Medical Sociology Study Group

Annual Conference Programme
Important Information

14 – 16 September 2022

University of Lancaster

Day 1 Abstract Book

Wednesday 14 September 13:25 -13:55

Inequalities and Intersectionality

Do collective bargaining systems affect health inequalities between migrant and native workers?

Laura Sochas, Aaron Reeves
(University of Oxford)

Work is both a key driver of international migration, a necessary condition for economic and social integration in one's host country, and an important social determinant of health (Flynn and Wickramage 2017). Quantitative literature on the institutional and policy determinants of migrant health is relatively new, and has focused on migrant integration policies (Juarez et al 2019, Giannoni et al 2016). This study focuses on another structural determinant of migrant health that is directly linked to the world of work: collective bargaining institutions.

On the one hand, strong and centralised collective bargaining institutions may improve the social determinants of migrant workers' health, by raising wages or improving working conditions for low-paid occupations, which migrants often do. On the other hand, political economy's "insider-outsider hypothesis" posits that in dualized labour markets, strong trade unions are more likely to defend the interests of labour market insiders at the expense of labour market outsiders. Migrants are more likely to be typical labour market outsiders, i.e.: on fixed-term or zero-hour contracts and with less access to social welfare benefits that are tied to employment status.

This study will investigate whether strong collective bargaining institutions (measured according to the share of labour force covered by a collective bargaining agreement) are associated with lower health inequalities between migrant and native workers. The study will use nested random effects and four waves of the European Labour Force Survey (1999, 2007, 2013, 2020) across 35 countries and with approximately 1.5 Million individual observations.

Experiences of Health and Illness

Conflict and the pursuit of recognition in the public-private experience of persistent physical pain

Susanne Main
*(*The Open University*)*

Living with persistent physical pain entails managing emotions and expectations of what it is to 'appear' in pain. The Exhibiting Pain doctoral research project explored responses to creative expressions of life with chronic physical pain, as well as the experience communicated in the works. Conflict was identified in the desire to elicit empathy and recognition of experiences living with pain, via the creative works, balanced with the desire to keep this personal experience private and the feeling that other people do not want to hear about the condition. The concept of public-private dualism will be used to discuss these conflicting emotions.

Critical Public Health

Public messaging on COVID-19, risk and reception: sanitary citizenship in pandemic times

Tanvi Rai, Kaveri Qureshi, Anna Dowrick, Sue Ziebland
*(*University of Oxford*)*

During the COVID-19 pandemic in the UK we received daily updates on the number of infections, hospitalisations, and deaths. The Prime Minister, Chief Medical Officer and Chief Scientific Advisor gave regular television appearances pronouncing the latest restrictions and rules. There were official reports in the news, as well as unofficial stories circulating on social media about the major Inequalities and Intersectionality in COVID-19 exposure and outcomes, whereby frontline workers and racially minoritised groups faced increased risk of severe illness and death.

In this paper, influenced by Lupton's analysis of moral identity in relation to 'risk' and the 'imperative of health' (1995), we explore how public discourses (official and unofficial) were received and understood, and influenced people's experiences of COVID-19. We interviewed 70 people, mainly from ethnic and religious minority backgrounds, who experienced and recovered from COVID-19 during the acute phases of the pandemic in 2020-21. We compare people's descriptions of feeling blamed for behaviour that was seen as increasing risk; essential workers' reflections on being simultaneously celebrated and demonised; and the challenges raised for some in being simultaneously instructed to work from home and appealed to, emotionally, to protect one another, whilst safety nets were not provided. We draw upon Brigg's (2003) work on the demarcation between 'sanitary citizens' and 'unsanitary subjects', but rather than focusing on the work of blame and deflection by statutory institutions, our focus is on how people made sense of this messaging, in line with their intersectional social positioning, and how they responded agentially, by articulating critique.

Diagnosis, Screening and Treatment

The social organisation of fibromyalgia diagnosis: a demonstration of how Institutional Ethnography (a 'Sociology for People') extends the Sociology of Diagnosis

Caroline Cupit, Teresa Finlay, Catherine Pope
*(*University of Oxford*)*

Dorothy Smith's Sociology for People [also known as 'Institutional Ethnography' (IE)] is an approach that has significant potential for the study of healthcare. Offering a clearly-articulated ontological framework and methodological tools to support the whole research process (not just data collection), IE focuses on people's everyday practices and their social organisation. Importantly, an IE researcher assumes a 'standpoint' in relation to socially-organised healthcare systems—recognising that positionality matters.

In this paper, we demonstrate how IE can be used to undertake a theoretically-informed literature review, focusing on the diagnosis of fibromyalgia syndrome. We highlight traces of patients' and healthcare practitioners' intersecting and socially-organised work. We demonstrate how IE's analytic tools (e.g. taking a standpoint position and analysing from that point) produce an alternative way of reading the literature, enabling us to uncover new areas for empirical study, with a focus on how systems are configured to serve or subjugate particular interests.
Our analysis extends beyond the settings in which fibromyalgia diagnosis is most obviously done, and into the less-visible world of management and policy. We take an investigative approach, exploring diagnostic systems within the wider social infrastructure (including e.g. biomedical or welfare benefits systems).

We conclude by discussing the value of IE for undertaking an explicitly-positioned literature analysis, and argue that IE can also provide an important contribution to the Sociology of Diagnosis—extending contemporary ways of studying diagnosis (as process, category, or consequence) by drawing connections between local diagnostic practices and the dominant social relations that organise them.

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

Talking cervixes: How time, objects and subjects are made in interactions during labour and birth

Sian Beynon-Jones, Ellen Annandale, Helen Baston, Lyn Brierley - Jones, Alsion Brodick,Paul Chappell, Josephine Green, Clare Jackson, Victoria Land, Tomasina Stacey

*(*University of York*)*

The clock occupies a prominent position in many feminist and midwifery critiques of the medicalisation of labour and birth. Concern has long focussed on the production of standardised ‘progress’ during labour, via the expectation that, once in ‘established’ labour, women’s cervixes should dilate at a particular rate, measurable in centimetres and clock time. Research has emphasised that women’s status as subjects is frequently undone through the measurement and recording of the behaviour of their cervixes. In this paper, we develop this work by exploring some of the complexities involved in constituting people in labour/their cervixes as objects/subjects. Our analysis draws on 37 video and audio recordings of women’s interactions with midwives in midwife-led units during labour in two English NHS trusts. We consider how the relations between women and their cervixes become differently constituted through clocks and measurements of dilation, as well as the role of women and midwives in these processes. It is through such fine-grained analysis, we suggest, that it becomes possible to pinpoint when and how clocks and cervical measurements trouble the positioning of people in labour as decision-making subjects. This study was funded by the National Institute of Health Research (NIHR).

Mental Health

Stigmatising on a blank page? On the obviousness of stigma in contemporary mental health research

Baptiste Brossard, Amy Chandler
*(*University of York*)*

Research on stigma is a core aspect of both qualitative and quantitative sociological research on mental health. Stigma research situates reactions to mental disorders at the core of a spiral of negative ‘outcomes’ that affects people’s lives, a perspective appropriated by many mental health campaigns advocating ‘mental health literacy’ or more directly working to ‘tackle stigma’.
Although the general objective of this approach is laudable - making stigmatisation processes visible - the way in which it is performed raises significant questions. Our review of recent mental health literature (Brossard & Chandler 2022 – Explaining Mental Illness: Sociological Perspectives) led us to delineate a ‘social psychological bias’, namely, the tendency to consider ‘stigma’ as a universal phenomena, comparable and neutral. Each mental disorder, depending on ‘social factors’, would lead individuals to experience a certain amount of negative feedback. However, people do not stigmatise on a blank page, they live in an already stratified world where stigma is only the tip of the iceberg. As such, we cannot cut stigmatising behaviours off from the historical processes that generate them and enable their existence in the first place, such as symbolic violence and marginalisation. Drawing in part on recent critical interventions into stigma theory (Tyler, 2000; Scambler 2018), we argue for greater attention within the sociology of mental health to the sociohistorical origins of what realises itself under the form of stigma.

STS and Medicine

Governing Digital Health Innovation: A Sociomaterial Framework

Benjamin Marent, Flis Henwood
*(*University of Sussex*)*

The notion of digital health often remains an empty signifier, employed strategically for a vast array of demands to attract investments and legitimise reforms. Rather scarce are attempts to develop digital health towards an analytic notion that provides avenues either for understanding and/or for governing such ongoing transformations in healthcare. This presentation elaborates a sociomaterial framework for governing digital health innovation. It first outlines the sociomaterial approach, developed within STS studies, to understanding digital health, showing how digitalisation affords practices of health and medicine to handle the combined and interrelated challenges of increases in quantification (data-intensive medicine), varieties of connectivity (telemedicine), and unprecedented modes of instantaneous calculation (algorithmic medicine). This enables an engagement with questions about what forms of knowledge, relationships and control are produced through certain manifestations of digital health. The presentation then sets out, in detail, an innovative digital health governance framework that can guide explorations and negotiations into the type of care we want to achieve through digital transformation. The framework embeds Karen Barad’s concept of agential cuts suggesting that responsible cuts towards the materialisation of digital health require participatory efforts that recognise the affordances and the generativity of technology developments. Such governance strategies can lay the foundations to reorient and sensitise innovation and care processes in order to create new possibilities and value-centric approaches for promoting health in digital societies as opposed to promoting digital health per se.

Health Service Delivery

No backstage: the relentless emotional labour of acute nursing through the Covid-19 pandemic

Aileen Grant, Nicola Torrance, Rosaleen O'brien, Flora Douglas, Debbie Baldie, Catriona Kennedy
*(*Robert Gordon University*)*

The Covid-19 pandemic disordered the routine delivery of health care. We explored nurses’ experiences working in Covid and non-Covid facing roles in the acute sector of one Scottish health board between April-July 2021 through 20 in-depth interviews. Interactions between patients, family members and nurses changed due to inflection control measures. Staff experienced a range of conflicting emotions, e.g. fear of infection and transmission but a strong sense professional duty to contribute to the pandemic effort. Nurses were dissatisfied with the care they provided and experienced moral dilemmas, distress and injury from the emotional labour of working under the infection control measures but also the virulence and uncertainty of this new disease. We draw on Goffman’s (1967) presentation of self, Hochschild’s (1983) work on emotional labour and Bolton and Boyd’s (2003) work furthering emotional labour to illustrate the usual rules and routines of interaction between patients, family and staff were abandoned. Nurses were able to mask their distress and injury but often unable to effectively deliver the correct emotional response due to infection control measures, such as protective clothing (PPE) and social distancing. The ‘backstage’ spaces, important for dealing with the emotion of front stage performances, were missing for those in Covid facing roles. The isolating work and the removal of spaces for the donning and doffing of PPE resulted in limited or no opportunity for humour and the enacting of collective care. Their private space offered little reprieve with the constant media attention on infection levels, death and nursing ‘heroes’.

Patient - Professional Interaction

Is shared-decision making in childbirth possible?

Ellen Annandale, Helen Baston, Sian Beynon-Jones, Lyn Brierley-Jones, Alison Brodrick, Paul Chappell, Josephine Green, Clare Jackson, Victoria Land, Tomasina Stacey
*(*University of York*)*

Patient involvement in decision making during birth is enshrined in UK policy and in practice guidelines, and consistently endorsed by practitioners and people giving birth. However, research consistently points to significant difficulties of translating this aspiration into practice. The tensions between ‘listening to women’, adherence to clinical guidelines concerning risk management and organisational cultures are well- documented and brought to the fore recently with the publication of The Ockenden Report.
We address why these perennial tensions persist by analysing how they play out in practice. The analysis draws on a mixed methods study (NIHR funded) involving video and audio recordings of 37 births captured in real time, pre- and post-natal surveys of over 100 women, and 20 semi-structured interviews with practitioners, in two English NHS midwife-led units. The analysis (which is completed) shows that despite midwives’ intentions to engage women in decisions, they initiated the majority of decisions in formats that did not invite participation (beyond consenting). Women were afforded limited optionality in decision-making as midwives oriented to guidelines/standard clinical practice in pursuing particular outcomes. However, the extent of optionality midwives varied by decision type; women had most involvement in decisions pertaining to pain relief and third stage of labour. Despite limited involvement in decision-making in actuality (compared to pre-natal expectations), postnatal satisfaction was high. We found no relationship between midwives’ use of different formats of decision-making and

aspects of satisfaction. However, women’s initiation of decisions, particularly relating to pain relief (e.g., making lots of requests), was associated with lower satisfaction.

Wednesday 14 September 14:00 - 14:30

Inequalities and Intersectionality

Racism and Mental Health in Professional Sport

Susan Litchfield, Dr Christopher Elsey, Nasreen Lodhi
*(*De Montfort University*)*

Racism has a long history within professional sport. Sadly, no aspect of sport can escape responsibility and blame. Racist abuse has been produced both on and off the field of play by players, coaching staff, referees or umpires, senior figures within sporting organisations and by fans (individually and collectively). Shining a light on instances of racism and discrimination in sport is necessary and vital to tackle the prejudice and to educate society. However, what is often missing from accounts of this type of incident is the negative long-term mental health impact that racism can cause.

This paper will bring together high-profile case studies in which a competitor working within professional sport experienced racist abuse or discrimination, resulting in mental health issues being disclosed. These incidents involve abuse from fellow players during matches, a young fan in the crowd, social media and from within a sporting organisation.

For the purposes of this analysis, we've been looking at specific incidents of racism aimed at individual players who later discuss how the incident (and the resultant fallout) impacted their mental health. Using the methods of ethnomethodology and conversation analysis our research draws on TV match coverage, sports media interviews, podcasts, documentary footage, social media and legal documentation. The analysis will focus on the players' own accounts, how they describe the events, and how they formulate their mental health.

The upshot of this research is that sporting authorities and organisations must pay attention to player welfare and well-being when racism and discrimination are reported.
Stream - Experiences of Health and Illness.

"I'm not going to die of Covid, because I'm going to die of cancer": Experiences of being diagnosed with colorectal cancer during the Covid-19 pandemic

Christina Dobson, Linda Sharp, Colin Rees, Vera Araujo-Soares, Jennifer Deane
*(*Newcastle University*)*

Background: Cancer is a leading cause of death in the UK and early diagnosis is crucial to survival. The onset of the Covid-19 pandemic affected the way NHS services were delivered and patients interacted with them. This study sought to understand how the pandemic affected patient's experiences of being diagnosed with colorectal cancer (CRC).
Methods: Patients diagnosed with CRC during the pandemic, at South Tyneside and Sunderland NHS Foundation Trust, were eligible. Remote semi-structured interviews were undertaken with 19 patients and explored diagnostic and treatment pathways, and how the pandemic influenced these. Interviews were audio-recorded and transcribed. Initial transcripts were independently coded by JD and CD and a code matrix collaboratively developed and applied to subsequent transcripts. Themes within the data were discussed and developed by the team.
Findings: Isolation was a core thread throughout participants' cancer pathways. Social distancing measures forced physical separation from usual support networks. Health care appointments, including being given a diagnosis, were often done via telephone, which presented additional challenges to the diagnostic moment. Patients were not allowed visitors to their wards, after treatment, however, this

experience of isolation was viewed positively, allowing them time to rest and recover, without being obligated to socialise or undertake the emotional work of supporting loved ones. Media reporting of Covid-19 impact on NHS services caused concern to patients at the beginning of their diagnostic pathways, however, very few examples of perceived delays were reported, and those that were, were seen as unavoidable and understandable within a pandemic context.

Critical Public Health

@CovidLives: Covid pandemic (sexual) cultures among young men who have sex with men in the UK

Karenza Moore, Ben Light, Lisa Garwood-Cross
*(*Newcastle University*)*

Public health measures to mitigate the spread of COVID-19 are translated into media messaging by organisations targeting the health of different population groups. Engaging experiences of the minority group of men who have sex with men (MSM), we present findings from the multi-method AHRC-funded study @CovidLives on responses to these messages in relation to using 'hook up apps' and other internet platforms to connect for sexual purposes. Such platforms are key sites where sex and romance are negotiated among young MSM, a trend which rapidly intensified during the pandemic.

Here we focus on our younger respondents aged 18 years to 30 years of age. We explore young MSM's experiences of both COVID-19 and sexual health messages, alongside their everyday practices, including hook-up app use. We examine the differences and similarities between these younger MSM and our wider cohort of respondents to our four snapshot online surveys carried out at key moments during the pandemic. We also analyse COVID-19 web resources aimed at this younger cohort. Findings included shifting personal attitudes and practices around hooking up in person, and changing notions of risk and morality, related in part to government pandemic messaging and later 'Partygate'.

Our study adds to the wealth of sociological and critical public health literature on MSM dating and hook up cultures online, and understandings of sexual practices, technology use, and public health messaging engagement in minority groups during the pandemic and beyond, including its current future-possible impact and what the 'new normal' might be for young MSM.

Diagnosis, Screening and Treatment

'I just need to know what they are and if you can help me': medicalisation and the search for legitimacy in people diagnosed with functional seizures.

Paul Bissell
*(*University of Chester*)*

This presentation reflects on the struggles for legitimacy expressed by those diagnosed with functional seizures (also known as non-epileptic attack disorder), a functional neurological condition which superficially resembles epileptic seizures. What marks out FS, is that unlike many other functional conditions, on further clinical investigation, there are none of the bodily changes associated with epilepsy. This therefore rules out providing a broadly 'organic' or biomedical explanation for those diagnosed with FS.

Drawing on a qualitative study of patients' accounts of diagnosis and treatment, we draw on the literature around medicalisation to argue that entry into the sick role (and thus a legitimate patient identity) is rendered problematic and thus adds to anxieties around legitimacy. We comment on the frustrations and ambivalence expressed around the diagnostic journey and crucially, the nature of explanations offered to those so diagnosed, which typically focus on stressful life events or 'psychological' factors. These, we argue, fail to grant the Parsonian 'claim to exemption' that is being sought by those with a diagnosis. These frustrations are sharpened, we argue, because of the relentless contemporary framing of all health conditions via a lens of 'responsibilisation', which is a core feature of neoliberalism. We discuss the ambivalent and multi- valent role of medicalization and medical expertise more generally in legitimising the social suffering of those diagnosed with FS. In so doing, we draw on research around so-called 'medically unexplained symptoms' to illustrate how FS fits into this broader literature.

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

Policy Implementation – Access to Safe Abortion Services in the Republic of Ireland: Service Users' Experiences.

Dyuti Chakravarty, Lorraine Grimes, Joanna Mishtal, Karli Reeves, Deirdre Duffy, Bianca Stifani, Mark Murphy, Trish Horgan, Mary Favier, Wendy Chavkin, Antonella Lavelanet
*(*University College Dublin*)*

After a referendum in May 2018, legal provision of abortion services in Ireland commenced on 1 January 2019. Between 2020 and April 2021, we conducted a study (supported by WHO-HRP) to examine the facilitators and barriers to abortion policy implementation in Ireland. This paper, as part of the larger study, focuses on the experiences of service users with accessing abortion care in Ireland. We conducted 108 in-depth qualitative interviews in Ireland between May 2020 and March 2021 with three participant samples: (a) 27 key informants (b) 51 healthcare providers (23 in the community and 28 in hospital settings) (c) 30 service users. This study draws on the experiences of service users and triangulates information from other samples to account for the experiences of service users from hard to access communities. Service users seeking care before 9 weeks and 6 days gestation have generally recorded having experiences with early medical abortions in the community. However, experiences with accessing abortions in the hospitals are more mixed. There are still several barriers that affect service users' access to the services, including unclear pathways from primary to hospital care between 10 weeks and 12 weeks' gestation, incomplete geographic distribution of services, mandatory 3-day wait, compulsory Personal Public Service Number (PPSN) for access to state-subsidized service and in cases of foetal anomalies.Although the new legislation has greatly expanded service provision in the country, there are barriers that pose challenges for service users, especially those located along multiple axes of social and economic Inequalities and Intersectionality

Mental Health

Examining Student Mental Health and Wellbeing Qualitatively: Preliminary Findings from an Elicited-Reflections Study

Heather Sutherland
*(*Northumbria University, Newcastle Upon Tyne*)*

Prior to the COVID19 pandemic, increasing rates of university student mental ill health (ONS, 2018: Shackle 2019) were being recorded; a continuing of this upward trend in distress levels remains apparent (ONS, 2020; Byrom, 2020; OfS, 2022). Current explorations and declarations pertaining to student mental health and wellbeing draw most heavily on quantitative approaches (Koshin et.al., 2017: 2501; Foster and Francis, 2019) to make sense of the growth and/or offer insight into intervention efficacy. On the contrary, qualitative understanding of student mental health and wellbeing is afforded less space, resulting in conversations where personal agency is frequently overlooked (Farrell et.al., 2017: 397), with gaps between awareness and fully effective support provision discernible (Dhingra et. al., 2018:1; Gask et al, 2017: 593; Yasuhiro, 2018), despite good institutional intentions.

This paper responds to such concerns by exploring and making visible the granularity of students' qualitative expressions regarding their mental health and wellbeing experiences. Drawing on elicitations from Free Association Narrative interviews with 21 undergraduate students, conducted at two timepoints across 2020-21, it describes the 'meaning of student mental health and wellbeing' for these participants, leading to an outline of three analysis-determined core strands to their mental health and wellbeing experiences – 'Balance and Stability', 'Governance for Self and Choice', and 'Validation and Recognition'. In highlighting these elements/strands, the paper invites a reconsideration and re-evaluation as to how university student mental health and wellbeing might be understood, simultaneously encouraging review of existing in-response university support approaches and mechanisms in light of the findings.

STS and Medicine

The data infrastructures of fertility tracking: Emerging issues in reproduction and digital health

Alina Geampana
*(*Aston University*)*

Fertility tracking technologies (FTTs) constitute one of the largest segments of the femtech market – a market comprised of new technologies aimed at improving women's health. Millions use FTTs to track their fertility and obtain predictions about their fertile windows. As a result, such technologies manage and generate an unprecedented amount of data about user fertility patterns. However, the impact of FTT data practices on reproductive care and knowledge has largely been overlooked by social scientists. Drawing on the scientific literature and key regulatory and policy documents, this research highlights emerging fertility data practices and the socio-technical network reconfigurations that such practices facilitate. I argue that there are three critical areas that have been impacted by FTT data developments: 1) the regulatory approval of reproductive technologies, 2) the production of scientific knowledge about fertility and 3) lay fertility knowledge diffusion. The findings point towards the need to further analyse fertility data infrastructures, specifically, how different stakeholders participate in the production, evaluation and diffusion of FTTs, their data and their predictive algorithms. The discussion proposes that the use of a socio-technical analytic framework is beneficial for capturing the interconnections between developers, users, medical professionals and FTT data. By exploring key digital health developments in reproductive care, this paper contributes to sociological discussions about the increased use of commercialised health technologies and their consequences – both intended and unintended.

Health Service Delivery

The remarkable invisibility of NHS 111 online

Catherine Pope, Jennifer Maclellan, Jane Prichard, Joanne Turnbull
*(*University of Oxford*)*

In 2017 the NHS telephone urgent care triage service was augmented by a web-based service, NHS 111 Online. Accessed using a smartphone, tablet or computer, the task of triage and assessment is accomplished by patients/callers themselves using a decision-support algorithm. NHS 111 online is an exemplar of 'digital-first', the push to enrol digital technologies to deliver public and private services, and viewed by policy-makers as a vehicle for reducing demand for other overburdened health services.

This paper reports the qualitative component of a larger multi-method study of NHS 111 online. We used qualitative interviews with 80 staff and stakeholders of primary, urgent and emergency care service delivery to explore the impact of NHS 111 online on healthcare work: NHS 111 online sends patients to these services and/or diverts them elsewhere. The analysis presented here owes an intellectual debt to Susie's Scott's work on the 'sociology of nothing' and theories of the marked and unmarked, which we reached for when confronted by the remarkable invisibility of this seemingly core NHS service, in the wider landscape of health care. Despite apparently high use (30 million visits over 6 months in the 2020 pandemic) we were surprised to find very low awareness among our interviewees. Confusion about nomenclature, an exceedingly crowded digital field (littered with alternative technologies and ways of accessing care) and constant change in service provision provide some cogent reasons for this invisibility. We explore how sociology might illuminate our data and how the invisible might be rendered visible.

Patient - Professional Interaction

Making sense of pregnant bodies, health information and care processes: Digital diagnostic work in the antenatal period

Nicola Mackintosh, Shona Agarwal, Qian (Sarah) Gong, Annette Briley, Jane Sandall, Natalie Armstrong

*(*University of Leicester*)*

Increasingly, global attention is shifting to risk management and digital self-care before, during and after pregnancy to reduce morbidity and mortality. Expectant mothers, partners and families routinely use websites, mobile phone apps, and social media platforms to learn about ‘normal’ pregnancy related changes and potential signs of a complication. This paper focuses on (self)diagnosis during the antenatal period as a distributed, reflexive and collaborative activity. We draw on interview data from 30 participants (mothers and maternity staff) exploring technology-in-use, drawn from a larger UK-based mixed-methods study. We use the notion of diagnostic work to provide a lens through which to understand social, embodied and material interactions in antenatal care. Apps and web resources act as diagnostic objects, which expectant mothers, partners and staff engage with to navigate circulating competing epistemic claims and contestations within the digital maternal health space. Mothers’ self-tracking practices highlight the performativity of the diagnostic act as, by using simple indicators, digital users shape the practices that they seek to understand. Mothers and staff also engage in digital sense-making and trouble-shooting. These sense-making and trouble-shooting acts are associated with asymmetries of expertise and authority as numeric values open up but also close off opportunities for mothers being taken seriously (e.g. as embodied knowledge, which defies articulation or codification, is discounted). We consider the implications of intersections between digitally mediated health, diagnosis, pregnant bodies and discourses of health and risk for pregnancy and childbirth, amidst current media attention on safety in maternity care.

Wednesday 14 September 14:35 -15:05

Inequalities and Intersectionality

Concepts of Racial Iatrogenesis, Biomedicine and 21st Century Health Inequality and their relationship to the Organ Trade in the United Kingdom.

Joanne Tanner
*(*University of West London*)*

The empirical evidence since the late 1980's has suggested a universal shortage of human organs for transplant. This global shortage has a symbiotic relationship with organised crime and healthcare which underpins an organ trade, which exists to fill the deficit of organs to perform lifesaving organ transplant surgery. The response to the emerging organ trade have been largely advisory or legislative and based in concepts of prohibition. While the introduction of statutory policies intent on improving donation through state run organ registers have been implemented to improve supply. The demand for organs has caused the phenomena of the movement of people from western nations to secure organs from the global south. The UK not only shares the same profile as other western nations but is one of the poorest performing in terms of organ donation, citing that our BAME communities drive these trends with high rates of disease, and low rates of donation reported to
be based in religious and cultural non engagement (Chugh:2016). This paper argues that firstly, to manage the supply chain in organs there is a need to explore concepts of racial iatrogenesis and Eurocentric approaches to healthcare. Then secondly, recognise that health inequality is a primary factor that both affects organ donation rates and bind us to the organ trade.

For the purpose of this paper and the wider study the 'Organ Trade' has been divided into four strands; Human Organ Trafficking, Transplant Tourism, Commercialised Human Organ Sales and lastly State Acquired Organs (associated with China).

Experiences of Health and Illness

Somewhere between "it's so good for you!" and "it's all about the social": An ethnographic study of cold water dipping

Kass Gibson
*(*Plymouth Marjon University*)*

Swimming in cold water has a long and widespread history. However, "dipping" - swimming in the sea (or other areas of open water) without swimming recognizable strokes in a manner that would constitute aerobic exercise – has undergone a notable resurgence in Britain over the last five years. In that time a (sub)culture of dipping, marked by a preponderance of middle- and later-life women, has grown in prominence and recognizability. This growth is entwined with research seeking to define therapeutic potential and health and wellbeing outcomes by specifying and quantifying psychological, physiological, and work-related "benefits" of dipping. With reference to my ongoing ethnographic research with cold-water dippers across Cornwall (including over 14 hours of participant-observation immersed in cold-water through 70 – and counting – dips as well as archival research), I explore how dippers define and conduct dipping as an act of health- and self-care. More specifically, I explore how the resurgent (sub)culture of dipping evidences an articulation of broader cultural positioning of epistemological and political shifts in health and healthcare. Especially regarding mental health. Then, by connecting longstanding observations within interpretive sociological research, classic social theory, and contemporary sociological imperatives to take embodiment seriously, I show health and wellbeing claims made in and through cold water immersion are more complicated and contradictory than acknowledged currently.

Critical Public Health

Insights from the evidence-engagement interface: An empirical examination of the relationship between evidence use and engagement across UK policy organisations

Clementine Hill O'connor, Katherine Smith, Ellen Stewart
*(*University of Strathclyde*)*

The past two decades have seen a contemporary resurgence in participatory visions of health policy that has occurred alongside efforts to strengthen the role of evidence, with surprisingly few attempts to explore how these developments are intersecting (Stewart et al, 2020). In this paper, we examine this intersection within three distinct policy organisations, each of which is working at a different level of UK policymaking. Employing a combination of interviews, observations and documentary analysis, we explore how individuals working in policy organisations assign value and meaning to the roles of evidence and public engagement, focusing particularly on understanding how evidence and public engagement are used, and how policymakers view the relationship between the two.

We identify four distinct views about the evidence-engagement interface: (1) public engagement as foundational for policymaking; (2) public engagement and evidence as strategic means of achieving support for policy proposals; (3) quantified evidence and data as the ideal basis of policy; and (4) a desire for better integrating quantified data with qualitative insights (the most common of the four views).

These findings underline calls to examine the disconnect between efforts to promote public engagement and efforts to promote evidence use in policy. Our data imply a desire to find ways to better integrate public engagement and evidence within policy settings. We conclude by outlining some possible mechanisms for such integration, while also reflecting on the challenges arising from the extent to which metrics appear to have been embedded within organisational systems and practices.

Diagnosis, Screening and Treatment

Diagnosing disorder: reimagining suicide in fatal accident reports

Amy Chandler, Sarah Huque, Rebecca Helman, Joe Anderson
*(*University of Edinburgh*)*

The relationships between suicide and medical-psychiatric governance and categorisation are long-standing and complex (Marsh, 2010). Although suicide itself is not a ‘diagnosis’, this paper engages with two intersecting ways in which suicide can be read through the sociology of diagnosis. Firstly, we address how suicide is used as evidence of pre-existing psychiatric disorders – a post-mortem diagnosis common in formal reports and some academic studies of suicide. Secondly, suicide is also often read as evidence of social pathology or breakdown, with high male suicide rates enrolled – for instance – in identifying and diagnosing a ‘crisis’ of masculinity (Jordan & Chandler, 2019).

In this paper we draw on a qualitative thematic analysis of 37 Fatal Accident Inquiry (FAI) reports concerning deaths by suicide of people in Scottish prisons since 2016. Our analysis addresses how suicide, and the lives of those who die, are constructed, represented, and made sense of. We address suicides in prisons as one site where meanings about suicide are produced, as part of a study concerned with how suicide is made sense of and practiced in diverse social and cultural locations across Scotland.

While the FAI reports offer a forum in which suicide could be approached as a ‘social diagnosis’ (Brown et al., 2011), our analysis suggests that within the reports suicide remains constructed as closely related to mental illness. We argue that this could be otherwise, and offer reflections on the role that sociology might play in reimagining the conclusions of formal inquiries into suicides.

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

Who has a stake in the decision to become an egg or sperm donor? Donors, their families, and the relational impact of donating

Petra Nordqvist, Leah Gilman
*(*University of Manchester*)*

A woman or man's decision to donate egg or sperm might at first glance appear to be their own autonomous decision. However, recent findings from a large-scale qualitative study, exploring how donating impacts donors' own personal lives, suggest that it affects a range of relationships and that relatives can feel themselves to have a stake in the decision too. Drawing on original data based on interviews with egg and sperm donors, their kin, and also fertility counsellors, this paper explores who, in their family, donors tell about their donation, when they do so and how they explain these decisions about disclosure. It also explores how family members engage with such news, and how people manage potential disagreements in family networks. We show that the two salient but contradictory discourses of adult autonomy, on the one hand, and reproductive connectedness, on the other, justle for position in the way in which stories of donating flow in families. We show that the discourses of autonomy and reproductive connectedness are invoked by different people at different times, in different contexts and in different combinations, so that they are emphasised to a greater or lesser degree, depending on the relationship in question. We demonstrate that people's thinking is informed by relational social norms, acting as guides for action and that such relational norms come into play in negotiating the meaning of genetics, biology and any potential sense of connection with donor offspring.

Mental Health

Public debates about concussion and dementia in sport

Alisha Warner, David Jones, Dr Christopher Elsey
*(*De Montfort University*)*

In professional sport, the long-term health implications of concussion and repeated head injury has become an issue of much public debate. The relatively recent 'discovery' and classification of Chronic Traumatic encephalopathy (CTE) in deceased American footballers and creation of Brain Banks research, forms one part of the debate. However, CTE is currently only diagnosable post-mortem and therefore has limited diagnostic and therapeutic application for retired players in later life. Instead, a growing number of retired sporting professionals are being diagnosed with dementia, such as Alzheimer's, that are later confirmed as CTE.

However, for professional sports like football and rugby the risks of developing dementia (and CTE), there are competing agendas and positions adopted by those involved (e.g. academic researchers, clinicians, sporting governing bodies, players themselves, players' families, advocacy groups). How the priorities addressed and stances taken vary between the different parties will be demonstrated in this paper.

Using the methods of ethnomethodology and conversation analysis this paper will use diverse sources of data such as academic research articles documenting the links between sport and brain health (with divergent press releases), World Rugby's Brain Health promotion video (emphasising modifiable risk factors), and family member contributions to public discourses (e.g. Blog posts and Webinar's for advocacy groups such Head For Change) in which the welfare and failures of duty of care within sport are expressed frankly and definitively (playing football "killed him").

These contrasting agendas and arguments exhibit concepts of risk in sport around individual/collective responsibility and (un)certainty in accounting practices.

STS and Medicine

A Sociology of the Medical Record: Technology, Knowledge, and The Clinic

Max Perry

*(*University of Bristol*)*
This presentation tells an empirical account of the enactments (both social and technological) that produce the Medical Record. In attending to what, how and why information is recorded, presented and managed I look to examine under what powers of control and legitimacy medical records and medical talk is made to represent truth and the potential for action.

STS produced a small number of accounts of the Medical Record at the beginning of the 21st century, Marc Berg, Annemarie Mol and Stefan Timmermans all wrote accounts of how this complex artefact affected unity and singularity in the delivery of care and the production of medical knowledge. Now, 20 years later, the Medical Record has, with vary degrees of success, been the subject of intensive programs of digital transformation. The promises of Precision Medicine, Population Health and other 'Big Data' and 'AI' leveraged transformation agendas hinge on the transformation of this object, from a bundle of papers to an array of interoperable databases.

But digitisation has been hard; frequently contested and subject to almost constant strategic revision. Here, I outline a sociological account of these tensions. I will focus on behaviour change projects that have looked to 'structure' medical talk via a codified clinical language (SNOMED CT) and the organisational imperatives that have shaped the practice of record keeping. By examining these empirical cases of contestation and struggle, we can unpack the important role played by the Medical Record in the processes of clinical knowledge production, and their continued legitimation.

Health Service Delivery

The ‘unrealistic simplicity’ of the NHS App as the ‘front-door’ to general practice in England: qualitative study

Chrysanthi Papoutsi, Claire Reidy, John Powell, Felix Greaves, Bernard Gudgin
*(*University of Oxford*)*

Launched in 2019, the NHS App promises to provide a ‘digital front door’ for the National Health Service in England. Its key features include GP appointment booking and repeat prescriptions, online consulting, patient access to records and Covid certification. Recently the Health and Social Care Secretary announced his ambition for 75% of adults in England to have downloaded the app by 2024 so they can have ‘healthcare literally in their hands’. In this presentation we will discuss findings from our national evaluation of the NHS App, drawing primarily on data from qualitative interviews and focus groups with 78 participants: 44 patients, 19 staff from 4 GP surgeries, and 15 policy and commissioning stakeholders.

We will consider what happens when a technology premised on the idea of ‘patient control’ comes against the complex reality of legacy systems and service-facing infrastructures. We will examine how use of the app requires patient ‘work’ in more or less visible ways, including: navigation work across related apps/portals and within the NHS App to make sense of functionality and reach the right service; moral work to be able to engage as responsible user (of the app and the service); curation and accountability work to update the record and fill real or perceived gaps in service provision; and inclusion work to avoid disadvantaging those without access. To conclude we will discuss how the NHS App has the potential to facilitate transactional aspects of service provision, but at the same time assumes responsibilities currently neglected in policy narratives.

Patient - Professional Interaction

Personal Health Data and HIV Clinical Care: Beyond discipline vs. empowerment

Emily Jay Nicholls, Karen Lloyd, Shema Tariq, Jo Gibbs, Caroline Claisse, Abigail Durrant
*(*University College London*)*

As a result of effective treatment, HIV is now a long-term, chronic condition in resource-rich settings. In this paper we use the practices of collecting and sharing personal health data (such as self-collected lifestyle data or clinician-collected data) as a lens to explore the changing nature of HIV care.

Critical scholarship has highlighted how contemporary, hegemonic notions of clinical and public health are moralised and centre upon individual responsibility, shaping subjectivity and citizenship. In this context, the increasing ubiquity of self-tracking personal health data has been critiqued as reinforcing neoliberal conceptions of individual responsibility. On the other hand, proponents of self-tracking highlight the possibilities such technologies might afford for empowerment, self-knowledge and service delivery.

In this paper we problematise this dichotomy. Drawing upon interviews with both service users and healthcare providers in an HIV clinic in London, we assert that personal health data is more than a means to optimise health, exploring its effects on the clinical encounter. In particular, we describe service users' decisions not to track their health data, unpacking what this tells us about the shifting weight of responsibility for health between healthcare providers and service users. We ask how much and what kinds of personal data are seen as useful in the HIV clinic, and seek to understand what such data tracking and sharing tells us about the conceptualisation of care in contemporary HIV practice.

Wednesday 14 September
15:10 -15:40

Inequalities and Intersectionality

Physical activity in the established-outsider relations: Theorising the figuration of Chinese communities in the UK

Ximing Fan
*(*Loughborough University*)*

To what extent do social identities impact the physical activity participation of ethnic minorities? With the increasing trend of migration and ever- changing dynamics in society, health and physical activity Inequalities and Intersectionality remain a socially relevant challenge for migrants and marginalised communities. As 'the most unknown' ethnic minority in the UK, this ethnographic research investigates the social processes that impact the physical activity behaviour of British Chinese communities. At a cursory glance, the ethnicity of the Chinese communities in the UK seems to create a homogenous identity, but a closer look reveals diverse differences in culture, generations, language and so forth. Thus, the research takes a figurational approach and is particularly guided by the theory of established-outsider. As a community largely consisting of immigrants and descendants, there remains an overlapping identity for the British Chinese, who simultaneously play the role of 'the established' and 'the outsider' due to their interdependent network within the society. The ethnographic fieldwork conducted in a Chinese community centre in Birmingham, has revealed preliminary findings that the we-image of the Chinese themselves creates 'group disgrace' that affects the self- identity and prevents them from engaging in physical activity with the established British society. The findings of this research contribute to the policy-making and well-being of ethnic minorities in general and seek to discover the social processes behind the health Inequalities and Intersectionality.

Experiences of Health and Illness

Embodying Infection: How Young Women Experience Chronic Vulvovaginal Thrush

Tori Ford
*(*University of Oxford*)*

Background: Female urogenital issues are one of the most common and costly burdens to primary care health systems. The second most prevalent female urogenital system disorder is vulvovaginal candidiasis, known colloquially as vaginal thrush. 75% of people assigned female at birth will experience thrush at least once, but 6% present symptoms on a repeated or constant basis. Despite its prevalence, this condition has received little medical or social attention.

Aim: To uncover how young women experience chronic vulvovaginal thrush.

Method: I conducted an in-depth qualitative interview study. I employed a feminist phenomenological lens and carried out a thematic analysis.

Results: Despite being perceived as a natural and normal affliction, chronic thrush dramatically impacts women's lives. Interviewees saw their genitals as antagonistic, confronted gender discourses that reinforced thrush as a woman's problem, and navigated a medical system in which chronic thrush was often trivialized. In my analysis, I propose a three-phase theoretical model for understanding how young women embody infection as they move their efforts from eradication to acceptance. I argue that young women with chronic thrush both problematize and normalize their experiences due to a lack of effective medical treatment and societal discourses tethering women’s gender and genitals to infection.

Conclusions: The upcoming UK Women’s Health Strategy highlights the need for targeted research on women’s health, including common gynaecological conditions. This study opens new ways of understanding normalization as a problematic and gendered process that affects how women’s “non-serious” chronic conditions are understood, experienced, and treated.

Critical Public Health

Mental wellbeing and intersectionality of chronic health conditions and ethnicity during the COVID-19 pandemic

Alison Fang-Wei Wu, Sevgi Aksoy, Carol Rivas, Ozan Aksoy
*(*Social Research Institute IOE UCL)

How the pandemic impacted some of the most vulnerable in our communities, namely people with chronic conditions is often overlooked. This group is disproportionately from minoritised ethnic groups and experienced additional restrictions on their daily lives which may have led to more serious health and psychological challenges compared with the general population. Coronavirus Chronic Conditions and Disabilities Awareness study (CICADA) is a novel longitudinal online survey aimed to address this gap. 4326 adults (42% non-white) completed the first wave (Aug2021 to Jan2022) which included information, inter alia, on demographic background and mental wellbeing. Respondents are currently (Apr2022) completing wave 2. A third wave will be conducted in Jul2022. The results show that people from minoritised ethnic groups have poorer mental wellbeing than White British respondents, and so do people with chronic health conditions than those without. However, people from minoritised ethnic groups and with chronic health conditions manifested better mental wellbeing than White British respondents with chronic health conditions. This might be because individuals from minoritised ethnic groups with chronic conditions received more social support from their communities than White British with chronic health conditions did. We discuss future research and possible policy interventions to mitigate the impact of the pandemic on people with chronic conditions.

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

Diagnosis, Screening and Treatment

Public Health, Violence Reduction and Neurobiological Idioms for Trauma

Hilary Jane Stewart, Joanna Goldthorpe, Fiona Ward, Koser Khan
(Lancaster University)

Following recent increases in violent crime in England and Wales the UK government has called for a public health approach to tackle the root causes of serious violent crime. The Serious Violence Strategy published by the Home Office (2018) identifies Adverse Childhood Experiences (ACEs) as a category of risk for future violence and health inequalities, and emphasises prevention through early intervention, as well as promoting new models of trauma-informed policing to respond to vulnerable populations.

Drawing upon findings from a project which has explored the implementation of trauma-informed approaches to violence reduction, this paper will explore how neurobiological idioms (Broer and Pickersgill, 2015) and technoscientific discourses on trauma and adversity are being deployed in the UK as part of a public health approach which envisions violence reduction through trauma-aware cultural change.

However, as we will show, instead of addressing root causes of inequalities, such neuroscientific discourses may fasten neuro-identities of vulnerability and bio-criminality to deprived communities under the benevolent, ‘neutral’ guise of technoscience, and may deepen stigmatisation amongst such communities whilst sidestepping broader socio-political structures that engender trauma (Benjamin, 2016).

Benjamin, R., 2016. Catching our breath: critical race STS and the carceral imagination. Engaging

Science, Technology, and Society, 2, pp.145-156.
Broer, T. and Pickersgill, M., 2015. Targeting brains, producing responsibilities: The use of neuroscience within British social policy. Social Science & Medicine, 132, pp.54-61.
Home Office. 2018. Serious Violence Strategy. April 2018. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/698009/serious-violence-strategy.pdf [Accessed 28/04/22]

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

Lifecourse experiences for women living with Multiple Scerosis (MS) and reflections on the medical responses to symptoms

Louise Dawson
*(*Self Employed Consultant in Advocacy Services*)*

This presentation will offer a lifecourse understanding of chronic illness for women living with Multiple Sclerosis (MS) for up to a 45 year period. The author had previously interviewed 16 women in 2008 who had been diagnosed with MS as part of her PhD scholarship in the Sociology of Health and Illness (awarded April 2012, University of Salford). This presentation explores follow-up interviews in 2021 with 10 of the women and examines their interviews from a lifecourse perspective. The author also lives with a diagnosis of MS so this research is underpinned with ethnographic principles.

The interviews were conducted face to face (where possible) and then on zoom. The methodology included a feminist epistemology rooted in temporal experiences of living with MS. The interviews specifically focused on exploring self-reflection with life story narratives, particularly around the onset of their MS symptoms and then critically evaluating medical responses over time. Due to previous familiarity the interviews were relaxed and were welcomed as a space 'for exploring lived experiences around chronic illness and the meaning of this within a context of aging'.

The author identifies four key themes of the women's lifecourse narratives of (a) early childhood experiences; (b) reflective understandings around onset of symptoms, (c) medical supports and access to these, and (d) aging and acceptance.

Mental Health

A different kind of sporting 'heartbreak': Living with dementia

Christopher Elsey, Alisha Warner, David Jones
*(*De Montfort University*)*

The physical toll of a professional sporting career on a retired player is widely understood.

In the last 20 years the long-term impact of concussion and repeated head injuries in sporting contexts has led to public debates about risk and issues of accountability. As such a Coroner categorised dementia and Chronic Traumatic Encephalopathy (CTE) in former football player Jeff Astle concluding that an 'industrial disease' had led to his premature death.

This paper will utilise testimonies from family members of retired players to explore the everyday impact that dementia had on the familial relationships and interactions. It will examine the language and discourse of loss or absence in which strong and successful players come to resemble "a physical shell" with no recollection of their careers. These powerful descriptions are explicitly intertwined with accounts of blame and anger towards the sports and the organisations that run them.

Using the methods of ethnomethodology and conversation analysis this paper will use a wide range of publicly available data sources. These include media interviews, Head for Change (brain health charity) blog posts, Concussion Legacy Foundation's (CLF) Webinar events, and social media posts, in which family members share their own experiences.

This paper explores the challenges families encounter and the emotional rollercoaster they articulate in order to foreground their often unheard voices in wider debates about concussion and brain health. As such the impetus to change sporting protocols and to expand academic research is often the upshot of these painful narratives.

STS and Medicine

Wearing Contraception: Reconfiguring Reproductive Knowledge

Adele Moore
*(*University of Liverpool*)*

Using a vaginal speculum was a powerful tool of the Women's Health Movement (WHM) during the 1970s and 80s, opening up orifices and ways of knowing which had previously been locked away from women, in both a literal and metaphorical sense (Tuana, 2006, p. 2). Reclaiming this tool enabled a complete feminist reconfiguration of caring for 'our bodies and ourselves' independent from androcentric, sexist institutions, such as medicine (Tuana, 2006, p. 2). Five decades have passed since the emergence of the WHM, yet the project of caring well for gendered and sexed bodies remains a focus of feminist STS scholars today. This paper is concerned with on-going reconfiguration in two ways. Firstly, reconfiguration that contraceptive wearers present via their practice, and secondly, through research methods. This paper explores the development of innovative contraceptive knowledges, taking seriously the ways that users reconfigure this knowledge. Working to prioritise the experience of contracepting in practice, this research demonstrates the importance of conducting an analysis of the way users wear their contraceptive technologies. This research employs social media analysis methodology, inspired by Marres' (2012) exploration of the 'redistribution of methods', which outlines the way in which digital research can and should be observed as a 'shared accomplishment' with various contributing actors, and facilitates exploration of contracepting as emergent, experimental, collaborative practices of wearing contraception.
Marres, N., 2012. The Redistribution of Methods: On Intervention in Digital Social Research, Broadly Conceived. The Sociological Review, 60(1), pp.139-165.

Health Service Delivery

Responsive and Resilient Healthcare? Post-hospitalisation care pathways for COVID-19 patients

Natalie Armstrong, Charlotte Overton, Tristan Emerson
*(*University of Leicester*)*

COVID-19 patients discharged from hospital often require ongoing support from healthcare services due to prolonged symptoms and unpredictable recovery trajectories. Within the UK, follow-up services post-discharge typically initially developed organically and subsequent guidance on service specification was based on expert opinion rather than research evidence. As part of a wider project linked to a large post- hospitalisation for COVID-19 study (PHOSP-COVID), we sought to understand how different types of follow-up service had developed, and how these had been experienced by patients.

We used a qualitative case study design with three purposively sampled NHS sites. Within each case study, we interviewed key members of staff (healthcare professionals and managers) who had been involved in the design and/or implementation of their organisation's post- hospitalisation pathway. Interviews focused on participants' accounts of how these pathway(s) were developed and implemented, why they took the form they did, and the influences shaping this. We also interviewed patients to explore their experiences of their local post- hospitalisation service and their views on how effectively it met their needs.

Drawing on literature around responsive and resilient healthcare organisations, in this presentation we will draw on comparative analysis across our case studies to understand what shaped the development of each pathway, how these were organised and delivered locally, which
group(s) of healthcare professionals were involved, and patients' views on their helpfulness. We will explore the different types of 'work' involved in getting these services up and running, and how this was accomplished during a time of national crisis.

Patient - Professional Interaction

"I felt very quickly that I had more knowledge than they did": Re-negotiating Authority and Knowledge in Women's Experiences of Pelvic Organ Prolapse

Sabrina Keating, Abigail Mcniven, Francine Toye, Ashley White
*(*University of Oxford Department of Primary Health Care*)*

The lifetime prevalence of pelvic organ prolapse (POP) is estimated at 30-50% of women, with some labelling the condition as a “silent epidemic”. Taboos around genitals and hygiene contribute to a culture of shame and silence, which may further compound feelings of isolation. In recent years, the increasing visibility of TVT mesh complications and the prominence of internet support groups has arguably contributed to a transformative rise in awareness and collective identity surrounding the condition. To examine experiences of POP, a sample of 35 in-depth narrative interviews has been aggregated for thematic analysis from a broader qualitative study on urogynaecological conditions. Maximum variation sampling was equipped to prioritise reaching a wide range of demographic backgrounds and health experiences.

Participants frequently highlighted their own cultivated expertise in the face of under-informed or dismissive clinicians. Low & Tumbarello (2012) point to biomedical knowledge as authoritative at the point of POP diagnosis, with women’s own experiential knowledge being rendered inconsequential to themselves and clinicians. Our findings challenge this claim, arguing that women contest the legitimacy of biomedical knowledge’s authority, and often come to privilege experiential and collective knowledge over the course of their illness trajectory. This ongoing re-negotiation of authority influences patient's navigation of care, including some participants seeking out the ‘right’ clinician who will account for their additional knowledge. With consideration of Kristin Barker’s work on medical authority and collective identity, we examine the ongoing tensions in claiming authority on POP and the continued struggle of meaningfully engaging with experiential knowledge.

Wednesday 14 September
15:45-16:15

Inequalities and Intersectionality

I am more than a number: The rights of children and their families in health data storage, linkage, and consent for data use

Cervantee Wild
*(*University of Oxford*)*

Child health data sharing and linkage has increased rapidly, along with increased secondary use of data in predictive analytics and models. Data linkage can reproduce racialized outcomes, posing challenges for Indigenous rights and interests; however, there is potential for societal gains when utilising large data sets. Our aim was to understand the views of children and their parents regarding child health data storage, linkage and consent for data use in Aotearoa/New Zealand. We undertook five focus groups (n=26) with children and their parents (approx.
65% Māori) informed by Kaupapa Māori theory principles, a critical Indigenous theory and de-colonial response to systemic racism and social inequities. We covered six key domains: health information, data sovereignty, storage, sharing, linkage and consent. Data was analysed thematically. Firstly , health data represented a unique, ongoing and evolving “Health Story” – being more than “just a number”. Secondly, data ownership was innately tied to parents being able to access their child’s data, which was a requirement of active and safe engagement in their health journeys. Finally, participants conceived informed consent for child data use and linkage as an active relationship built on trust. Fair and informed consent processes built on trust may facilitate open data sharing and may be healing relationships within the health system, especially for marginalised, dis-empowered groups. Similarly, critical, Indigenous approaches to research have the potential to actualise community-centred social change by resisting persistent power imbalances and the continued use of cultural deficit theory to explain Inequalities and Intersectionality.

Experiences of Health and Illness

Women’s experiences of living with a chronic vulval skin condition: shame, secrecy, and loss

Sophie Rees, Susanne Arnold
*(*University of Bristol*)*

Vulval lichen sclerosus is a chronic skin condition. It causes profound itching, burning, and small painful tears in the vulval skin. Scarring and thickening of the skin causes anatomical changes where the labia can fuse and the clitoris can be buried. Vulval lichen sclerosus has a major impact on quality of life, but the experiences of those with the condition are under-explored.
We interviewed 20 women living with vulval lichen sclerosus, using remote semi-structured in-depth interviews. Social constructionist grounded theory method was used to guide the analysis. Discussions with a patient advisory panel helped design the topic guide and informed the developing interpretation. We found that societal attitudes towards women’s bodies and secrecy around the vulva constrained agency and contributed to delayed diagnosis and years of suffering with symptoms before accessing treatment. A lack of health provider knowledge and willingness to dismiss or invalidate women’s feelings also delayed diagnosis. Lack of awareness about lichen sclerosus caused women to experience shame about their condition. Talking about the vulva was experienced as taboo, and living with vulval lichen sclerosus involved living in secret. Women felt silenced and unable to share their experiences.

Critical Public Health

Empowering people and communities? Volunteering, wellbeing, and health Inequalities: an ethnographic psycho-social study

Simon Armour
*(*Manchester Metropolitan University*)*

The Covid-19 pandemic and increasing poverty make addressing the long-standing health Inequalities and Intersectionality in the UK even more pressing. Experiences of shame, stress, and social isolation have been identified as mediators of the health consequences of structural Inequalities and, while volunteering is widely cited as beneficial to psychological wellbeing, potentially mitigating these effects. Asset-based approaches to public health seek to 'empower' individuals and communities through voluntary and community action, but have been criticised for endorsing neoliberal discourses used to justify austerity policies. This study sought to understand how these claimed effects may play out in people's lived experiences and the implications for public health.

The literature on volunteering and wellbeing tends to centre on psychological constructs, operating at an individual level, with little focus on the wider social, political and economic contexts. Power relations, implicated in analyses of health Inequalities and Intersectionality, are largely invisible in theories of volunteer wellbeing. Adopting an ethnographic psycho-social approach, in two different settings, has enabled development of a deeper understanding of how volunteering may affect psychological wellbeing within socio-economically disadvantaged communities.

This identified psycho-social practices by which volunteers defended against the symbolic violence of denigrating constructions of poor, working-class, and racialised communities and individuals, while narratives of shared purpose reinforced feelings of belonging. However, the organisations' assimilation of discourses of individual responsibility, together with largely unrecognised power dynamics, undermined their potential to facilitate any collective empowerment that might challenge systemic Inequalities and Intersectionality. In this context, volunteers often drew instead on narratives of powerlessness or collective victimhood, leading to ressentiment.

Diagnosis, Screening and Treatment

Navigating perceived overdiagnosis and overtreatment in breast cancer

Shavez Jeffers
*(*University of Leicester*)*

Overdiagnosis and overtreatment are potential harms of the NHS Breast Screening Programme (BSP). Hence, individuals are encouraged to make an informed choice about whether to participate in screening and any follow-on interventions. Even though it has been explicitly stated that individuals have the freedom of choice, making the decision to decline has been found to be met with unsupportive responses and is not viewed as a behavioural norm. Therefore, the aim was to explore the experiences of people who decline screening and/or treatment after being invited to the NHS BSP. A qualitative methodology was used and 20 semi-structured interviews were conducted with women who had chosen to decline. A thematic analysis was conducted and the findings revealed that the majority of women interviewed were doctors and/or academics.
Some of the women found themselves sharing their knowledge of the harms of screening with others through activities such as posting blogs online. However, some of the women felt that they did not want to share their decision to decline with others due to fear of being misunderstood and/or not wanting to spoil the narratives of those who had chosen to accept screening under the assumption that it does no harm. In conclusion, the women in this study may have had a better understanding of the information on the benefits and harms of screening due to them being medically/scientifically trained. These women did not regret their decision to decline, as they believed it was a direct/indirect way of avoiding overdiagnosis and/or overtreatment.

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

Introducing a mixed methods approach to operationalising Reproductive Justice

Laura Sochas
*(*University of Oxford*)*

The concept of Reproductive Justice originates in critical and qualitative literatures, strongly influenced by critical race theory. For this reason, quantitative or mixed methods operationalisations of Reproductive Justice are very rare. However, this paper argues that such approaches are also important, particularly when attempting to link Reproductive Justice to health outcomes or other measures of people's wellbeing.

A quantitative approach allows for a systematic, comparative analysis of the association between the ways in which countries' policies affect Reproductive Justice and health outcomes, while taking into account variation at the individual-level. However, there are limits to what a solely quantitative analysis can achieve in operationalising Reproductive Justice: a mixed methods approach is needed to highlight possible mechanisms behind health harms; explore the meaning of unjust policies in a context-specific way; and illuminate marginalised populations' agency.

This paper outlines a mixed methods approach to operationalise Reproductive Justice, by demonstrating how quantitative and qualitative methods can be used in conversation with each other to honour key aspects of the Reproductive Justice concept: (1) Positive rights; (2) Intersectionality; and (3) A focus on reproductive desires rather than fertility outcomes. The approach will be demonstrated with respect to a specific research plan to investigate how family and migration policies in Europe constrain stigmatised populations' rights to have children and to parent with dignity, and the effect this has on people's health and wellbeing.

STS and Medicine

The logics of invited and uninvited material participation: Bringing blood pressure self-monitoring into the clinic.

Kate Weiner, Flis Henwood, Jacob Andrews, Catherine Will, Ros Williams
*(*University of Sheffield*)*

This paper talks to the 'participatory turn' in healthcare, focussing on the case of blood pressure self-monitoring. The existence of a consumer market for self-monitoring devices and an increasing call for self-monitoring within health policy both appear to offer invitations for people to participate in their own health care. In our analysis we have considered what this participation looks like when it enters the clinic. Drawing on the notions of material participation and of uninvited engagement, the paper considers how patients' home blood pressure self-monitoring is incorporated into clinical care, how materials mediate participation and how to characterise the participation that is evident within everyday clinic practices. The paper draws on data collected as part of a 3-year study of self-monitoring, including interviews with people who self- monitor their blood pressure and focus groups with primary care professionals.

We argue that when clinicians imagine or invite participation, this aligns with a logic of 'participation made easy', whereas the uninvited participation our interviewees discussed aligned with a logic of 'the more invested, the more engaged' in participation. The paper makes two new moves. First, it troubles characterisations of invited and uninvited participation as distinct and separate, observing movement between these. Second, it suggests that the logic of 'participation made easy' might be extended to apply to professionals as well as lay people. The analysis brings to light the way materials are mobilised to facilitate invited and uninvited participation and movements between these, and speaks to the on-going asymmetries in doctor patient relationships.

Health Service Delivery

Antibiotic stewardship in primary and secondary care settings: a problem of collective action

Carolyn Tarrant, Emma Richardson
*(*University of Leicester*)*

Overuse of antibiotics contributes to antimicrobial resistance. Healthcare organisations are implementing antimicrobial stewardship programmes to reduce antibiotic overuse, primarily targeting individual prescribing behaviour. We argue that antibiotic overuse is a collective, rather than individual, problem. AMR has been characterised as a social dilemma – in which overuse of antibiotics to provide short-term individual benefit results in the undesirable collective outcome of loss of antibiotic efficacy. Addressing problems of this type requires cooperative action within communities around longer-term goals. We aim to explore the factors shaping cooperation toward reducing antibiotic use, based on interviews and ethnographic research in five primary care organisations and four acute hospitals in the UK. We identify distinct dynamics of risk, trust, norms and interdependencies between stakeholders, which shape cooperative action, in primary and secondary care. In primary care, the risks of withholding antibiotics are negotiated between a GP and a patient: GP efforts to optimise antibiotic use are dependent on the risk profile of patients and organisational support for safety netting, and trust that colleagues will not undermine their efforts by prescribing freely. In secondary care risks related to reducing antibiotic use are managed by multiple health professionals along the patient journey: in this context, consensus of goals, and agreement on roles and responsibilities for coordinated action towards achieving these goals, are critical. We conclude that antimicrobial stewardship interventions should recognise the collective nature of the problem of antibiotic overuse, and take into account the dynamics of cooperation and coordination in different types of healthcare setting.

Patient - Professional Interaction

How do older people experience care? The theorisation of person-centred care in an integrated context and an exploration of older people's experiences and perspectives of an integrated care intervention in Ireland.

Sarah Murphy
*(*Atlantic Technological University*)*

Little is known about how recent care transformation has impacted on the lived experiences of older people in integrated care contexts or the extent to which person-centred care is experienced. While the majority of evaluations of integrated care often focus on systemic or clinical outputs, theoretically informed research emphasising the voice of older persons on the experiential dimensions of person-centred integrated care and what they value most is less prominent.

This paper will explore the theorisation of care and its related empirical application. In focusing on the case of the Integrated Care Programme for Older Persons in Ireland (ICPOP), this paper will critically analyse the potential contribution that specific epistemological stances, theories and approaches to theorising care can make to our understanding of the experiential dimension of PCC in an integrated care context. These theories have been sourced in the literature review phase of an ongoing PhD project aimed at exploring older persons' interpretations and experiences of PCIC at three ICPOP sites in Ireland. Specifically under consideration will be the commensurability of theories including social constructionism, personal construct and embodiment theories and ethics of care approaches. The application of these theories in an empirical context will also be considered in the context of pilot and early stage qualitative data generated from May-August 2022.

The presentation will summarise key insights gained from this literature and related theories and how these can inform understandings of conceptualisations and constructions of care and care experiences and evaluations of person-centred care in an integrated context.

Wednesday 14 September
16:20-16:50

Inequalities and Intersectionality

Building cultural health capital to manage stigma and health care access: an evaluation of a homeless health peer support service in London, UK

Andrew Guise, Pj Annand, Paniz Hosseini, Sujit Rathod, Lucy Platt
*(*King's College London*)*

Background
Peer support is promoted to mitigate the health system barriers and stigma experienced by people who are homeless. Peer services are also described as ‘empowering’ service users and fostering independence in accessing health care. Social theory and critical attention relating to these goals is limited.

Methods
Data are drawn from the qualitative arm of a mixed-methods evaluation of a homeless health peer advocacy service in London, UK. Principal data are semi-structured interviews with people using the service (n=36) and running it (n=31). Thematic analysis was framed by theory of cultural health capital, drawing on Bourdieu and Shim.

Results
Across the many possible mechanisms and outcomes of the peer support service we report three principal themes. First, are processes of ‘empowerment’ where cultural health capital is ‘built’ through peer advocacy, to allow future independent care access. Second, cultural health capital is ‘loaned’ and ongoing support is needed; whilst in tension with claims of empowerment these processes are supportive of health.
Third, where clients already have high cultural health capital, and instead peer advocacy supports care access through lending social capital; here peer support is making health care bearable.

Discussion
The analysis helps theorise health care in relation to experiences of exclusion and stigma and develops application of Bourdieu’s social practice theory to health services. We reflect on claims for empowerment, especially for how efforts to ‘build’ or ‘loan’ cultural health capital relate to broader social processes of symbolic violence.

STS and Medicine

Exploring the use of complementary and alternative approaches to health care on UK dairy farms

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Exploration into the use of complementary and alternative medicine is warranted to 1) determine if CAM use has potential to reduce unnecessary antibiotic use and support the global efforts against antimicrobial resistance and 2) to ensure that antimicrobials and other conventional treatment approaches are used where appropriate.
Semi-structured interviews were conducted with 24 farmers through face-to-face, telephone and videoconferencing modalities necessitated by movement restrictions during the Covid-19 pandemic. 16

farms were visited to collect ethnographic fieldnotes and photographs. Topic guides were used to explore participants' experience of CAM and how CAM might influence the use of conventional medicines such as antibiotics. Data on conventional and CAM medicine storage, CAM usage and farm management systems was collected and analysed thematically, using NViVo software.
Drivers to use CAM included farmers own personal [or friends' and relations'] experiences, the views of influential people and advisors, networks within the farming community and a reported greater sense of autonomy in health-based decision making. Farmers frequently referred to their motivation to reduce antimicrobial use to encourage exploration of CAM. Milk buyers, organic guidelines a desire 'to do something' for the animal were also reasons given for CAM use. Farmers associated CAM with other holistic health management practices, human-animal interactions and animal welfare; suggesting that CAM use is seen as part of wider ethos and belief about medicine use.
More open discussion surrounding the use of CAM on dairy farms might identify methods of reducing antimicrobial use responsibly, with veterinary support.

Health Service Delivery

A qualitative study into the impact of digital changes to the primary healthcare system in the UK on socioeconomically marginalised groups

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In response to COVID-19 there has been a shift in the way in which healthcare services are accessed in the UK with most non-acute healthcare service delivery made remote. This is against a background of strong and persistent inequities in health outcomes and healthcare access in the UK. Whilst there are hopes that digital healthcare will remove many barriers to accessing healthcare it is also possible that this form of service delivery will both create new types of inequities as well as replicate and re-embed existing ones. My PhD research uses the ideas of responsibilisation, work, and candidacy to explore how processes of marginalisation shape experiences of digital GP healthcare in the UK.

I am taking an ethnographic approach involving observation and interviews, conducted across a range of field sites in London. These include a foodbank, an advice centre for refugees and asylum seekers and a charity offering digital support. The analysis explores the 'responsibilisation' of individuals to self-manage their healthcare, the 'work' which individuals must do to engage with and navigate the healthcare system, and finally 'candidacy' for healthcare and how this is negotiated by patients and providers. I also consider how patient 'work' is constructed by changes to the healthcare system and how this is passed around and negotiated by individuals through strategies developed to manage their healthcare.

Patient - Professional Interaction

Negotiation of prescribing and de-prescribing in general practice consultations

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Prescribing and (increasingly) de-prescribing activities are part and parcel of everyday conversations in general practice and yet we know surprisingly little about how these play out and the role of patients in these interactions. Prescribing decisions are usually seen as situated within the domain of the doctor. We argue for the need to examine and understand patients' work in relation to prescribing, be it resistance to the offer of a prescription or support or resistance to efforts to enact deprescribing.
Our data set contains 281 video-recorded primary care consultations. Prescribing and deprescribing are particularly salient in the consideration of mental health. We therefore draw on the 46 consultations in which mental health is discussed.
Using conversation analysis (CA), we will systematically explore how work is relation to prescribing is done. CA is concerned with how social action is accomplished through talk-in-interaction. We will consider who initiates talk about treatments and how this is received. Special attention will be given to

identifying interactional sources of trouble when interlocutors raise treatment/medication and negotiate decisions around starting and stopping treatment.

This examination of prescribing as it occurs in practice will provide an understanding of the ways in which prescribing and deprescribing are interactionally achieved in primary care consultations.