# Medical Sociology Study Group

## Annual Conference Programme

**13 – 15 September 2023**

**University of Sussex**

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Presentations taking place on Friday 15 September

# Friday 15 September

# 10:10-10:40

## Room G36 - Health Policy

### The power of silence: exploring the (non-)construction of Roma people in English health and social policy

*Lois Orton*

*(University Of Sheffield, UK)*

Roma people are a hypervisible racialised ‘other’ surrounded by negative stereotypes. They are also thought to experience some of the poorest health and social outcomes in Europe. Much has been written about the political construction and categorisation of Roma across continental Europe (see Jan Grill, Mihai Surdu, etc). But what about England? Even before Brexit, when we were required to have a National Roma Integration Strategy, it was almost impossible to find specific measures targeting Roma. Drawing on Bourdieu (policy silences) and Lukes (the second face of power), this paper explores the (non-)construction of Roma in English health and social policy and the effects of these (non-)constructions. Findings are based on analysis of 31 English public health and social policy documents produced 2000-2022 and 10 semi-structured interviews with those involved in developing and/or implementing them. An adapted version of Jennifer Dodge’s Frame Analysis (2017) is used to explore how textual and verbal discourses reinforce or challenge one another (at the local, regional and national level). I suggest that the elision of Roma happens through the persistence of specific ignorances about who Roma are, where they ‘came from originally’ and whose responsibility they now should be (within English policy structures). I argue that the perception of Roma as both ‘white’ European migrants and their conflation with our own ‘British’ minorities - ‘Gypsies and Travellers’ - provides a unique context in which the health and social needs of a hypervisible group become invisibilised in the void that is created by confusion.

## Room 155 - Health Service Delivery

### Rescue trajectories and the politics of improvement

*Nicola Mackintosh, Liz Sutton*

*(University of Leicester)*

Managing deterioration and escalating care across hierarchical, professional and organisational boundaries can be seen as an enduring wicked problem within acute care, despite two decades of efforts to improve the identification and response process. We present data from an ethnographic evaluation of the implementation of a programme of interventions designed to improve the rescue process in surgical settings. The interventions focus at system, team and patient and family level and include: a patient-led escalation system; team strengthening activities; redesign of escalation operating procedures; and use of a shared language to enable boundary work across departments. Data collection included fieldwork (observing intervention development and implementation, as well as routine surgical ward work), interviews with a range of clinical and managerial staff, patients and their relatives, and documentary review. Strauss et al.’s (1985) notion of the patient trajectory offers a useful theoretical resource for us to explore how unfolding trajectories of patient deterioration and rescue are embedded within core features of surgical work, and what is routinely prioritised or elides attention. We consider the organisational work undertaken to accomplish rescue trajectories and how the different interventions aligned with or disrupted these trajectories and the consequences for staff involved. Lastly, we bring a macro-level lens to explore the 3 case study sites as social systems. We review the context within which these interventions were being applied to understand the significance of varying political expectations and professional rationalities for supporting improvements around rescue.

# Room 135 – Critical Public Health

### Falling between the cracks of COVID-19 outbreak management: navigating the high-tension zone in between established categories

*Lea Loesch*

*(Vrije Universiteit Amsterdam)*

This paper presents a project between the Vrije Universiteit Amsterdam and the Dutch Institute for Public Health and the Environment exploring the potential for AI methods to include experience-based knowledge from professionals, patients and citizens in clinical guideline development, including the Dutch COVID-19 vaccination guideline.

While we intended to contribute to knowledge inclusion, this project equally became a device for learning about the dynamics and reasons for knowledge exclusions, in a visceral sense. How to address frequent exceptions and individual experiences while developing a population-based guideline? How should I, as an individual with a gene mutation predisposing me to deep vein thrombosis, deal with the high-tension zone between the two inapplicable but seemingly only possible categories of “anti-vax” and “vaccinated”?

Drawing on my own experiences, I first analyse what it meant to resist this classification and how to navigate the high-tension zone of not fitting in either category. Second, I seek to identify situations that empirically illuminate some of the dynamics that led to the marginalisation of certain people and knowledge during the Dutch COVID-19 pandemic response. Thereby, I try to make visible experiences that often went untold and to show how outbreak management affected those not fitting into the standard categories. This paper is about those, as Star (1990) wrote, who are “permanently escaping, subverting, but nevertheless in relationship with the standardized. It is not non

# Room G31 - Mental Health

### Reconsidering trauma: an ethnographic study of social suffering in mental health services

*Shoshana Lauter*

*(London School of Economics and Political Science)*

What is the impact of being told one 'has' trauma? Over the past three decades, the trauma concept has pervaded Western therapeutic culture, moving past the warzone to depict untold forms of social suffering. But the growing popularity and dynamism of this term has received very little study, particularly in regard to its effects amongst those most vulnerable. Individuals with complex and serious mental illnesses, who navigate psychiatric and social services often and intimately, are adopting a trauma-informed discourse. The trauma-informed model is moreover proving to be a formidable voice as the broader field struggles to address the current mental health crisis. Understanding how service users reframe their narratives under its remit has never been more pressing. This presentation will consider how the trauma concept is constructed by, and constructs meaning for, this population.

I will present the first year of findings from my ongoing ethnography at two trauma-informed services in London: an NHS women's residential crisis house and a charity-based adult psychosis psychotherapy program. Observations of the sites' daily activities and in-depth, life-course interviews with service users are analysed to understand the impact of trauma-informed practices on individuals' illness narratives.

The value and challenges of using these psychosocial methodologies in clinical settings will be discussed. A brief genealogy of the modern evolution and use of 'trauma' in public services contextualizes the fieldwork. Ultimately, a theory as to how traumatization reframes marginalization, and the implications of this for mental healthcare policy and practice, will be presented.

# Room G35 - Inequalities and Intersectionality

### Desperately Seeking Intersectionality in Digital Health Disparity Research: Narrative Review to Inform a Richer Theorisation of Multiple Disadvantage

*Laiba Husain*

*(University of Oxford)*

Background - The COVID-19 pandemic has led to an increase in digital consultations between patients and clinicians. However, questions have arisen about how digital health disparities impact disadvantaged populations, including older adults, individuals with lower socioeconomic status, and limited English proficiency.

Aims - This paper aims to review the literature on how multiple disadvantage has been conceptualized, theorized, and studied empirically in relation to digital consultations.

Methods/Approach -The authors analyzed papers that met inclusion criteria and summarized their key findings using GRADE-CERQual and critically examined explanations for digital disparities. A subsequent search was conducted to identify theoretical lenses on multiple disadvantage.

Results/Evaluation - Empirical studies were small, rapidly conducted, and lacked strong theoretical lenses. Proposed solutions focused on identifying and removing barriers, but they generally overlooked the pervasive impact of multiple layers of disadvantage. The data set included no theoretically informed studies that examined how different dimensions of disadvantage combined to affect digital health disparities. Authors identified three theoretical approaches that might help account for these digital disparities, including Intersectionality Theory, which posits that systems of oppression are inherently bound together.

Conclusions - The lack of attention to how digital health disparities emerge and play out within and across categories of disadvantage means that proposed solutions may be oversimplistic and insufficient. Theories of multiple disadvantage have bearing on digital health, and there may be others of relevance besides those discussed in this paper. The authors call for greater interdisciplinary dialogue between theoretical research on multiple disadvantage and empirical studies on digital health disparities.

# Room 115 - Open

### Out of sync: Understanding parent -carers experiences of caring for a child with rare genetic disease

*Catherine Coveney*

*(Loughborough University)*

Theoretically, this paper builds on a long tradition of attempts to understand experiences of chronic illness within the sociology of health and illness and draws on the concept ‘crip time’ from within critical disability studies. While much scholarship has been devoted towards rights, needs and ethics of care, foregrounding the agency, experience, and value of disabled people, less attention has been given to the experiences of parent -carers and the impacts that caring for a child with rare genetic disease has on their identities, biographies and trajectories. In this paper I ask, how does living in ‘crip time’ impact on parent -carers? In what ways does caregiving impact on their temporal autonomy? How do they fit their non-normative lives into the hegemonic time order?

Data were collected via a mixed methods study (online survey and photo-elicitation interviews) with 67 families living with one rare genetic disease, Noonan Syndrome (NS). Analysis is nearing completion.

Findings show how parent - carers are living in and between multiple yet distinct temporal rhythms. Constraints on time are a dominant feature of parent- carers narratives, who describe having to juggle their child's care needs with competing demands of family life, employment and other relationships. On-going medical needs punctuate the night, impacting on sleep and leading to constant tiredness, fatigue, exhaustion, and stress. In disentangling these temporalities, and how they are socially and politically produced, I suggest a new chronopolitics of care that supports parent carers to regain their temporal autonomy.

# Room 118 - Experiences of Health and Illness

**The incurable self: authenticity, belonging and dis/connection with metastatic breast cancer**

*Sophie Lewis, Giselle Newton, Katherine Kenny, Frances Boyle*

*(University of Sydney)*

As the culture of silence that once surrounded cancer has gradually given way to greater public awareness, normative visions of what cancer survivorship should entail have proliferated. Central to contemporary imaginings of cancer survivorship are an emphasis on positivity and perseverance in pursuit of a cure. While this vision provides comfort to many, for people living with metastatic disease – and for those around them – the emphasis on cure can undermine their sense of belonging to the broader collective of people living-with cancer. Drawing on semi-structured interviews with 38 Australian women living with metastatic breast cancer, and ideas around biosociality and social bonds, we examine the affective push and pull that variously bind and repel fellow sufferers towards and away from one another, often according to dis/similar diagnoses. Our analysis explores the tenuousness of many of these women's social bonds and how issues of (in)visibility, (in)authenticity and (in)validation circulate within these women's daily lives, and across the general public more broadly. Specifically, through our analysis we conceptualise four social bonds: flexible social bonds based on mutual understanding, attuned peer social bonds based on mutual identification, threatened bonds strained by misunderstanding, suppression or omission, and severed bonds where the relationship is ruptured due to misunderstanding. More broadly, we illustrate the persistence of normative visions of cancer survivorship and their enduring effects on those whom such visions exclude.

# Room G22 - Health Care Organisations

**PROMs in transition: a computational analysis of the literature (1992-2022)**

*Tiago Moreira, Trayten Zhang, Alina Geampana, Salman Khan, Joanne Greenhalgh*

*(Durham University)*

Patient-reported Outcome Measures (PROMs/PRO) are tools to assess patients' health status or health-related quality of life (HRQoL). In the last decade or so, these have been mobilised across healthcare systems to link clinical and governance decisions to "what matters to patients" (WHO, 2017). In part, this reflects a general trend away from producing measures of life and death towards metrics of 'quality of life'.  However, little is understood about the processes by which such latter measures of experience are made meaningful in interaction with epistemic, normative and institutional scaffolds to deploy infrastructures of care. Previous research on the development of HRQoL instruments between 1970s and 2000s has identified a shift from conceptual and methodological concerns towards a focus on outcome measurement (Armstrong, Lilford et al, 2007; Armstrong, 2009). This paper focuses specifically on the dynamics of the PROMs/PRO research field in the last 3 decades through the use of computational data approaches, such as heterogeneous network mapping and topic modelling. We analyse the topic/thematic relationships within and across three large bibliographic data sets – PROMs, PRO and HRQoL – and identify a set of clinical areas where discrete interventions, methodological standards and efficiency/efficacy aims come together to articulate robust and actionable measures. We discuss how PROMs policy initiatives often mistake these contingent configurations as replicable, implementable, transformative models for health care change.

# Room 144 - Pedagogy and Methods

### Exploring Imagined Futures of Sexual Health using Creative Workshops

*Chase Ledin (Virtual Presentation)*

*(The University of Edinburgh)*

With increasing pressure placed on UK healthcare services, approaches to rethinking the role of community members in healthcare is essential for improving health outcomes. This paper will draw from a series of ongoing creative workshops which explore the role of imagined futures in negotiating, accessing, normalising, and/or contesting sexual health in Scotland. The paper will explore methodological questions about creative workshops, specifically assessing the critical capacities of workshops to conceptualise and integrate imagined futures within community-driven healthcare initiatives. Centrally, the paper will ask: What role do imagine futures play within community understandings of sexual health, and if/how can participatory methods empower critical perspectives about the conditions of sexual health services and care in Scotland? The paper will situate creative workshops in relation to participatory health research and provide a critical definition and exploration of community and activist engagement within sexual health practice and engagement. More broadly, the project seeks to develop participatory praxis (informed by existing theories about sexual health, public engagement, and community-driven health activism) and to empower community members through strategizing the impact of potential futures. This paper thus will reflect upon the potentials and limitations of participatory research and methods for interdisciplinary health studies and medical sociology.

# Friday 15 September

# 10:45-11:15

## Room G36 – Health Policy

### Childhood Covid-19 vaccination in Italy and Cuba: a comparative study

*Alice Scavarda, Claudio Marciano    (Virtual Presentation)*

*(Università di Torino)*

After more than one year since the COVID-19 childhood vaccination campaigns began, the Cuban and the Italian vaccination coverage rates are opposite. While in Cuba the 97% of the childhood population aged 5-11 is fully immunised, in Italy this percentage is lower than the 35%. The reasons of this coverage gap may be identified in the different diffusion of vaccine hesitancy in the two countries. Vaccine hesitancy is the delay in acceptance or refusal of vaccination. The Vaccine Hesitancy Determinants Matrix shows that factors influencing vaccine hesitancy are also contextual elements, and vaccine/vaccination-specific influences. In our qualitative study we focused our attention on the management of vaccination campaigns in the two countries: the governance models structuring the vaccination supply (incentives, constraints and sanctions), the involvement of paediatric associations on service delivery, the access points to vaccination services and the communication activities devoted to families. We also considered the different choices related to the technological platform used to develop the vaccines (subunit protein and mRNA formulas).

We carried out 15 in depth interviews with vaccination campaign managers, members of national paediatric associations and healthcare professionals working in vaccine clinics. The preliminary results show that the two countries managed childhood vaccination services with highly differentiated governance models (centralised in Cuba and decentralised in Italy) and with a far different level of involvement of paediatric associations (high in Cuba and low in Italy). This is due to the political and cultural value attributed to vaccination by local healthcare authorities in the two countries.

## Room 155 - Health Service Delivery – Special Event

### Inequality in health care - empirical studies on health care professions and health care delivery’

*Anette Lykke Hindhede, Marte Feiring, Per Koren Solvang*

*(University of Copenhagen/ /OsloMet)*

Many Western countries are experiencing increased insecurity due to climate change, warfare, and a post-pandemic situation. It is assumed that these unstable situations would further increase healthcare inequality and sustain it. In this session, we will apply various critical socio-cultural theories to illustrate how current healthcare trends entrench health inequalities. While social inequalities in health and social life have been documented in many studies around the Western world, inequality is usually defined by family socio-economic background and social class status. However, there has been less focus on the relationships that create and reproduce social inequality in health or the way that tensions and struggles within the healthcare field participate in shaping inequality. At a time when corporatization and privatization of healthcare coexist or subsume traditional bases of public provision, we need new ways of explaining emergent structures of inequality.

With the goal of strengthening social sustainability as well as social equality of healthcare services, modern healthcare systems are currently rethinking their institutional and professional boundaries, between public and private, as well as between experts and laypeople. This results in the shifting of responsibility and tasks across different groups of health professionals, the voluntary sector, patients/clients, and their relatives. The papers in this session will draw on empirical work from a range of contexts to examine health inequality and task shifting in healthcare, with a particular focus on healthcare financing and care within institutions such as public and private hospitals, outpatient clinics, rehabilitation centres, and individual investments in health.

### Exploring the complexity in distributed decision-making for spinal surgery

*Per Koren Solvang, Karen Synne Groven, Margreth Grotle, Tone-Dahl Michelsen*

*(OsloMet)*

Background - Primarily, two approaches are available in the treatment of lower back pain: Conservative treatment and/or spine surgery. The decision for surgery is a critical incidence where a wide range of factors are given consideration.

Aim - To understand how evidence is applied in the decision-making process in the treatment of lower spine disorders.

Theory - Distributed decision making. Here, decision making is a process involving a broad set of actors and types of considerations.

Methods - Case study at one hospital department where interviews with spine neurosurgeons and lower back pain patients were carried out.

Results - The consultation emerges as a teaching session where the patient is introduced to clinical reasoning and invited to take an active role in the decision making. In this process, patients' socio-cognitive abilities and surgeons' communicative abilities become decisive. Further, patient lifeworld and the meaning of physical activity is given high priority in the decision-making process. This implies that the risk of surgery is weighted against patient activity level and patient risk perception.

Discussion - What this study adds to previous studies is clarity to the professional identity of the spine neurosurgeon as a skilled facilitator for patient participation in complex evidence-based clinical decision-making. The study also adds depth to the understanding of the patient everyday life as a balancing act between a need to pass as healthy on the one side and managing severe activity restrictions and gaining the skills to take active part in treatment decision making on the other side.

### ***Sorting it all out*** **- classifying clients' hand conditions and their movements between primary and secondary care** *Marte Feiring, Silje Zink, Ingvild Kjeken*

*(OsloMet)*

Diagnosis is the main classification tool of modern medicine, and diagnosing is a powerful social process. Understanding this process is critical to interpret and improve the relationship between doctors and their clients. This study asks how general practitioners diagnose and treat persons with painful hand conditions. We are also interested in why some clients are referred to secondary healthcare more often than others.

Our theoretical lens is inspired by critical socio-cultural approaches to professional and scientific boundary work as well as the work of Annmarie G Jutel on diagnosis, and Pierre Bourdieu on inequality. Empirically we are analysing 23 anonymized electronic medical records (EMR) extracts of texts made by general practitioners (GPs). The clients' type and level of education and work status were registered.

According to our analysis, we have identified four ways of diagnosing hand conditions: by symptoms, by physical function or activity performance, by formal classification systems (ICD or ICPC) or by a complex process including treatment. We further identified three treatment trajectories: some clients only met with the GP and were advised to self-care, other clients encountered the GP and a rheumatology specialist, and a third group were referred to an orthopaedic surgeon for treatment. The third group were also frequently referred for further consultations with other health professionals as occupational therapists and physical therapists. We also discovered that clients in the third group had higher (educational) cultural capital than the others.

### Developing an experiment with reallocation and transformation of institutional healthcare responsibilities - The genealogy of an innovative, public health intervention for the multimorbid

*Nicolas Tristan Munk, Kristian Larsen, Tom Møller, Trine Schifter Larsen*

*(University of CopenhagenRUC)*

Background and aim - With this article we wish to inspire and inform future public health interventions. The research object is the development of our public health intervention, “Welfare And Relations” (WeARe), which is characterized by collaborative action research and experimentation with new roles for healthcare professionals outplaced in a local community.

Methods - Inspired by ‘historical epistemology’ we examine inter-related components and choices (methods, theory, empirical data, practical and personal), which made the intervention possible. Data consists of peer reviewed literature, grey literature, personal emails, project description drafts and presentations, ethnographic fieldnotes and interviews, collaboration notes, and contracts.

Results - Following interrelated themes were constructed; 1) ‘Provisional theories’ through literature search and subject positions; 2) Raising capital and mobilizing capitals – between community and clinic; 3) Fieldwork & interviews for ‘provisional theory’ and accumulating cultural- and social capital; 4) Narrowing the scope and qualifying ideas through literature and peer discussions; 5) Consolidating research perspectives and relations with “clinic and community”.

Conclusion - Through this article we demonstrate how ‘iterative-inductive’ research designs and theories of social knowledge can guide processes of creating innovative and collaborative public health interventions. The themes constitute syntheses of research practices and can serve as areas of attention when developing public health interventions. Across themes we show how collaboration, interdisciplinarity, and open-endedness have been practiced in a variety of ways and through multiple, non-linear phases of research practices.

### Against all odds –how social nurses succeed in caring for socially vulnerable patients *Karin Højbjerg*

*(University College Copenhagen)*

Social nursing is a relatively new function at Danish hospitals. The overall purpose is to reduce social inequality by meeting socially vulnerable patients’ special needs. Suffering from multi-illness the patients have difficulties in meeting health care system’s expectations of being a legitimate patient. Health professionals perceive the patients as difficult to cooperate with and difficult to accommodate. Conversely, the socially vulnerables feel misunderstood, unwanted, and discriminated against. The frustrations of both patients and health professionals constantly pose the risk of patients leaving treatment which must be restarted in the event of acute and chaotic readmissions. Organizational changes such as New Public Management and LEAN to streamline health care services have reenforced the challenges to focus on the affective/relational work which is of particularly high importance to meet the needs of this patient group.

This paper explores how social nurses - against all odds- manage to practice successfully as a professional with this low positioned patient group.

In a Bourdieu-inspired perspective we analyze data consisting of ethnographic field notes and individual interviews with 12 hospital-based social nurses. We investigate social nurses’ strategies when practicing their relatively new, hybrid role. Our findings point out strategies mirroring a feel for the game, i.e. respecting and supporting

- the dominant logic of diagnosis and treatment,

- economic and effective argumentation,
- politically consensus of usage of specific professional tools in treatment
- ethical and moral actions and argumentation towards an extremely vulnerable patient group

### Health capital among patients: What does illness mean for the way patients invest in their bodies?

*Anette Lykke Hindhede, Kristian Larsen*

*(University of Copenhagen)*

An illness is often experienced as a disruption of everyday life structures. The way individuals experience their illness affects how they understand and react to its symptoms, treatment and, not least, changes in daily life. Some diseases and disorders have a significant impact on how one relates to one's own body, treatment methods, diets, etc., while others seem less important. This paper reports on how illness affects the health behaviour of a heterogeneous sample of hospitalized patients in the Copenhagen area of Denmark. The aim is to understand how illness can affect people's everyday lives, and the effect it has on the way individuals think and act regarding their own well-being and the well-being across patient groups (diagnosis, class, capital, age, gender).

Based on Bourdieu's relational sociology, we employ the concept of Health Capital as a typology of five ways of investing in the surgical body, the chemical body, the nutritional body, the physical body, and the mental body - and the socially differentiated combination of these. Data will be collected via a survey with approximately 600 hospitalized patients (acute and chronic diseases and somatic as well as mental illnesses) and in-depth qualitative interviews with 30 patients. The survey data will be processed quantitatively using the statistical program Multiple Correspondence Analysis (MCA). This study focuses on the social and unequal implications of illness, adding to studies of illness as a biographical disruption.

### Dynamic role boundaries within Norwegian healthcare *Silje Zink, Ingvild Kjeken, Marte Feiring*

*(OsloMet)*

Professional boundaries within the healthcare workforce are increasingly coming under new pressures due to staffing shortages, economic demands and changing care models. Task-shifting between physicians and other health professionals is progressively used as a strategy to meet these new demands. The current study explores task-shifting as dynamic boundary work between rheumatologists and occupational therapists (OTs) and we apply hand osteoarthritis care in a Norwegian healthcare setting as our empirical case.

In-depth semi-structured qualitative interviews were conducted with 17 participants; 9 rheumatologists and 8 OTs, at 2 different hospitals where task-shifting had taken place. We explore the dynamic role processes within professions, as well as between professions.

The theoretical lens used to explore the data is inspired by Susan Nancarrow's (2005) work on dynamic role boundaries. Nancarrow's analytical terms Diversification and Specification are employed to analyse processes occurring within the roles of the OTs and the rheumatologists (intraprofessional change), and Horizontal and Vertical Substitution is used to explore processes occurring between professions (interprofessional change).

Our preliminary results show that there were both formal and informal shifting of tasks between OTs and rheumatologists. OTs were diversified by gaining tasks and responsibilities outside the traditional scope of their role. However, some reported added responsibility to be anxiety-inducing and highlighted the need for further training. Rheumatologists expressed a wish to retain traditional doctor-related tasks that fall exclusively under their jurisdiction, leading to increased specification of their role and profession. Vertical substitution took place when rheumatologists delegated tasks formerly carried out by them, to OTs.

# Room 135 - Critical Public Health

### "… it's that balance between 'knowledge is power' and 'ignorance is bliss',": What do men with a rare, degenerative condition think about diagnosis through newborn screening?

*Jennifer Jones, Sara Hunt, Karen Harrison, Amy Hunter*

*(Genetic Alliance UK)*

Background: In 2021 the UK National Screening Committee declined to add adrenoleukodystrophy (ALD) into the newborn screening programme, citing (among other concerns) uncertainties about the impact of receiving an early diagnosis for those with 'adult-onset' conditions such as adrenomyeloneuropathy (AMN). ALD and AMN are caused by changes in the same gene and are untreatable in adulthood, however ALD is treatable in childhood.

Methods: This study investigated the attitudes towards newborn screening by interviewing four males with an adult diagnosis of ALD or AMN and an online survey of 29 respondents including family members. The interview transcripts and the open-ended questions from the survey were analysed using thematic analysis.

Results: The interviewees outlined the benefits (shortening the diagnostic journey, being able to make reproductive choices and preparing for the future) and risks (being a "patient in waiting" and potential impacts on how they were parented) which they associated with knowledge of a diagnosis in childhood before symptoms arose. They acknowledged that it was challenging to decide whether they would have wanted to know about their condition sooner. However, most of the interviewees and survey respondents stated that the benefits of newborn screening for ALD outweighed the risks.

Conclusion: Men diagnosed with AMN/ALD as adults are able to describe the potential benefits and risks if they had been diagnosed earlier through the newborn screening programme but indicated it was a difficult balance. In this small-scale study the consensus was in favour of newborn screening for ALD in the UK.

# Room G31 - Mental Health

### Exploring the contribution of Black-led community organisations to promoting mental well-being in Black communities

*Stephanie Ejegi-Memeh, Zara Makinta, Sarah Salway*

*(University of Sheffield)*

In the UK, people from Black communities have a higher prevalence of mental health conditions, are less likely to seek help for mental health conditions and are less likely to have their mental health conditions detected by professionals.

Community organisations often step in where statutory services fail, but their initiatives are precariously funded, rarely documented nor the focus of research.

This project drew on a Black Emancipatory Action Research (BEAR) framework and Critical Race Theory (CRT) to document the contributions of Black-led community organisations in promoting mental well-being in Black communities, and explored the ways in which they navigate inequitable systems of power.

Stages - Exploration of decolonial, anti-racist, emancipatory research methods;

Activity mapping - Volunteering and discussions with stakeholders from Black-led community organisations;

Development of composite stories - Reflecting the BEAR and CRT underpinnings, this project used novel methods including working with a Black activist/community researcher on the design and delivery of the project, focusing the interview schedule on healing and imagination as well as challenges, and being “in-service” to social justice causes.

Black-led community organisations bridge the gap between statutory mental health services and members of Black communities. Community leaders countered the system of racism by providing opportunities for unifying, celebratory activities and activities to support mental health e.g counselling, mentoring. Volunteers reported that involvement with organisations was a restorative activity, contributing to a sense of safety and healing. Those involved with organisations reported that these organisations contribute to Black self-esteem, the reduction of loneliness and the development of critical consciousness.

# Room G35 - Inequalities and Intersectionality

**Life with type 2 diabetes from a gendered and classed perspective**

*Louise Hansen, Nicole Thualagant*

*(Roskilde University)*

Epidemiological studies point to a frequent and obvious causality between men, particularly men in vulnerable positions, and lack of adherence and self-management skills, thus calling for health professionals to address this non-adherence or deficiency. A prevailing discourse on men's health is emphasizing the differences in relation to the binary opposite (women) and often explains this with inappropriate health choices which are linked to norms of masculinity. This contributes to a stereotyped approach to men as disadvantaged patients.

In this paper, we aim to move beyond these normative understandings of so-called non-adherence by inquiring into the complexities of everyday life and by exploring the lived experience of positions offered in medical encounters. We explore how gender intersects with class as social constructs and potentially reproduce positions of inequality which affect the demanding challenges of life with a chronic disease. The study includes 12 men who are receiving diabetes treatment and who, by the healthcare system are characterized as vulnerable based on socioeconomic parameters. Based on qualitative interviews, which all were conducted after observations of healthcare encounters, this analysis points to the following challenges: The men embody a script where gendered and classed relations are reproduced and where, among other findings, (female) health professionals are offered particular feminized positions associated with other authoritative positions of care encountered earlier in life (mothers, educators, teachers, social workers). These findings highlight the difficulty of transgressing stereotyped boundaries of class and gender.

# Room 115 - Open

**Social media live events as a health communication tool: Interaction in an Egyptian breast cancer awareness campaign.**

*Basma Salem, Prof. Paula Saukko, Dr. Jessica Robles*

*(Loughborough University)*

Breast cancer mortality rates in Egypt are comparatively high, due to fear of it being always fatal and leading to loss of femininity, health illiteracy and poor access to screening. Charities have used social media live streaming for breast cancer awareness as it is economical, creates a sense of social presence and enables interaction with audience through chat. However, as live events are new, there is hardly any research on them in health research. We analysed interaction in seven highly engaged (thousands of comments) Facebook live awareness-raising events by two Egyptian charities, using digital conversation analysis focusing on turn-talking, especially adjacency pairs of signals and expected answers. The vast majority of user contributions were compliments, in the form of religious praises for the charity, responded to by an appreciation (heart emoji), fomenting ritualistic phatic communication. Medical questions by users were answered through chat, orally by the streamer or via direct messaging, with different advantages and disadvantages. However, many questions went unanswered creating a notable absence. Users could post their questions numerous times, signalling frustration and that they expected an answer, or alternatively users answered each others' questions, jumping turns and creating a somewhat chaotic parallel floor of conversation. Much of the communication in live events, combining elements of interpersonal interaction and broadcasting, did not live up to what Goffman defines as focused interaction. We will conclude with reflecting how interaction in such events could be defined, what users' expectations are and what practical challenges these create.

# Room 118 - Experiences of Health and Illness

### A World of In/difference? Living with Learning Disability in the UK

*Gareth Thomas*

*(Cardiff University)*

Despite policies designed to improve the lives of learning-disabled people, they remain at the margins of UK society. Frequently excluded in hostile and unforgiving environments, learning-disabled people are assumed, perpetuated by popular representations, to be miserable and subjects of pity and tragedy. This ideological marginalisation violates the experience of being learning-disabled and avoids dismantling problematic stereotypes. But how do learning-disabled people – frequently spoken for by proxies or excluded from research altogether – reflect upon their lives?

In this talk, drawing on ethnographic fieldwork at various sites (e.g. theatre company; community café), I explore how adults with a learning disability confront dominant oppressive narratives and articulate their lives in affirmative terms. To do this, I discuss three key findings. First, learning-disabled people resist popular configurations of vulnerability, passivity, isolation, and exclusion, to talk in affirmative terms of inclusion, resistance, and in/terdependence. Second, people with a learning disability cultivate positive modes of public storytelling that, arguably, 'expand the social fund of knowledge about disability' (Rapp and Ginsburg 2001). This includes reflecting on their (disabled) future not as a 'fate worse than death' (Kafer 2013), but as liveable; they 'cripped' common narratives by re-storying disability and enacting a 'crip futurity' (Rice et al. 2017). Third, I identify how such efforts are inhibited by barriers (structural, cultural, social) that threaten to, or do, disrupt the possibility of learning disabled people living a 'good life'. I conclude by identifying how disability constitutes a core area of analytic enquiry in medical sociology and beyond.

# Room G22 - Health Care Organisations

### Treating the System. The Invisible Work of Doctors in Finnish End-of-Life Care

*Elina Yrjola*

*(University of Helsinki)*

The concept of invisible work is currently taking root within the study of nursing work and that of other health professionals. However, there is a scarcity of research about how health care organizations fail to recognize crucial aspects of doctoring.

My study on critical pathways of end-of-life care in Finland focuses on invisible tasks conducted by doctors in their everyday work. Based on semi-structured thematic interviews (N=22), I point out various kinds of non-medical tasks the doctors constantly take care of. Even though the work is often rooted in the particular circumstances of the doctor's organizational field, it remains organizationally invisible and is not acknowledged formally. However, doctors feel compelled to conduct it for the purpose of achieving good care.

The invisible work includes tasks as making sure that the patient transfers smoothly from hospital to hospice care or home care; or making sure that the patient gets all the help needed at home and the same services as another patient living in the next town. Invisible work also occurs when end-of-life care doctors negotiate with doctors of other specialties about specialty boundaries.

# Room 144 – Pedagogy and Methods

### If you don't build it, they will still come: an ethnographic exploration of healthcare provision in a 'Deep End' coastal community.

*Sam Hillyard*

*(University of Lincoln)*

Remote coastal regions have been termed 'Deep End' communities, where demand for healthcare services far out strips provision. Yet some coastal locales continue to be in demand/ a destination of choice. Based on preliminary findings of an ethnographic project within one Lincolnshire community funded by a key service provider, the paper explores emerging tensions through a variety of lenses. These include: the medical practice view, the service departments within the practice, patients' experience of such practices and the social and historical context of the locale itself.

Provisional findings are that difficulties are experienced by both practice and patient, in terms of resource, communication and the amenities to be found in the case study locale. Some tensions found in rural areas (length of residence/ gentrification) are less prevalent). More resource is identified as desirable but also not the solution. The paper concludes with a number of key questions for ongoing research. These primarily include the need to understand the synergy between people and place.

# Friday 15 September

# 11:20-11:50

## Room G36 - Health Policy

### Refugee & Asylum Seeker Healthcare Professionals’ (RASHPs) journey and experiences transitioning into the NHS

*Heidi Miu, Ross Goldstone, Brigita Serguis*

*(NHSE)*

Despite the expertise and potential of Refugee and Asylum Seeker Healthcare Professionals (RASHPs) as a unique opportunity to support the healthcare workforce in the face of shortages, the process to enter the NHS is a lengthy and arduous struggle. To explore these challenges, a mixed-methods study was conducted, consisting of an online survey (N=106) and semi-structured interviews (N=12) conducted between Feb-May 2022. Our findings highlight distinct challenges meeting the linguistic, clinical, and verification requirements for professional registration whilst managing unique socio-economic circumstances. At each step, RASHPs face uncertainty and lack of access to timely information with the risk of delays potentially detrimental to their registration. Upon successfully registering, RASHPs struggle to obtain relevant NHS working experience which would not only enhance their employability but also promote integration and retention upon entering an unfamiliar healthcare system. RASHPs must also navigate the strategies and nuances of interviewing and job seeking in the NHS whilst competing with UK and international graduates. Throughout the entire journey, RASHPs are hindered by a lack of access to timely information, logistical and practical limitations to resources, and difficult financial decisions at every step. The findings also point to potential disparities between doctors' and nurses' experiences, overall highlighting the need for additional advancements to assist RASHPs who wish to restart their professional practise in the NHS.

## Room 135 - Critical Public Health

### Normalising medical or medicalising normal; processes of diagnosis for adolescent menstruation in medical discourse

*Sharon Dixon, Flora Holloway, Katy Vincent, Claire Duddy, Neda Taghinejadi, Sue Ziebland*

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

Background - Menstrual pain (dysmenorrhoea) is prevalent in adolescence, affecting up to 94% of those who menstruate. Dysmenorrhoea is typically characterised by clinicians and researchers into primary (no known underlying pelvic pathology) or secondary (associated with pelvic pathology). While guidance suggests distinguishing between these is straightforward, delays in diagnosis of the most common cause of secondary dysmenorrhoea (endometriosis) highlight the complexity of this task.

Aim - To describe how dysmenorrhoea is represented in medical discourse and consider why inconsistencies matter.

Method - Narrative mixed-methods synthesis exploring adolescent dysmenorrhoea (PROSPERO 256458), including 323 full-text papers. We mapped how descriptions of menstrual pain evolve with ‘scientific discovery’ from neurosis into the medical sphere and described how the process of ‘diagnosing’ primary and secondary dysmenorrhoea is characterised. We drew on sociological theories of diagnosis (Jutel) and prognosis (Timmermans) to frame our findings.

Findings - Inconsistencies in how primary dysmenorrhoea is characterised in medical discourse suggest that the symptomatic experience of pain is conflated with the diagnostic entity primary dysmenorrhoea, leaving diagnostic reasoning built on unstable foundations. We identify disparities in descriptions of menstrual pain as a (bio)-medical entity, including co-opting terminology such as ‘healthy’ to describe the absence of menstrual pain. Uncertainty about the natural history of dysmenorrhoea and endometriosis is integral to challenges of diagnosis.

Conclusions - If clinicians conflate symptoms with diagnosis, this likely constrains clinical reasoning, and contributes to the acknowledged delays in diagnosing endometriosis. People with dysmenorrhea will benefit from transparent conversations with their clinicians about the uncertainty around the diagnosis and its implications.

# Room G31 - Mental Health

**Representations of suicide behavior and people who attempt suicide in suicide prevention policies in Denmark**

*Joanna Wisbech, Alexandra Jønsson, Mari Holen*

*(Roskilde University)*

Political documents and action plans are seen as an important part of reducing suicide and suicide attempts. They define what actions must be prioritized, while also providing narrative resources for understanding ‘problems’ relating to suicide experience. The aim of this article is to analyze how suicide behavior and people who attempt suicide are portrayed in political documents in a Danish context. Inspired by Bacchi and Goodwin’s poststructural policy analysis we explore 1) how the problem of suicide behavior and people who attempt suicide are represented in the documents, 2) what the underlying assumptions are, 3) what is silenced in these problem representations and 4) the possible effects of prioritized prevention actions and narrative resources the policies provide. We draw on documents published by significant stakeholders and decisionmakers in a national partnership for the prevention of suicide and suicide attempts. The findings show that people who attempt suicide are predominantly positioned as being at risk and risky due to persistent individual vulnerabilities and mental illness. We argue that people who attempt suicide are both constructed as risky due to their engagement with suicide behavior, through poor ‘inner’ coping skills. While simultaneously being (passively) ‘at risk’ by suicide due to factors ‘outside’ their control such as mental illness or strained life circumstances. These dominant individualistic problem representations could reduce and maintain prevention to individual support and treatment, excluding broader structural, social and relational solutions and understandings.

# Room G35 - Inequalities and Intersectionality

**“I see you”: Making end of life care accessible for all**

*Zoebia Islam, Kristian Pollock, Anne Patterson, Matilda Hanjari, Louise .M. Wallace, Christina Faull*

*(LOROS Hospice, Research and Education, Leicester; University of Nottingham, School of Health Sciences; The Open University, Faculty of Wellbeing, Education and Language Studies, Milton Keynes UK)*

Background/aims: Evidence suggests many healthcare professionals lack awareness, confidence, knowledge and skills in providing culturally sensitive end-of-life care for ethnic minority patients. The ‘Thinking Ahead’ (NIHR HS&DR 17/05/30) research study explored how terminally ill patients from ethnically diverse backgrounds, and their family care givers, think ahead about deterioration, dying and engaging with healthcare professionals to optimise care. Study findings underpinned the development of resources to support healthcare professionals in talking about end- of- life and goals of care for patients and families from ethnic minority groups.

Methods: A qualitative study including comparative thematic and cross case analysis from 18 longitudinal patient case studies (93 interviews), 19 interviews with bereaved family members and workshops with 50 public and professional stakeholders.

Results: The key message arising from this research resonates with the Zulu greeting “Sawubona” which literally translates to “I/we see you”. Where people feel known, especially in respect of any ethnically-or culturally-driven values or stances, greater trust can be engendered resulting in care that is more relevant, timely and personalised. Outputs from this work include e-learning resources, a number of audio stories and a learning guide.

Conclusions: The resources hosted on the Health Education England End of Life Care for All (e-ELCA) e-learning programme and LOROS Hospice websites (https://loros.co.uk/research-at-loros/thinking-ahead/thinking-ahead-stories) are a step towards reducing inequity by developing and building professional confidence and expertise in supporting people from ethnically diverse backgrounds to engage in thinking ahead about deterioration and dying at a time and at a level with which they feel comfortable.

# Room 115 - Open

### Experiences and perceptions of well-being during the work-capability re-assessment process

*David Fassioms, Paula Holland, Faraz Ahmed*

*(Lancaster University)*

Research on the work-capability assessment (WCA) has shown that the assessment process can have an adverse effect on mental health and can be anxiety-provoking, something to be feared, or re-traumatising (Barr et al., 2015; Garthwaite, 2014; Scullion and Curchin, 2022). Yet no study has focussed specifically on recipients in the Employment Support Allowance Support Group or Universal Credit Limited Capability for Work and Work-Related Activity Group, who must undergo repeated re-assessments of their eligibility for benefits. To understand the re-assessment process from this viewpoint is important, as it focuses on individuals with chronic physical and/or mental health problems, who have navigated the benefits system for a prolonged period of time. Eighteen in-depth narrative interviews were conducted with people in the above stated groups who were undergoing or anticipating re-assessment of their eligibility for benefits. The study found the re-assessment process to be fraught with difficulties that can lead to stress, or can exacerbate existing physical and/or mental health symptoms. The cycle of re-assessments were perceived as never ending, harmful to health and led to social struggles including financial difficulties, food and energy poverty. There was evidence of stigma with some feeling judged for being in receipt of benefits, adding to the already arduous process of navigating the re-assessment process. Policy recommendations were made for the assessment provider of the WCA, Department for Work and Pensions and Job Centre Plus, which would improve the experience of benefit recipients who have been in the benefits system for a prolonged period of time.

# Room 118 - Experiences of Health and Illness

### Biographical dialectics: the ongoing and creative problem solving required to negotiate the biographical disruption of chronic illness.

*Victoria Cluley*

*(University of Nottingham)*

In this presentation the term ‘biographical dialectics’ is proposed as a sister term to ‘biographical disruption’ to capture the ongoing problem solving that characterises the lives of many people living with life limiting chronic illnesses. The presentation draws on the experiences of 35 adults with end-stage kidney disease (ESKD) in receipt of haemodialysis. Photovoice and semi-structured interviews showed that ESKD and the use of haemodialysis was widely agreed to be biographically disruptive. In talking about and showing disruption through photographs, the participants’ ongoing problem solving was identified as universal across their diverse experiences. ‘Biographical disruption’ and Hegelian dialectical logic, are drawn on to make sense of these actions and to further understand the personal and disruptive experience of chronic illness. Based on this, ‘biographical dialectics’ captures the work that is required to account for and manage the enduring and biographical impact of chronic illness that follows the initial disruption of diagnosis and continues as life progresses.

# Room G22 - Health Care Organisations

### Sailing through the Wind Tunnel Test of Neoliberalism: York Hospital as a Spatiotemporal Archival Assemblage

*Emincan Fidan*

*(University of York)*

York Hospital, an acute healthcare facility in North Yorkshire, has a history spanning nearly six decades. Envisioned first in 1965, designed in 1967, and opened in 1977; the hospital we experience today is composed of several layers and components, superimposed upon each other and it reflects varying periods of the NHS and the healthcare provision in the UK. The current result is a curious amalgamation of various material, technological, medical, managerial, social, political, and economic frameworks. And it cannot be taken for granted for the black-boxed space that it represents. This paper; employing a Deleuzo-Guattarian assemblage framework, and benefiting from archival research focusing on the hospital archives, will situate York Hospital as a “spatiotemporal assemblage”, by introducing novel ways of problematising the spatial (re)configuration of built healthcare environments. To do that, three different time periods in the history of York Hospital will be prioritised: mid-1970s (constitution phase), mid-1990s (the introduction of the NHS Trust structure), and mid-2000s (the transformation into a teaching hospital Trust). Backed up by examples grounded upon archival data, the main objective of this inquiry is to provide a material account of neoliberalisation of healthcare settings in the UK, based on a tangible account of spatial composition, reconfiguration, and evolution of York Hospital. Thus, the study will try to offer an alternative and localised account of the much-disputed concept, that is neoliberalisation, without resting upon grander theorisations such as the top-down iterations produced by Neo-Marxist scholarship, or the Foucauldian bottom-up conceptualisations provided by the governmentality studies.

# Room 144 - Pedagogy and Methods

### Evaluating Hispanic Cultural Competency Training in US Universities for Drug Abuse Treatment in Los Angeles

*Veronica Fish (Virtual Presentation)*

*(Cambridge Centre for International Research)*

Studies have shown that Hispanics in the United States report attitudinal barriers to drug abuse treatment more than any other racial/ethnic group. Hispanics report feeling that drug abuse treatment providers do not understand their unique cultural needs and are unfamiliar with their experiences of discrimination and immigration (Pinedo 2018). By taking this concern to its center, this study investigates the extent to which US universities train counselors to address the culturally-specific needs of Hispanic patients and how this is reflected in practice in Los Angeles County. Los Angeles County is the focus of this study because it has the largest Hispanic population at 4.8 million, accounting for 9% of the total US Hispanic population (Pew Research 2022, Census Bureau 2022). Based on a content analysis of the required courses, syllabi, and course descriptions at 30 universities related to culture/race/racism/ethnicity/diversity at the undergraduate and graduate level on the addiction therapist track, and discourse analysis of seven in-depth interviews with counselors working in outpatient rehabilitation centers in Los Angeles, I argue that cultural competency education for drug abuse counselors is too surface-level and infrequent to adequately prepare students for a career in addiction counseling for Hispanic clients. Significant changes must be made to how cultural diversity is valued and prioritized in the field of Psychology to provide better care for Hispanic people with a substance use disorder.

# Friday 15 September

# 11:55-12:25

## Room G36 - Health Policy

### An exploratory study of the relational ties between the Nigerian national health policy and patient safety.

*Pauline Odeyemi*

*(Nottingham Trent University)*

Iatrogenic harm in hospitals is a global issue affecting countries at all levels of development. It is described as the absence of preventable harm to a patient while receiving healthcare. The burden of unsafe care explains the magnitude and scale of this problem since most adverse events happen in low- and middle-income countries.

This study aligns with the international interrogation of the role of health policy in achieving positive patient outcomes in clinical practice by exploring the impact of health policy on Patient Safety (PS) in Nigerian health systems.

The study goal is achieved by applying the methodological process of Actor-Network-Theory (ANT) as an interpretive approach of qualitative research based on epistemological understandings of interpretations and meanings that are not visibly observable. Methodologically, ANT deploys the twin methods of observations and semi-structured interviews amongst policy administrators and clinicians in Abuja, Nigeria, at the Federal Ministry of Health (FMoH) and four acute care settings. An actor network was established and interpreted through Bruno Latour's four moments of translation.

Findings show that PS is unstable in the network because of constant interference by mediators and intermediaries, causing a disconnect between the Nigerian National Health Policy and clinical practice; there are unquantified PS occurrences and limited knowledge of health policy concepts and PS science among administrators and clinicians.

Recommendations include suggestions to establish a PS department to focus on closing the gap between health policies and practice by establishing clinical governance leadership, improving policy processes, and evaluating PS health policies in practice.

## Room 135 - Critical Public Health

### "Who should be treated? The ethical challenges of administering medication for opioid use disorder (MOUD) for people who inject drugs during COVID-19."

*Roberto Abadie*

*(University of Nebraska-Lincoln)*

COVID-19 dramatically altered the provision of medication for opioid use disorder (MOUD). In the United States, the relaxation of drug testing and a shift to telehealth were introduced. While enrolled participants welcomed these changes, the pandemic forced those on waiting lists to remain out of treatment. This paper asks who should receive treatment in the event of a pandemic or natural disaster and addresses the ethical challenges of modifications in MOUD to people who inject drugs (PWID) during COVID-19.

While several public health ethics frameworks exist, given the novelty of the pandemic and the treatment needs of PWID, little is known regarding their applicability to MOUD treatment in historically marginalized communities.

Drawing on qualitative methods, this study explores the lived experiences of patients (N=24), healthcare providers, and health administrators (N=26) seeking or receiving treatment during the San Juan, Puerto Rico, pandemic.

Findings show that while the Centers for Disease Control (CDC) recommended standardized measures, the implementations were not uniform, even when considering a single city. PWID were not consulted about the measures to be implemented. Those in a community-based clinic felt respected and reassured by the implementation; patients in a larger state-sponsored clinic did not. Similarly, depending on their institutional responses, providers had very different views about implementation and who should receive care. With environmental damage making natural disasters and pandemic events more likely, better coordination and planning will be required.

# Room G31 - Mental Health

### Caregiving Experience Associated with Carers of Persons with Schizophrenia: A Scoping Review

*Yu-Ching Liu*

*(University of Bath*)

Background: De-institutionalisation policies have led to increasing caregiving stress within the family, which has been measured by researchers as caregiver burden.

Aims: This review focuses on how the caregiving experience of carers of people with schizophrenia is understood in the literature.

Methods: A scoping review was employed using Arksey and O’Malley’s (2005) framework. A total of 106 studies were included.

Results: The review found publications on this topic have steadily increased over the past two decades. Most studies derived from India, the UK, and China, and predominantly used quantitative research designs. Findings show that domains of financial problems, disruption to social life and family relationships were commonly evaluated to be objective burdens, while the domains of the care recipient relapsing, carers suffering from violence from care recipients and experiencing discrimination were identified as subjective burdens. There was a lack of evidence regarding the effectiveness of care services and social supports, the positive aspects of caring, and carer’s physical burdens in the reviewed studies.

Conclusions: Research needs to pay more attention to what social support are beneficial to carers and the effectiveness of formal services in responding to caregiver burdens faced by carers.

# Room 144 - Professions

### 'He can shove his claps ... somewhere else!': covid-19 and the care worker retention crisis

*Eleanor Johnson*

*(University of Bristol)*

Paid care roles have, historically, offered little in the way of financial reward or recognition, yet workers continue doing the job of care. A common explanation of this trend is that workers are more willing to accept a lower wage if they consider their work to be rewarding or fulfilling. However, in the wake of the Covid-19 pandemic, staff vacancy rates for adult social care in England have reached record levels; workers are proving difficult to recruit and retain. Drawing upon two research projects undertaken preand post-March 2020, I explore how paid caring roles have changed in relation to the pandemic. COVID-19 safety measures – such PPE use and social distancing – have impacted upon the close and interpersonal relationships between care workers and care recipients, which were formerly regarded as a source of dignity for care workers. In addition, in the post-2020 study, care workers spoke about a more general devaluing of their roles, which had, in some cases, come to resemble factory work. Others perceived attempts to show appreciation for their work – such as the 'Clap for Our Carers' initiative – as inauthentic and hollow, since it was not underpinned by increased financial remuneration or meaningful policy/structural changes. I argue, then, that the 'moral currencies' – such as hugs, smiles, and thank yous – upon which care worker retention used to precariously rest, are beginning to lose their clout in the wake of the pandemic, and that recruitment and retention issues are one symptom of this.

# Room 115 - Open

### 'The impact on them is much greater than we could ever know': Using decentred theory to explore contested narratives surrounding Covid-19 and prison healthcare in England

*Laura Sheard, Lucy Wainwright, Sarah Senker, Krysia Canvin*

*(University of York)*

The prison system in England has been shattered by 13 years of austerity politics with its funding reduced by 22% whilst the number of people in prison remains high. Within this discourse of deterioration sits prison healthcare, with vastly depleted staffing levels. The impact of Covid-19 on this already fragile milieu has proved devastating, in complex and contradictory ways.

Decentred theory (Bevir) will be employed as a sensitising concept to frame contested narratives about policy and governance decisions taken regarding Covid-19 and the prison estate. We will discuss how actors discursively constructed oppositional narratives in order to regain power in the face of their lack of autonomy within a failing system. We draw upon 44 qualitative interviews conducted across England in late 2021.

We present three main ideas. First, a conflict was witnessed whereby chronicles of suffering, anguish and trauma resulted in a sense of dichotomous collective but compartmentalised hurt. Healthcare staff felt emotionally and physically exhausted working in unsafe conditions whilst people in prison felt abandoned and neglected. Second, a tense disconnect existed between increased funding secured by leaders that did not perceptibly reach the healthcare shop floor. Third, participants and stakeholders sought to resist the research process itself including: whistleblowing attempts, declining to be 'on record', vetting of findings and patient representatives rejecting interim findings.

Prison healthcare is set centre stage within a devalued healthcare arena where actors have been harmed by habiting space within a failing institution during the largest public health crisis of the past century.

# Room 118 - Experiences of Health and Illness

### Do breast cancer survivors in Gaza face social and marital challenges after illness? a self-administered cross-sectional survey

*Walaa Shehada, Piet Bracke, Khaled Abusaman*

*(Ghent University)*

Background: Breast cancer (BC) is a traumatic illness. BC is the leading female cancer in Palestine. Complex socio-political dynamics impact patients' lives, resulting in an increasing need for social support to develop resilience after illness.

Method: Data was collected through a cross-sectional survey targeting women living in the Gaza Strip who had been diagnosed with BC. The survey was self-administered and distributed to 350 women between 1 March and 30 May 2021. Descriptive statistics and multinomial logistic regression analysis (SPSS, version 28.0) were used to explore perceived support, post-illness social and marital changes and the association between these changes and socio-demographic, illness-related and support-related variables.

Findings: About four-fifth of the women with BC felt supported after illness, either fully or partially, mainly by family members, spouses, non-governmental organisations, and peers. Nevertheless, nearly half of the women perceived negative social changes after illness and about 40% of married or formerly married women perceived negative changes in their marital life. Survivors' lived experiences varied by age, marital status, motherhood, prescribed treatment (specifically mastectomy), and the absence of informal support in social life and lack of partner support among married or formerly married women.

Conclusion: This study shows how BC undermines the social status of women and further exacerbates existing social vulnerabilities. Survivors experience uncertainties and changes in their life that differed by age, marital status, motherhood, undergoing surgery and (un)available sources of support. Guiding partners, families and friends on providing emotional and instrumental support will help survivors to cope better during recovery.

# Room 144 - Pedagogy and Methods

### Understanding everyday health practices: adding long duration photo-elicitation to the empirical toolkit

*Kate Weiner, Lauren White, Ros Williams, Catherine Will, Flis Henwood*

*(University of Sheffield)*

Researching everyday health practices can be tricky as they often take place in domestic spaces and at varying times. Sustained observation is impractical and likely to be seen as intrusive. Interviews might be enrolled, but are also seen to have their limitations. Homes and Hall (2020) note a discontent with these ‘traditional methods’ and call for an expansion of ‘the empirical toolkit’. This aligns with the increasing use of materials (objects, diaries, photos) to prompt and anchor reflections in interviews.

This paper will discuss the use of long-duration photo-elicitation in our study of everyday self-monitoring. Following initial interviews with people who monitor their blood pressure or weight/BMI, we invited a subset of our participants to take photographs of the occasions when they self-monitored over a six-month period and used these as prompts for a follow-up interview. Photo-elicitation over this length of time is relatively novel, as it is generally enrolled for shorter periods (weeks rather than months). The paper discusses why we did this, our deliberations in devising the procedure, and what we think we learnt from it. This includes our concerns that the method would act as an intervention, and the insights we gained about why people monitor on specific occasions, as well as the spatial, temporal and social organisation of monitoring in people’s homes.

We end with a frank discussion of what the method added as well as the aspects of practice it was less helpful in documenting.

# Friday 15 September

# 12:30-13:00

## Room G36 - Health Policy

### Infant feeding as a transgressive practice in the context of HIV in the UK: a qualitative interview study

*Tanvi Rai, Bakita Kasadha, Shema Tariq, Sabrina Keating, Lisa Hinton, Angelina Namiba, Catherine Pope*

*(University of Oxford)*

New mothers living with HIV in the UK, the majority of whom are of Black African ethnicity, navigate powerful and contradictory medical and social discourses regarding infant feeding. UK clinical guidance on pregnancy and HIV recommends exclusively formula feeding the baby, but this contrasts sharply with World Health Organisation (WHO) guidance, which recommends exclusive breastfeeding. Adding to this basic health policy-level paradox are multiple other discourses around “good” motherhood that valourise breastfeeding, including the unambiguous “breast is best” messages endorsed more widely in society and by public health bodies. Meanwhile, HIV remains stigmatised and formula feeding can signal one’s HIV status to others, especially within African diasporic communities living in the UK.

We interviewed 36 new mothers living with HIV (either pregnant or given birth in the 12 months preceding) about their experiences of making decisions regarding infant feeding. Specifically, we used the concept of transgression (the idea that people act in ways that breach existing authoritative social or legal codes of behaviour) in order to understand this phenomenon. As Donnan and MacGowan reflect, referring to sexual transgression, “transgressive nonconformity allows us to see through issues of power and control that are variously public and private, implicit and explicit, verbalised and embodied across a range of diverse social structures and cultural forms” (Donnan and Magowan 2009) (p.3). Through a critical feminist lens, we explored how structural and social forces that surveil and control new mothers with HIV push them into transgressive spaces, irrespective of how they feed their babies.

## Room 135 - Critical Public Health

### Outbreak distress: characterising moral distress amongst international healthcare workers responding to mpox in 2022

*Rosalie Hayes, Anthony K J Smith, Vanessa Apea, Chloe Orkin, Sara Paparini*

*(SHARE Collaborative, Queen Mary University of London)*

In May 2022, the world witnessed the most extensive and geographically widespread outbreak of mpox - a virus transmitted via contact with bodily fluids or lesions on the skin - and the first in which sustained human transmission was reported outside endemic countries. Healthcare workers in regions that had not experienced the virus before were faced with responding to an unfamiliar infectious disease within health systems still reeling from the impact of the COVID-19 pandemic. This outbreak particularly affected sexually active gay, bisexual, and other men who have sex with men, drawing comparisons to the early decades of the HIV pandemic, including the lack of timely access to vaccines and treatments. In this fraught context, we sought to understand the experiences of healthcare workers during the mpox outbreak, including identifying ethical and workforce challenges. An online survey was distributed amongst the SHARE-net international research collaborative of clinicians responding to mpox, yielding 1231 responses from 91 countries. Drawing on the concept of ‘moral distress’, we present a comparative thematic analysis of qualitative free-text responses in the survey, exploring varying forms of moral distress described by respondents and differences in experiences between regions and professions. Our analysis explores responses to mpox as 'outbreak distress', involving moral distress, uncertainty, fractured health responses, resource inequities, and challenges providing quality care, with consequences for professional wellbeing. We identify protective factors at the structural, interpersonal, and individual levels to support recommendations for future outbreaks.

Temporalities of the dementia journey: insights from the IDEAL programme.

# Room G31 - Mental Health

**Waiting for change: the politics of balance in UK suicide prevention.**

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

*(University of Edinburgh)*

In the UK suicide prevention is portrayed as a ubiquitous good, uniting politicians across party divides, and therefore is often granted an apolitical status, alluding critical interrogation. This paper seeks to disrupt the status quo, re-politicising suicide prevention through a sociologically informed interdisciplinary project which used arts practices across seven workshop series to engage with communities known to be disproportionately affected by suicide, and practitioners working with them. Our workshops facilitated opportunities to explore, critique and 'speak back' to UK suicide prevention policies and the political debates surrounding them 2009-2019. Through creative works and associated collaborative discussions, participants critiqued radical individualism in suicide prevention planning as inadequate for addressing the more structural nature of suicidal distress. This was particularly the case in marginalised communities who were often conceptualised in policies and political debates as so different, so other, that they could not be provided for within mainstream suicide prevention; instead pushing responsibility for this work back onto already over-worked and under-resourced communities, with little to no additional support. Working abductively between art, narrative, and theory this paper critically explores participants' negotiation of the balance between calling for structural change led by a government whom they lacked any faith in; whilst also wanting to undertake the everyday labours of suicide prevention to prevent further deaths in marginalised communities, which was viewed by some as enacting a complicity in governmental evasion of responsibility. Ultimately, this paper therefore reflects on a key ethical question: what should we do whilst we wait for change?

# Room 118 - Experiences of Health & Illness

**Experiences of Health and Illness of Street Children in the Capital City of Delhi**

*Ajit Kumar (Virtual Presentation)*

*(Jawaharlal Nehru University)*

The sociological understanding of health and illness is based on social constructs, unlike the medical belief, which is based on biomedical knowledge of signs and symptoms. The tension between sociological and medical understanding of health and illness led to the reformulation of the understanding in which medicine has started to recognize a person in the social context, and sociology has come to an approach where it accepts the physical as well as lived body as a central part.

UNICEF classifies street children into three broad categories: (i) street-living children; (ii) street-working children; (iii) children living with families on the street. Due to the vulnerability of the population group, they are also exposed to health risk factors and face barriers in seeking health services. Diwakar (2016) reports that organizations working with such marginal populations do not consider their perception or social aspects of health but instead adopt biomedical practices. So, there is a need to understand street children's health and illness from their perspectives.

The study is based on qualitative Grounded Theory Methodology and the research in New Delhi, India. The researcher will use four core principles of GTM identified by (Timonen et al., 2018), i.e., (1) Taking the Word “Grounded” Seriously, (2) Capturing and Explaining Context-Related Processes and Phenomena, (3) Pursuing Theory Through Engagement with Data, (4) Pursuing Theory Through Theoretical Sampling. The data will be collected using Interview Schedule, Observation Guide and Group Discussion Guide.

This is an ongoing work; the study is in the data collection phase.

# Room G22 - Health Care Organisations

### Like a Social Breath: Homecare’s Contributions to Social Inclusion and Connectedness of Older Adults – implications for policy and homeservices development

*Reidun Norvoll, Christine Øye, Astrid Skatvedt*

*(Oslo Metropolitan University (OsloMet), Work Research Institute)*

The detrimental effects of social isolation on health and well-being bring forward the need for increasing social inclusion and connectedness for older, homebound adults. Homecare services may be a source of social inclusion, but the inclusive dimension sand mechanisms of care have been less explored. This published study (JoSI, Vol 13, 2022) aimed to develop more knowledge on how homecare can contribute to social inclusion by exploring older adults’ experiences with care visits as social encounters.

The study utilised interviews with older adults from four municipalities in Norway and Denmark from 2018 to 2019 and drew on a combination of social inclusion theories and Goffmanian microinteractionism.

Positive accounts of care encounters comprised three overlapping thematic dimensions: 1) bringing social life into the house, 2) creating connections to the outside world and 3) providing opportunities to participate in a broader array of social roles and identities. Despite variations, care visits could encompass social inclusive and connective aspects that enhanced thriving and wellbeing. Care visits increased opportunities for social participation and support of a valued self and comprised bonding, bridging and linking social capital. Care workers could be important interpersonal network resources at home, providing support and social stimulation, engagement and fun, and also bridge to the outside society through conversations or by linking to services that increased social participation and bonding with peers outside the house.

The presentation will elaborate on the needs to support the inclusive resources embedded in homecare in policy and practice to increase older people’s inclusion.

# Room 144 - Pedagogy and Methods

### Reflections on the method of qualitative cross-country comparative health research

*Jacob Heath, Maeve Moran, Anna Dowrick*

*(University of Oxford)*

Qualitative cross-country comparative research, an emerging area in medical sociology, is a method used to compare various aspects of two or more countries to generate new insights and understandings for research, policy and practice. This method requires careful planning and execution to ensure that the data collected is comparable and meaningful.

The purpose of this presentation is to reflect on qualitative cross-country comparative research as applied to the Covid-19 pandemic by the DIPEx International network (DI), who have been working together to produce eight cross-country comparisons of Covid-19 patient experiences for a special issue in Social Science and Medicine: Qualitative Research in Health. We base our presentation on data that we collected from 21 semi-structured interviews with DI researchers from each project and the UK, Brazil, Japan, Germany, Spain, Australia, Canada, and USA teams.

Through our data, we explore the advantages and challenges of qualitative cross-country comparative research, as well as our interviewee’s experiences of working in international and interdisciplinary teams for the project. Significant points that we discuss surround Anglo-centrism, working across disciplines, data translation, analysis, and ‘burdens’.

The presentation concludes by proposing some recommendations for future qualitative cross-country comparative research endeavours. We make such recommendations to encourage more qualitative research in the cross-country comparative landscape which is largely dominated by quantitative research. We emphasise the potential of qualitative cross-country comparative research to significantly develop medical sociology and the social sciences generally, along with our understanding of complex, potentially global, phenomena such as peoples' experiences of a pandemic.