviews were analysed to explore this theme further.

Results: Informal caregivers described challenges to seeking help and intervention from medical professionals when changing behaviour emerged in the person living with dementia. For some, behaviours became noticeable and were exacerbated by the Covid-19 pandemic. Long-term management of informal and formal care became increasingly complicated for informal caregivers. Informal caregivers formed strategies to accommodate for changing behaviour that helped prevent or dispel distress in the person living with dementia.

Conclusions: Behaviours that challenge dementia care management are a primary stressor of caregiver burden and can be experienced as early as the pre-diagnostic period. Without appropriate care and support, caregiver burden can lead to a risk of caregiver burnout. Caregiver burnout can interfere with the quality of life of the person living with dementia.

Room 0.11 – Lifecourse

'You kind of want the world to stop, and it did': Shared experiences of widowhood during and following Covid-19

Tracy Collins, Shannon Allen, Gemma Wilson-Menzfeld

(Northumbria University)

Transitions, such as widowhood, can have a negative impact on health and well-being. The death of a spouse is ranked as one of the most stressful life events and coping with the transition can be a lengthy process, sometimes spanning several years.

Previous research indicates that social support, extending activities, and group memberships provide stability and facilitate adjustment during widowhood. This is critical during the 'transition phase' of widowhood, 1-3 years after the passing of a loved one, where the surviving spouse re-establishes social roles and relationships.

The incidence and negative consequences of widowhood may have been compounded during Covid-19, as the social distancing measures imposed during the pandemic in the UK resulted in reduced contact with others preventing access to social support and services - the main factors known to be curative.

The aim of this study is to explore widowhood experiences during and following Covid-19, including the challenges and facilitators to adaptation. The study utilises a phased multi-method design, including focus groups, a national survey, and a collaborative workshop involving key stakeholders. The findings will provide evidence to enable recommendations to influence policy, inform practice and support services.

This presentation will outline initial findings from the focus group phase of the study. This will include themes which illustrate the complexity of widowhood and the specific challenges and facilitators to adaptation during and following the pandemic. The use of focus groups to explore multiple perspectives and facilitate the sharing of similar experiences during exceptional circumstances will also be discussed.

Room 0.13 – Professions

From policy to practice: Nurses as instruments in health policy implementation

Camilla Bernild

(Region Hovedstaden)

The shortage of nurses is a pervasive issue globally, with Denmark adopting a political strategy to address it by restructuring and redistributing shift work among hospital nurses (source: <https://sum.dk/Media/638336462586551242/Robusthed-Samlet-Rapport-TILG.pdf>). Consequently, nurses in units without traditional shift work are mandated to undertake weekend shifts in other units. This study employs an institutional ethnographic approach (Smith, 2006) to investigate the implications at organizational, professional, and individual levels when political directives intersect with practical implementation (Meyer & Rowan, 2022). Drawing on a case study (Priya, 2021) conducted in a hospital setting, this presentation aims to explore the concept of legitimacy within the dynamic tension between the nursing profession (Witz, 1990) as both gendered and generic, and the organizing of professional work (Evetts, 2018) within a specialized healthcare system.

Room 0.19 – STS and Medicine

Exploring patients' health capital: Inequalities in navigating Disease in real-life contexts

Mette Roerth, Anette Lykke Hindhede, Kristian Larsen

(Center for Health Research & University of Copenhagen)

Illness often represents a significant disruption and alteration to everyday life. Furthermore, heterogeneous positioned individuals respond differently to their illness, its symptoms, treatment, and especially to the changes it introduces into their daily routines. However, there is limited understanding of the interaction between patients' diverse resources and their management and practices concerning various illnesses.

This paper investigates how patients manage their illnesses in real-life contexts, examining the resources they utilize and their effectiveness in enhancing or maintaining health capital. Drawing upon Bourdieu's (1984) concepts of habitus, capital and field; Bury's (1982) notion of biographical disruption and Larsen et al (2021) health capital, we aim to deepen our understanding of health & disease complexities in a Danish context of specialized healthcare field and address issues of inequality in health practices.

Using a mixed-methods approach involving 30+ interviews and 500+ questionnaires, our research explores patients' health capital in a broad spectrum of patients affected by acute and chronic illnesses, somatic and psychiatric. We study the disparities in resources available to patients and how these influence their healthcare experiences, from navigating hospital stays to accessing informational resources. Abductively, we bridge deductive approaches from health capital studies with inductive methods to construct new insights into patient experiences.

Patients' different amount and composition of capitals explain very unequal abilities to handle illness. Our study elaborates and sets the stage for the discussion the importance of addressing the diverse needs of patients, particularly considering increased hospital specialization, short stay at hospital and disease complexity.

Room 0.20 – Theory

The space between health and illness as a diagnostic of practices of health: practices of self-care in and around the space of suboptimal health

Lijiaozi Cheng

(The University of Sheffield)

This paper investigates the concept of 'suboptimal health,' a term popularized by Traditional Chinese Medicine (TCM) professionals in the 1990s and described as a significant contemporary health concern. Emerging during the commercial boom in health foods, 'suboptimal health' provides a lens to explore

the nuanced interplay between discursive and material practices in health maintenance. Utilizing data from virtual ethnography on the Chinese social media platform Weibo and interviews with young Chinese individuals, this study maps the articulation and enactment of 'suboptimal health' in daily activities such as eating, drinking, exercising, and attending therapy sessions. The analytical framework is informed by Theodore Schatzki's concept of the "teleoaffective structure," which examines the motivational and emotional dimensions guiding health-related behaviors, alongside Alan Warde's theories on practices that frame these activities as performances embedded within social contexts. This research scrutinizes the challenges in establishing a cohesive set of practices around 'suboptimal health' and investigates the concept's role in shaping and being shaped by the material and discursive practices of those it purports to describe. The findings reveal significant insights into the dynamics of health narratives and their implications for understanding contemporary health management in a global context.

SPECIAL EVENTS

FRIDAY 13 SEPTEMBER

10:45-12:25

Room 0.08 – Pedagogy and Methods

What do “imposter participants” mean for the future of medical sociology?

Anna Dowrick, Tom Witney, Jaime Garcia Iglesias

(University of Oxford, University College London, University of Edinburgh)

This special event explores the issue of ‘imposter participants’ in sociological research on health and illness. While not a new challenge, encounters with participants who may not be who they say they are has been more common since the widespread uptake of remote/online methods. We take the disruptive phenomena of imposter participants as an opportunity to reflect on what is at stake in sociological research and how this is troubled by these encounters. We will surface tensions in emerging approaches for addressing the problem, creating space for a reflexive discussion considering the impact of responses to imposters across the research lifecycle, particularly for maintaining a focus on social justice.

Part 1 of the special event will offer attendees an overview of the emerging literature on this topic, drawing attention to the tensions and trade-offs that are relevant for sociological research. Grappling with how to respond to fabricated accounts, researchers are debating how to balance inclusive research practices and data integrity. Some advocate for more stringent screening processes for research participants, expressing concern about impacts on data reliability, effects on other participants and consequences for policy and practice. We explore whether such guidance on imposter participants inadvertently embeds positivist epistemologies inherited from psychology and quantitative methodologies. Other literature foregrounds the risk of such measures on inclusive research approaches and examines the impact of more stringent verification criteria on marginalised and stigmatised communities, engaging with questions of truth and objectivity in qualitative research.

Part 2 will reflect on these ideas in the context of empirical research on sexuality, gender and health. One example will address a research project focused on trans and gender diverse people’s experiences of sexual health services. It will focus on one research encounter, which raised suspicions about the authenticity of a participant’s account. It will examine the interview, its emotional impact on the research team and its subsequent influence on the research project. The experience surfaced tensions around how to establish participant authenticity and made explicit expectations for participant accounts to be consistent and legible to researchers. This case problematizes emerging narratives relating to imposter participants, particularly in research relying on self-identification conducted with multiply marginalised populations.

To end the special event, we will facilitate a creative exploration of the issues raised and how they resonate with attendees’ experiences. This will involve working in small groups to discuss reflections to the previous talks and develop a productive response using collage and other creative methods. Provocations for the discussions will include:

- Do these issues need responding to?
- Can it ever be ethical to verify participant identities?
- What are the gains and losses of different responses?
- How does the development of ‘inclusive’ exclusionary practices affect researcher identities?
- Can ‘solutions’ be future-proofed?

Room 0.13 – Critical Public Health

Corporate and philanthropic actors: The ‘invisible hand’ in public health?

Interventions to improve the public health are increasingly instigated, funded and delivered by a range of commercial and philanthropic actors. Moving beyond the ‘commercial determinants of health’ frame, this panel explores the shifting cast of actors who are enrolled not just in creating the conditions that erode health, but the production of solutions through public health interventions.

Philanthropy, commercialism and the fragmentation of public health

Judith Green

(University of Exeter)

In a context of austerity, public health commissioners in the UK are increasingly reliant on a range of commercial and philanthropic actors to provide health improvement programmes. Austerity has also incentivised providers of leisure and educational services to highlight the health benefits of their activities, to help leverage resources for activities as diverse as djembe drumming, photography and gardening. This paper draws on empirical examples of the interplay of statutory and other agencies in this health improvement field: a study of social enterprises in public health provision in one London borough; the implementation of a school health promotion programme promoted by an industry-funded charity; and creative Bibliotherapy (reading fiction as an intervention for public mental health). These examples suggest a fragmentation of health promotion, in which both post-Foucauldian analyses of public health as biopower and the ‘commercial determinants of health’ frame start to unravel. At a local level, non-state actors have a complex role, neither straightforwardly aligning with neoliberal governmentality nor necessarily antithetical to health projects. Commercial and philanthropic organisations are oriented to various logics. These can include profit-maximisation and the traditional Foucauldian disciplining of docile, efficient bodies. However, other logics resist alignment with contemporary biomedicine, such as holistic practice, missionary zeal or demedicalisation. As non-statutory actors become entangled in local health systems, these logics loop back into public health, unsettling traditional framings of evidence and effect. Intersecting logics are remaking both ‘health’ and ‘publics’.

The Janus face of philanthropy? Exploring the organisational hypocrisy of corporate humanitarianism

Rob Ralston

(The University of Edinburgh)

The fragmentation of global governance, from established patterns of multilateralism to a more complex landscape of institutions and organisations, is characterized by the emergence and spread of new forms of multistakeholder engagement between state and non-state actors. As part of this shift, corporations have increasingly positioned themselves as humanitarian actors concerned with the common good. This paper examines the role of philanthropy in the construction of corporate humanitarianism using an empirical study of Coca-Cola’s response to the COVID-19 crisis. Drawing on the sociological concept of organisational hypocrisy, the paper analyses investor reports, earnings calls and communications made by the company to political and public audiences. It highlights the Janus face of philanthropy, detailing inconsistencies between corporate talk, intention and action. The analysis shows how Coca-Cola presented its decision to suspend product marketing to different audiences: investor reports reveal an intent to limit operating costs in response to economic uncertainty, with this decision reframed to the public as an act of corporate humanitarianism. We contend that the organisational hypocrisy of philanthropy performs an important function, obscuring certain aspects of political and economic strategy, while constructing an image of corporate citizenship. This contributes to the literature on corporate philanthropy by explaining how organisational and rhetorical practices allow corporations to

act or perform as humanitarian actors, and points to the implications of this organisational hypocrisy for public policy.

Mapping digital mental health technologies: A comparative study of digital mental health in Australia and the Philippines

Benjamin Hanckel, Jan Bernadas, Pryor Placino

(Western Sydney University; De La Salle University)

Digital mental health has emerged as a contemporary site for the provision of mental health services, support and stigma reduction. Situated within the emergence of broader global digital health tools, digital mental health promises decreased costs of implementation, reduced barriers to access and ease of navigation of existing complex systems. Yet such promises often obscure the ways that such tools emerge, their logics and the actors involved in their emergence. This work-in-progress paper interrogates and examines the emergence of digital mental health tools across two contexts: Australia and the Philippines. We use a situational analysis (drawing on documentary analysis and interviews with people working in digital mental health across the two national contexts) to examine the emergence of digital mental health, how it is understood within the field and the actors who are involved. Our findings point to how the production of 'digital mental health' is entangled with the broader promises of digital health, emergent start up cultures, as well as global concerns of mental health, particularly following COVID-19. These new tools enrol varied actors across both contexts, including the state, which is often imagined in varied ways, as well as private organisations, which fund and support the development, design, and coding underlying the tools, alongside clinicians and researchers as part of the 'corporate-clinical nexus' (Flore, 2023). The findings point to the importance of partnerships and (im)possibilities with industry, that orient programs towards solving user issues, connecting them to services, as well as personalising and tailoring programs for individuals. Users play a critical role, from those experiencing mental illness or tough times, to service providers who can take up the tools. These users are positioned in varied ways, from consumers to co-designers of services for the future, but tools have a focus on their individual needs being met, and aspirations for technologies to change behaviours. The findings also show how, within this nexus, the future imaginaries of participants situate private organisations and the state as critical actors in the ongoing production of digital mental health and validation of digital tools for the future. We discuss how the intensification and fragmentation of actors and elements coming together in temporal socio-political and cultural environments work to produce 'digital mental health' in place, which, we argue, has implications for global public health.

The (un)contested logics and promises of air pollution data platforms in UK local government

Emma Garnett

(University of Exeter)

Regulatory monitors measure air pollutants at scales necessary for legislative reporting and policy requirements in the UK and Europe. These same data inform Air Quality Indexes which have become a central public health tool for informing when and how citizens can reduce exposure risks. There is growing awareness in science, policy, and activist communities that these data and their mobilisation also have limitations for protecting public health: they don't reflect people's actual breathing risks nor capture important differences and inequalities in exposure within cities. Lower-cost sensors are marketed to citizens and civil society groups by technology companies as devices for better representing the air they breathe and reflecting 'real-time' hazards. They are also being used in participatory science projects which recruit people to use these sensors to generate data about their everyday exposures. The same companies selling sensors to monitor air quality provide platforms for 'users' (governments, citizens) to store, process, map, and share data for multiple uses. These changing data practices are transforming spaces of knowledge production and enrolling new actors in managing and imagining health. This paper draws on work on 'the platform society' to critically examine who is involved in the knowing of air and by extension who is involved in the production of health. I do this in the context of research of the new responsibilities (albeit without more resources) of local

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10:45-12:25

SPECIAL EVENTS

governments for managing local air quality in the UK (e.g. Environment Bill, 2019). Local Authorities are obliged to share accessible and transparent data to local residents/visitors and provide relevant information for informed decision-making. As social analyses of platforms argue, a 'double logic' underscores data platforms that appeal to personal health gain (granular information to reduce risks) and the greater common good (improving research and public health) (van Dijck et al. 2018). However, these logics obscure corporate interests. Although new ways of monitoring the air promise solidarity and equality they are also creating powerful relationships and path dependencies. Focusing on the practices of local government data platforms, I consider how they encourage specific uses and features of air pollution data that in turn potentially preconfigure public health solutions.

FRIDAY 13 SEPTEMBER

10:45-11:15

Room 0.09 – Mental Health

The application and reflection of remote measurement technology in mental health

Haoyang Liu, Qigang Deng
(*The University of Sheffield*)

Mobile technology can deliver precise, impactful data on mental health, potentially enhancing health management and facilitating early relapse detection. While several barriers to and facilitators of technology use are common across different therapeutic areas and types of technology, many are also specific to particular cultural and health contexts. According to the National Health Commission Bureau of Disease Control and Prevention, the prevalence rates of depression and anxiety in China are 2.1% and 4.98% separately. However, public awareness around mental health issues are notably insufficient. This highlights the imperative needs to design a more comprehensive infrastructure to support mental healthcare, such as, building systems of early detection and prevention. In this context, remote measurement technologies using smartphones and wearable devices are being integrated into the mental health management in different countries. These technologies collect the real-time, high-resolution data, has the potential of bridging the gap between doctors and patients, and enabling remote health assessments. Taking RADAR-base, a European fully functional remote data collection platform, as an example, this paper evaluated the potential challenges and opportunities in digital health area. Although based on the technologies from Europe, the investigation on its facilitators and barriers can offer valuable reference for the future development of smart mental health in broader context.

Room 0.17 – Experiences of Health and Illness

Remembering and forgetting HIV and COVID-19: Gay men's experiences in a UK context

Sophie Atherton, Jaime García-Iglesias
(*Usher Institute, The University of Edinburgh*)

The relationship between HIV and COVID-19 has often been described as a need to remember lessons from HIV and apply them to COVID-19, including public health strategies (Hargreaves and Davey, 2020; Logie, 2020; Quinn et al, 2021; Daroya et al, 2022). However, as work in the sociology of memory has argued, an important part of remembering is forgetting (Zerubavel, 1996; Jedlowski, 2001; Schwartz, 2009; Conway, 2010) and literature to date has often ignored how 'forgetting' may have played a role in the relationships between HIV and COVID-19. By understanding remembering and forgetting as social acts in line with the sociology of memory, we explore how, what and why gay men forgot about HIV during the COVID-19 pandemic. In particular, we explore how for some gay men, memories and thoughts about HIV paled in comparison to the perceived (and real) devastation of COVID, whilst others placed much more emphasis on their memories of developments in HIV bio-medicine than on HIV activism. This paper is informed by emerging findings from the ESRC project: 'Viral Memories: From HIV to COVID-19 and Beyond' which explores gay men's experiences of COVID-19 in the UK and their memories of HIV. Data is derived from around 50 qualitative interviews (ongoing) with a diverse group of gay men. Our findings have implications for public health messaging and community organisations by delving into the role of forgetting in gay men's navigation's of risk and safety in pandemic contexts.

Room 0.11 – Lifecourse

"The existential crunch that is middle age": Exploring the experiential impact of life course events on the psychosocial wellbeing of women at midlife in the UK

Jacqui Merchant

(University of Sunderland)

A gap in knowledge exists in the experiential understanding of midlife which this presentation intends to address. Using biographical narrative interviews with 14 women in the northeast of England, this working PhD thesis will present preliminary findings which contribute towards knowledge of lived experiences of midlife, specifically regarding vulnerability factors that can impact on psychosocial wellbeing. A multi-layered approach will be taken in understanding mental wellbeing and health in women that seeks to understand the multiple factors that shape people's lives, placing individual and family development in cultural and historical contexts and which acknowledges the impact of time of place. Biopsychosocial aspects of health are also inherent to a lifecourse approach and what it means to experience midlife in the current social context, considering significant social change as well as the persistence of inequalities and how these impact upon wellbeing.

McQuaide (1998) wrote that the cultural narrative provided for women at midlife is either medical and menopause oriented or socially devaluing, (e.g., "empty nest"). Without alternative images these demoralizing cultural stereotypes can become a self-fulfilling prophecy. Blanchflower et al (2008) have found that mental distress tends to reach a maximum in middle age - influences include income, education, and marriage. Hence, this presentation intends to address this gap in knowledge which is often dismissed as hormonal and treated with anti-depressant or hormone replacement medication, rather than the psychosocial focus. Recommendations will also be made for positive adaptation for the midlife stage for women moving forwards.

Room 0.18 – STS and Medicine

"Well, this shouldn't hurt, I don't know what's wrong with you": Exploring the tensions between contraceptive patient experience and medical evidence-based knowledge

Adele Moore

(University of Liverpool)

A myriad of contraceptive technologies are available in the UK; existing literature has illuminated some tensions which arise during contraceptive appointments; through the process of risk assessment (Geampana, 2019), the framework of individual choice (Mann, 2022), and the arena of decision making (Dalessandro et al., 2021). Drawing on empirical data, this paper employs a feminist STS approach to explore agencies of human and non-human actants at play in contraceptive knowledge practices. Data collection involved Instagram netnography, surveys, and interviews with contraceptive users and providers. My findings demonstrate conflicting understandings between the ways contraceptive technologies are approached and interpreted. For providers, contraception symbolises care, ease, and protection from unplanned pregnancies; patients are framed as vulnerable. Whilst contraceptive users express concern regarding the materiality of the technologies, citing potential risks and (side) effects. Opening up contraception as a research site for examining the contestation of medical knowledge practices, I explore how providers' knowledge often distorts their perception about patient knowledge. So much so, that at times they are unable to acknowledge patients in severe pain. In developing an analysis of these tensions, the paper examines Instagram as a site for contesting contraceptive knowledge production. I show how it provides a platform for users to not only share their stories, but to question the status of facts and evidence in medical knowledge. I argue this provides a space for contestation: It is shared health information that stimulates users to call into question medical knowledge and to privilege their own experiential and tinkering practices.

Room 0.19 – Health Care Organisations

Dilemmas of collaboration: Open purpose and Primary Care Networks

*Simon Bailey, Jon Hammond, Lynsey Warwick-Giles, Donna Bramwell, Kath Checkland
(University of Kent)*

Primary Care Networks (PCNs) were introduced to the English National Health Service (NHS) in 2019, as part of the longer-term attempt to encourage collaboration within primary care and between primary, secondary, and social care. However, from their inception, policy makers and implementors associated PCNs with multiple purposes and there was little explicit guidance as to how these objectives should be prioritised, combined or sequenced. We present qualitative data from a multi-phase longitudinal study of the implementation of PCNs to explore how networks attempted to make sense of emergent and potentially conflicting purposes. We theorise our data with organisational literature on 'open purpose' which describes institutional shifts in the relationship between economic and social purposes, showing how the dynamic flexibility of open purpose can enable commercial organisations to 'do well and do good' (Clegg et al. 2021). Situating our study in four decades of public policy reform we observe the reverse effect, in which the social purpose of the NHS and other public services has increasingly been 'opened' to economized logics of calculability and optimality. Our findings show how open purpose and its associated process logic of 'becoming' encourages differentiation at the potential cost of both standardisation and sustainability. This undermines the stated aims of the current policy push towards integration. In the absence of appropriate regulation and in the broader political-economic context of austerity, our study suggests that the continued absence of formal purpose from policy design will continue to drive economized logics and the differentiation that accompanies them.

Room 0.20 – Patient-Professional Interaction

Undiscussed spaces and self-surveillance: Exploring patient and healthcare professional perspectives surrounding at-home fetal Doppler use

*Rosa Mackay, Sabrina Keating, Abigail Mcniven, Jennifer Maclellan, Sharon Dixon
(University of Oxford)*

Fetal Dopplers are widely commercially available, yet clinical guidance strongly advises against their at-home use. This creates a paradox which Doppler users - and healthcare professionals (HCPs) - must navigate. Previous qualitative work by Middlemiss emphasises the contradictory discourses in decision-making around at-home Doppler use, but less is known about HCP perspectives.

We will report on findings from 20 interviews with people who chose to use or not use at-home Dopplers during pregnancy, alongside reflections from HCP focus groups and interviews. Our analysis thus far indicates that pregnant people construct nuanced framings of acceptable and unacceptable usage, influenced by safety concerns and awareness of anti-Doppler messaging. This drives stigma and a culture of secrecy around Doppler use, risking undisclosed concerns and missed opportunities within patient-HCP interactions. Whilst many HCPs were sympathetic to Doppler users' perspectives, there were incongruencies in perceptions of the devices as medical or non-medical and the function and value of reassurance. Many HCPs acknowledged the potential for current messaging to silence conversations around safe Doppler use.

By triangulating the perspectives of pregnant people and HCPs, we will explore the undiscussed spaces around risk, reassurance, and Doppler use. Building on existing literature around responsabilisation and medicalisation, we will contribute to understandings of patient-HCP dynamics in the context of medical technology commercialisation and the self-surveillance of 'risky' pregnant bodies (Lupton, 2011). There is potential to improve clinical communication and better support pregnant people by considering how patient experiences of at-home Doppler use can be reconciled with clinical practice.

FRIDAY 13 SEPTEMBER

11:20-11:50

Room 0.09 – Mental Health

Mental health of domestic workers: A sociological study in Delhi

Sada

(Guru Gobind Singh Indraprastha University)

Introduction: Domestic workers play a crucial yet often invisible role in maintaining households and supporting urban economies. Despite their indispensable contributions, domestic workers are frequently subjected to precarious employment conditions, social marginalization, and limited access to resources, all of which can significantly impact their mental health. In the context of Delhi, a rapidly growing urban center characterized by socio-economic disparities and diverse migrant populations, understanding the mental health dynamics of domestic workers is of paramount importance.

Objective:

1. This sociological study aims to investigate the mental health dynamics of domestic workers in Delhi, with a focus on understanding the intersectional factors influencing their well-being.
2. By exploring the lived experiences of domestic workers through an intersectional lens, this study seeks to uncover the complex interplay of structural inequalities, socio-cultural norms, challenges and individual agency in shaping mental health outcomes.

Methods: Qualitative research methods were employed, including in-depth interviews, participant observation, and focus group discussions. A purposive sampling technique was used to select participants, comprising domestic workers from diverse socio-economic backgrounds in different areas of Delhi.

Room 0.17 – Experiences of Health and Illness

Complex emotions and repositioning the self: The lived experience of solid organ transplant recipients

Siân Russell, Ben Rimmer, Rebeka Jenkins, Linda Sharp, Cath Exley

(Newcastle University)

Solid organ transplantation, while lifesaving, often comes with clinical and psychosocial challenges. We conducted in-depth interviews with a diverse sample of 22 heart, lung, liver, kidney, and pancreas transplant recipients, one to 30 years post-surgery. Utilising a constructivist grounded theory approach, our analysis reveals that transplantation can come with complex juxtapositions, which can affect self-identity.

Gratitude and Guilt: The narrative of transplantation as a “gift” and an associated sense of gratitude was woven through the data. However, this notion could have negative consequences; the pressure of a moral imperative to make the most of a “second chance”, feelings of guilt and grief towards the donor, and concerns over their own deservedness.

Between and between: Recipients’ extended life contains regular reminders that it is fragile; reliance on immunosuppressants and further medication to balance their side-effects, ongoing clinical checks and

interventions, and experiences and fears of transplant rejection. Therefore, recipients can be said to exist in a liminal space between wellness and illness.

Reframing and repositioning: Participants reflected upon how transplantation had caused shifts in their identity. Some created a new normality, shifting priorities, or becoming active in the “transplant community” anchoring their identity on their transplant. Others grieved for their former selves or struggled to repair their sense of self. Social, cultural, and financial resources eased this reframing and repositioning process for some more than others.

Facing organ failure and becoming a transplant recipient can result in complex emotions and shifts in sense of self that can continue many years post-surgery.

Room 0.11 – Lifecourse

Buying time: Terminal prognosis, temporal uncertainty and the costs of metastatic breast cancer.

Sophie Lewis

(University of Sydney)

Although novel treatments like targeted and immunotherapies mean people with some incurable cancers are living longer, this creates new challenges that can impact on quality of life. Understandings of what it means to live well in contexts of incurable, life-limiting disease are scarce, particularly in relation to those who have lived beyond their expected prognosis. This paper explores how living with/in prognosis, and with the knowledge of a likely ‘contracted future’, affects how one lives (well) in the present, drawing on scholarship on cram parenting, temporal disturbances, and the sociology of prognosis. Using data from interviews with 38 women with metastatic breast cancer, we examine how a terminal prognosis shifts how time is experienced, what meanings are ascribed to (quality) time, and with what consequences. Findings reveal that using time well in the present could act as a pressure for many women; as could the expectation to plan and prepare for an uncertain future. Living beyond prognosis, while something that was strived for and embraced, could also create new challenges and responsibilities – financial, social and emotional. Findings reveal how considerations of time, longevity, and economic resources (and their interplay) are heightened in the lives of those with metastatic cancer. Over time, as the shadow of mortality edged closer, these questions of time and money became more pronounced; their consequences looming larger in women’s daily lives and extending out to their futures as well as their relationships with others.

Room 0.18 – STS and Medicine

Pharmaceutical regimes: People, pills and politics

Paul Martin, Jon Gabe, Katie Coveney

(University of Sheffield)

The ‘pharmaceuticalisation’ of society has intensified in recent decades as markets for pharmaceuticals have expanded, new medical conditions have been identified for treatment and novel drugs produced for new markets (Martin & Gabe, 2023). From this perspective pharmaceuticalisation is about the transformation of human conditions, capabilities and capacities into opportunities for pharmaceutical intervention. As noted in our previous discussion of this concept (Williams et al 2011; Gabe et al, 2015), such processes potentially extend far beyond the realms of the strictly medical to encompass non-medical uses for lifestyle or enhancement purposes (Coveney et al, 2013). While physicians remain the primary gatekeepers for access to many drugs (see for example, Coveney et al, 2019), pharmaceutical companies are increasingly targeting their marketing at members of the public alongside physicians in

various direct and indirect ways. As a result, the reliance on, and overuse of medicines is being exacerbated in some areas. This is fuelling further debates not simply about expanding markets, but also about the appropriate/ inappropriate use of medicines, including both over and under use. In this paper we focus on the globalisation of pharmaceuticals and their regulation, consumer demand and resistance to pills, and the politics of human futures to consider i) The new dynamics of pharmaceuticalisation; ii) The making of pharmaceutical subjects iii) Resistance and the limits of pharmaceutical solutions and iv) Alternative sustainable and equitable pharmaceutical futures. To conclude, we turn to debates around the concept of pharmaceuticalisation and its manifestation in key areas.

Room 0.19 – Health Care Organisations

“We are draining NHS resources by sending people to hospital for basic needs”: How a lack of embedded Healthcare Professionals in police custody impacts detainees, police and wider healthcare delivery

Gethin Rees

(Newcastle University)

Healthcare Professionals (HCPs) have taken the lead role in the delivery of healthcare in police custody suites since 2003, when the Police and Criminal Evidence Act was amended to allow nurses as well as doctors to deliver healthcare in police environments. Since then, HCPs have become the predominant medical actors in police custody suites, working for private healthcare companies. One key reason for this transition is that it is possible to embed HCPs within the custody suite for a shift, whereas doctors, in contrast, will only attend custody when requested. Embedded HCPs are considered a sea change in custody healthcare due to the role they play in managing and preventing risk by being onsite.

Using a range of methods (observation, interviews and documentary analysis of custody logs), our ESRC-funded study “What is Equivalence in Police Custody Healthcare?” found that embedding was rare and that HCPs were often responsible for multiple custody suites during a shift, often many hours travel apart. Not having an HCP onsite has consequences for the police, the detained persons and the healthcare resources of the wider area. For instance, medications need to be reviewed by an HCP; if one is not available, a detainee might be transferred to a local hospital, putting additional pressure on overstretched local NHS resources. In this paper we will set out the multiple impacts of the absence of embedded HCPs and provide guidance for both the private healthcare companies and the commissioners in order to help them avoid these harmful consequences.

Room 0.20 – Patient-Professional Interaction

“Are they a sensible patient?” Respiratory clinicians’ views on offering patients emergency medication packs for COPD self-management after exacerbation

Karolina Kuberska, Graham Martin

(University of Cambridge)

Emergency medication packs (rescue packs) for COPD exacerbations, consisting of a course of antibiotics and steroids, have become part of self-management strategies for many patients living with COPD. They are commonly prescribed by primary care teams but not routinely offered following an admission related to COPD exacerbation. This study examined hospital-based respiratory clinicians’ views on offering patients rescue packs following hospitalisation for COPD exacerbations. We conducted online interviews with over 30 clinicians (consultant physicians and specialist nurses) to understand variation in practice around, and attitudes towards, offering rescue packs to COPD patients on discharge. Clinicians’ attitudes to offering rescue packs to COPD patients were a mixture of concerns

and recognition of potential benefits. Concerns included antimicrobial resistance, individual overuse of antibiotics, and potential side effects of steroids, especially in patients with poorer understanding of their own condition, with lower self-management skills, or who found it difficult to access primary care. Recognised benefits included the potential to prevent future exacerbations, empowering patients by supporting COPD self-management, and circumventing the difficulties of securing an urgent GP appointment. Building on the concept of the logic of care (Mol 2008), this paper explores the tension between supporting patients' self-management of a chronic condition and the duties of clinicians to prevent harm from inappropriate use of medication with serious side effects. Evaluating COPD patients' self-management abilities involves minimising uncertainty. Clinicians navigate these frictions by identifying "sensible patients", whose ability to use medication correctly is tested in conversations prior to discharge before a prescription is issued.

FRIDAY 13 SEPTEMBER

11:55-12:25

Room 0.09 – Mental Health

The “One in Five” – study: An interdisciplinary exploration of poor mental health and self-injurious behavior in the adolescent, general non-diagnosed Danish population

Kirstine Roll Vestergaard, Kristian Larsen

(UCSF - Center for Health Science Research)

Introduction: One in five Danish adolescents in grade 9 report experience with self-injurious behaviour, regardless of psychiatric diagnostic status. With the dramatic increase in poor mental health and self-injury, self-injury can no longer be seen as an individual psychological symptom, but rather as a growing public health concern and a socially driven, 'fuzzy' pathology. Heightened performance demands, societal pressures, and the psychologisation of language has been proposed to influence the contemporary youth culture. The self as a reflexive project may be more relevant than ever. There is a lack of a more integrated and interdisciplinary understanding of how adolescents in general integrate, navigate and cope with this complex social context, both physically and mentally, by means of e.g. self-injury.

Methodology: A mixed methods approach will be adopted, including literature reviews, cross-generational qualitative studies and comparative analyses. Data collection methods will include focus groups, individual interviews and thematic synthesis, intersectional analysis and interdisciplinarity facilitated by a diverse research team.

Expected outcomes: A comprehensive understanding of the interplay between common mental health problems and self-injury among Danish adolescents. This knowledge will inform the development of evidence-based interventions and contribute to the broader sociological theory on adolescent well-being.

Conclusions: This study provides a thorough, mixed-method, interdisciplinary exploration of the sociocultural dimensions of self-injury and poor mental health among Danish adolescents. By understanding synergistic risk factors, the study aims to develop a robust, integrative and contemporary bio-psycho-social conceptual framework for targeted intervention development, ultimately fostering greater resilience and well-being among Danish youth.

Room 0.17 – Experiences of Health and Illness

Healthcare access in police custody healthcare as denied care: Stigma and dehumanisation whilst detained in police custody in England, UK

Stephanie Mulrine

(Newcastle University)

Against a backdrop of reduced care and social services, it is often the police who are the first responders and may have to administer physical/mental healthcare. Given this context, it is essential to understand the ways in which police custody suites provide care to persons in detention or ensure that they do not die either whilst detained or shortly afterwards. This Economic and Social Research Council funded project is mixed-methods, with data 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 retrospective narrative accounts (n = 43) given by those with lived experience of being detained in police custody. This study highlights a clash between a policy of duty of care and lived reality. Participants referred to the power and control that is removed from them by police when detained, and whilst they understood the reason for this, concerns were raised about the lack of compassion and care shown by staff in police custody (including healthcare professionals) that ultimately led to their dehumanisation. They believed those charged with their care should ensure that they do not suffer needlessly or leave the space in a worse condition than when they arrived. Given police custody is a site for potential intervention, it was a disappointment to many that more support is not offered for those seeking rehabilitation. Ensuring stigmatisation of those entering police custody is avoided would improve conditions.

Room 0.11 – Lifecourse

Institutional readiness and digital technologies: The adoption of telemedicine services in Bangladesh

Shamama Alam
(Aston University)

Telemedicine is a component of e-health that uses digital technologies to deliver medical education and services across geographic areas, which renders it particularly useful in diverse and populous countries. Bangladesh is one of the most populated countries in the world, with 140 million people. According to the World Health Organization, Bangladesh has 6.7 doctors for every 1000 citizens. Across the country, there is a severe shortage of nurses, hospitals, and medical personnel, with substantial differences in access to healthcare facilities between urban and rural areas.

Telemedicine has been indicated as an approach for tackling these disparities and enhancing healthcare universality in Bangladesh. For this reason, the national government is engaged in implementing telemedicine into clinical practice. Telemedicine was introduced by the Ministry of Health & Family Welfare in public hospitals, partially achieving the 2021 Digital Bangladesh objective. This has included the delivery of online consultations to patients, as well as online training to healthcare workers. However, there are many challenges that can limit the adoption of telemedicine. Inequalities, low digital literacy, insufficient digital infrastructure, and problems of internet connectivity are some of the factors that have shaped the adoption of telemedicine in Bangladesh. In this way, we are dealing with an interesting case for the analysis of institutional readiness in a lower-middle-income country.

Based on a Masters Degree study, this presentation focuses on the main challenges associated with the adoption of telemedicine in Bangladesh.

Room 0.18 – STS and Medicine

How are vaccines 'domesticated'? Vaccination inside and outside the clinic

Pru Hobson-West, Kate Weiner
(University of Nottingham)

Vaccines are symbolically powerful technologies, widely identified as one of the greatest scientific and public health achievements. Vaccines are also held up as embodying hopes for future health, including against chronic conditions. Decades of empirical work in medical sociology has helped further understanding of many aspects of vaccines and vaccination, including vaccine hesitancy. Theories such as lay epidemiology, trust, post-truth and risk remain central to this literature. However, this body of

work tends to explore patient attitudes to vaccination, focuses on one type of vaccine (e.g. MMR or Covid-19), and has almost universally assumed the clinic as the site where vaccination takes place, at least in the UK.

This paper will propose a new conceptual approach to the sociological study of vaccines and vaccination, based on understanding vaccination as social practice, with particular geographies and materialities. The argument will proceed in three steps. First, we draw on new ethnographic data from an EU-funded project which demonstrates the importance of space and place in how the vaccine encounter is created. Second, we argue that the variety of settings in which vaccination takes place has proliferated, but demonstrate that this is not yet reflected in the published sociological literature. Finally, we argue that the STS concept of 'domestication' can function as a productive lens through which to understand vaccination, and the way in which technologies are appropriated, re-made or resisted in different spaces.

Room 0.19 – Health Care Organisations

Working as a system? Community health services, hospital avoidance and Ostrom's 'common pool resources' in Integrated Care Systems

Mhorag Goff

(University of Manchester)

The NHS Long-Term Plan (2019) emphasised the pivotal role of Community Health Services (CHS) within Integrated Care Systems (ICSs) in England. ICSs shift the emphasis towards collaborative services delivery with 'system partners' across healthcare settings within a geographic footprint. 'System working' aims to enable system efficiency and to better meet the needs of their populations, including addressing health inequalities and for CHS, 'boosting out of hospital care'. Fixed system budgets within which to provide services bring issues related to the use of common pool resources to the fore.

Our qualitative study explored how adult CHS are commissioned to match supply and demand for services and staff in the context of ICSs and priorities around hospital avoidance. We used Ostrom's (1990) principles for managing common pool (i.e. shared) resources to analyse data from semi-structured interviews with CHS providers and commissioners in four case study sites in different ICSs in England.

We find CHS are disadvantaged by block contract payments that mean 'rewards' for contributions to the common pool cannot accommodate fluctuating patient complexity or support for other providers, such as with hospital avoidance. It is challenging for CHS to evidence prevention that is not formalised 'out of hospital' work to argue for redistributing resources from acute providers. There is epistemic injustice in the skewing of the system to 'knowing' and 'seeing' community health services in terms of 'hard', transactional measures that fail to capture the character of CHS work. System working will require better understanding of different forms of contribution.

Room 0.20 – Patient-Professional Interaction

Beyond "bad apples": The nature and extent of sexual misconduct in medicine

Emma Yapp, Natasha Mulvhill, Hannah Richards, Nathan Birdsall

(Bristol University)

Within the last decade, there have been myriad research and policy developments in relation to sexual misconduct in medicine. From the operating room to the psychiatric clinical setting, both patients and medical professionals report experiences of sexual harassment and misconduct. In this presentation,

we will present preliminary findings from our review of the extant literature on sexual misconduct perpetrated by medical professionals. Focusing on the UK context, we map out the nature and extent of the problem. In so doing, we draw attention to the various factors that contribute to higher rates of sexual misconduct in health contexts. Rather than being perpetrated by a few “bad apples”, this presentation instead demonstrates that sexual misconduct is a pervasive problem amongst medical professionals. The continued failure to identify and prevent sexual misconduct reveals wider problems within the culture of medicine itself, and provides new insights into the power dynamics that give rise to the particular case of sexual misconduct in medical contexts.