Unpacking perceptions of risks of cervical cancer in the context of screening non-attendance

Aasbø, Gunvor, Solbraekke, K. N.
(Department of Research, Cancer Registry of Norway / Institute of Health and Society, University of Oslo)

In mainstream public health theory and praxis, citizens’ ability to comply to healthy and preventative behaviour is often interpreted to be a question of knowledge. However, knowledge is complex, including a blend of scientific knowledge, cultural attitudes, individual convictions and ignorance, in addition to personal uncertainties. Thus, in the context of cervical screening attendance, social constructions of risks may enhance understandings of rationalities towards screening (non)attendance. In this study, we address the research question: How do women late for cervical cancer screening reflect on risks of cervical cancer?

Nine focus group interviews (FGI) were completed with women who had not attended screening for four years or more. We recruited the participants through the Cancer Registry of Norway.

In the discussions, existential uncertainties were salient aspects of their attitudes towards information about cancer. The participants articulated generalised understandings of risks of acquiring cervical cancer, and it was typically understood as randomly acquired. Interestingly, more specific epidemiological knowledge presented in the FGIs generated new interpretations of risks of acquiring cervical cancer. Furthermore, the purpose of screening was understood as for diagnosing, prevention and data gathering purposes.

This study's findings interestingly points to how the uncertainties in epidemiology serve as point of departure for lay interpretations of risks for acquiring cervical cancer, and constructing understandings of personal and public responsibility for reducing such risks. In this study, we wish to discuss how understandings of risks and health promotion/behaviour are interpreted within a broader social and cultural framework beyond epidemiological ‘evidence’.

Disaster in America: The Perversion of Progress in Industrial and Regulatory Science of Arthritis Drug Treatment

Abraham, John
(King’s College London)

Since the 1960s, arthritis has been treated using (prescription) non-steroidal anti-inflammatory drugs (NSAIDs). A significant limitation of NSAID treatment is the adverse side effect of gastro-intestinal bleeding. An effective anti-arthritis drug that could safely treat patients without causing gastro-intestinal bleeding would, therefore, present real therapeutic progress with a huge market. From the 1990s, the medical, scientific, and commercial worlds sought to meet this challenge by developing a new class of arthritis drugs, known as cox-2 inhibitors. Drawing conceptually on the field of realist controversy studies plus years of empirical investigation involving stakeholder interviews combined with documentary analysis of scientific literature and industry/government files released via freedom of information requests and litigation, this paper examines how promising medical progress led to the production, regulatory approval, and marketing of the biggest single prescription drug disaster in US history. Conservative estimates are that rofecoxib, the first cox-2 inhibitor approved for marketing in the UK, and the second in the US, caused at least 60,000 premature strokes and heart attacks (many fatal) in the US alone. The paper explains how such a drug disaster could have come about in a context of substantial increases in scientific knowledge and government regulatory capacities relative to other notorious past drug disasters, such as thalidomide, practolol, and benoxaprofen. It demonstrates the power of commercial interests, corporate bias and promissory science to compromise potential for pharmaceutical progress in the interests of public health, and hence the vital role of sociological/political understanding to inform countervailing public-health-progressive pharmaceutical policy.

Transition to early parenthood after successful IVF: the effects of infertility and IVF on previously infertile couples' experiences of early parenthood.

Allan, Helen, Mounce, G., Culley, L., van den Akker, O., Hudson, R.
(Middlesex University)
Research on previously infertile parents' transition to parenthood after successful in vitro fertilisation (IVF) is underexplored. We draw on findings from qualitative joint interviews with 16 non-donor IVF couples who were first-time parents of singleton children. We identify three themes which shape this transition: preparing for parenthood, becoming a parent, and considering a sibling. These themes conceptualise the transition to early parenthood for infertile parents after successful IVF as a time where couples continue to be affected by their infertility. We discuss how non-donor IVF couples' describe their identity as parents following the losses and grief of infertility and the stresses of assisted conception. We present findings illustrating their emerging family relationships following parenthood which challenge the normative, naturalised view of non-donor IVF parenthood. Our findings suggest that the transition to parenthood for these couples is not straightforward as the effects of infertility continue to shape their transition to parenthood.

Thursday 12 September 2019 at 09:35 - 10:05
Gender
PT007

Are we so different after all? About women, men and health.

Anderssen, Jorid
(UiT The Arctic University of Norway)

Medicalization is often understood as a process where a growing number of human problems are defined and treated as medical problems. Medicalization is frequently related to the modern health consumption, including women's use of health services. Studies has shown that women and men differ both in use and demand for health services. This paper discuss changes in women and men's attitude to health in their everyday life. The paper is based on data from four separate fieldworks over a 35-year period in a small coastal community in Norway. During this period, there has been tremendous changes, both in use of health services and what kind of health problems people are concerned about. Prevention and risk are gradually becoming a part of people's health concerns. Health issues is primarily a part of women's responsibility in the family. Women try to do their best, and health is prioritized in everyday life, i.e. in their relationship to preventive medical controls, food choices and body weight. During the study period, men have become more involved in health issues in the family. They oppose women's understanding of what is best for the family members, and they challenge women's understanding of health. They also challenge women's understanding of how to achieve a good health. Based on the data obtained in the study, the paper discuss the different positions of women and men in health matters. Is medicalization a suitable description of women's relationship to health problems? How do men contribute to demedicalization of everyday life?

Thursday 12 September 2019 at 15:10 - 15:40
Lifecourse
PT007

Promoting ageing in the community: a framework for an integrated approach

André, Mário
(Santa Casa da Misericórdia de Lisboa)

Socio-demographic dynamics of Western societies, as well the multiplicity and interdependence of factors related with Longevity & Ageing in the community context, call us to explore integrated methodologies that try to overcome traditional disciplinary and sectorial silos, and develop integrated policies based on a life-cycle perspective. In this sense, based on socio-ecological paradigms of aging and the principles of collaborative, inter-sectorial and inter-disciplinary strategies, we sought to create an integrated governance framework — as a sustainable process of co-construction, development and maintenance of inter-organizational relationships that ensure the management of integrated collaborative processes to approach the key-dimensions of community ageing promotion — that aim to became a methodological tool to develop inclusive communities where everyone, particularly older people, could live, as long as possible, in their familiar environment, near their informal and formal social support networks, in order to avoid or delay institutionalization.

The construction process of this framework resulted from an in-depth theoretical analysis, as well as a set of empirical dynamics and methods of gathering information among privileged actors (Workshops, group dynamics, World coffee, interviews, conferences, videoconferences, panels of experts, dynamics with the participation of older people...) carried out over the last four years in a Portuguese civil society initiative, the Forum for Integrated Governance, (http://www.forumgovernacaointegrada.pt/).

Thursday 12 September 2019 at 10:45 - 11:15
STS
PL005

Interspecies entanglement in clinical end of life care

Ashall, Vanessa, Latimer, J., Johnson, M.
This paper describes how the concept of interspecies entanglement is being applied to the development of a new stream of interdisciplinary health research on end of life care. Post-human approaches in social science are destabilising traditional barriers between humans and non-human animals through acknowledging complex interspecies relationships within contemporary society. ‘Interspecies entanglement’ has recently been described within sociological studies of biomedicine and healthcare; illuminating how scientific advancement and the increasing significance of pets within families are creating new spaces for the study of health. Previous research has used the veterinary treatment of pets as an empirical space from which to access unique accounts of experiences related to the medical treatment of humans.

The current study utilises the disparities and growing similarities between veterinary and medical healthcare approaches to create a unique and novel environment for end of life care research. The paper discusses the outcomes of three events designed to support the future development of this novel research stream: first, healthcare professionals from the medical and veterinary settings shared their experiences of ‘interspecies entanglement’ during end of life care; second, an academic networking and workshop event explored how such interspecies entanglements offer opportunities to connect existing streams of research and create new interdisciplinary spaces; finally, policy influencers and regulators were invited to comment on how an interspecies approach might bring new perspectives to pressing policy discussions.

This ‘work in progress’ presentation offers a first glance at the foundations of an exciting new direction in end of life care research.

Wednesday 11 September 2019 at 16:20 - 16:50
CAMS
PL002

Community of Us: Cancer patients’ motivations for using Traditional Healers (THs) in Ghana: a constructivist Grounded Theory approach.

Badu Appiah, Isaac, Arber, A., Marcu, A.
(University Of Surrey)

Background: Traditional Herbal Medicine is embedded in the socio-cultural traditions of most Ghanaian communities, with about 70-80% of the population using it alone or in parallel with conventional medicine.

Aim/Objective: To explore the motivations for, and experiences of, using Traditional Healers among cancer patients in Ghana.

Methods: Semi-structured interviews with cancer patients, aged 25-76 years (n=35) and field observations of participants interactions with staffs in participating hospitals and traditional herbal clinics. The audio recorded interviews were analysed using constant comparison.

Results: Emerged categories include: TRUSTING IDENTITIES (Tradition, language, familiarity, Reputation, Compassion) CONVIVIALITY of setting, AVOIDING DISTRESS, WHITENESS: distrust with doctors. The findings identify trust as the basis of the participants’ relationships with THs. Trusting identities and relationships motivated participants and influenced their socio-cultural dynamics of interactions and experiences of conviviality and emotional management in using the THs services. Contrary, Whiteness (European) as revealed in the behaviour of the hospital doctors was experienced as a foreign adulteration to the community of Us (the shared social-cultural dynamic with THs) and signified a lack of trust in doctors. The power imbalance, socio-economic inequalities and the cultural divide between participants and conventional doctors meant that the medical staff were not part of the ‘community of us’ due to their perceived lack of attention to socio-cultural norms and expectations.

Conclusions

This study provides evidence that the motivations of cancer patients to use traditional healers in Ghana is more profound than mere socio-economic factors that most previous studies have identified.

Thursday 12 September 2019 at 10:45 - 11:15
Methods
PT111

Qualitative longitudinal analysis of stigma trajectories in stories of undergoing bariatric surgery and living with bariatric bodies

Berg, Anita
(Nord University)

Qualitative longitudinal research (QLR) is an evolving methodology and has become increasingly popular to understand lived experience of health and illness. The method is described as particularly useful to provide a more nuanced insight in social phenomena, as in this case the experience of stigma and change over time.

This paper discusses the use of QLR to analysing stigma trajectories in stories of being obese, undergoing bariatric surgery and living with bariatric bodies. The discussion will draw upon my empirical material based on four in-depth follow up interviews with seven persons 8 years after bariatric surgery.
First I will give a brief overview of QLR as well as previous studies on stigma trajectories. Then I will share my reflections on researcher reflexivity and on coping with time and texture in QLR based on my own study of stigma trajectories.

Friday 13 September 2019 at 11:55 - 12:25
Theory
PL005

The concept of communication in medical sociology and STS: for a communicative approach to biomedicine

Bicudo, Edison
(University of Sussex)

Medical sociology and STS have been dominated by theories emphasizing conflicts and hierarchies. The actor-network theory proposes to open the black boxes of socio-technical systems, revealing the disputed nature of science. The Bourdieusian approach analyses the differential ownership of various types of capital in the biomedical field. The Foucaultian approach depicts the micro-politics of science through which identities are created while being controlled.

The communicative approach, proposed by various authors since the 1980s, has deserved little attention in medical sociology and STS. Yet it could shed light on different aspects of biomedicine. Drawing on authors such as Schutz, Wittgenstein, Dummet, Habermas, Chomsky, and others, this presentation briefly describes how medical sociology and STS could be revitalized by the communicative approach.

Such approach can enrich the description of political life. It shows that the exercise of control and power have to do not only with deception, oppression, and control, but also with negotiation and convencement. Due to its links to critical theory, the communicative approach offers interpretive resources to identify political alternatives in contemporary biomedicine. Frequently, the confrontation of a merchant and neoliberal organization of biomedicine is carried out by communities whose coherence is guaranteed by ideological and communicative bounds.

On the empirical side, this presentation draws on lessons from projects I have joined over the last fifteen years, focusing on topics such as pharmaceuticals, clinical trials, bioinformatics, neuroimaging software, bioprinting, and others. On the theoretical side, I draw on an ongoing review of communicative approaches proposed by various authors.

Friday 13 September 2019 at 10:10 - 10:40
Life course
PT006

Ageing with type 2 diabetes.

A Mediterranean-style Diet as ‘secular’ discipline and medicine for a chronic illness.

Bimbi, Franca
(University of Padua)

A group of Italian old women, suffering for a chronic disease - type 2 diabetes- are engaged in the self-management of their own diets developing diverse personal interpretations of the medical Mediterranean Diet. A severe modification of their feeding style entails daily responsibility for an ‘illness work’ that involves body and emotions. The paper presents the A.’s account about her auto-ethnographic path together with a group of six women, and some considerations on critical aspects of social constructions and myths of medical narratives relating to the Mediterranean-style diet (s). Using MD Pyramids as vignettes the group shares experiences, memories and intergenerational expertise, recognizing in their biographies traces of the ‘cultural transplantation’ which reverberate from the poor cuisines of the past to today’s medical prescriptions and eating styles, redefining practices, taste and cultures. Ethnography, and auto-ethnography, highlights the reconstructions of biographical illusion of healthy life in which strategies for an appropriate eating and a tailored diet are confronted with risks and discontinuities produced by the chronic illness. The two parts of this ongoing research highlight problems encountered in transplanting an apparently similar cultural capital of yesterday’s Italian regional cuisines to today's medical discourses on MD suggesting healthy food and ‘appropriate’ tastes for urban middle classes.

Thursday 12 September 2019 at 10:10 - 10:40
Critical Public Health
PL002

Obesity and social practice: reconceptualising the obesogenic environment

Blue, Stanley, Shove, E.
(Lancaster University)

Nearly two-thirds of adults (63%) in England were classed as being overweight or obese in 2015. By 2050, obesity is predicted to affect 60% of men, 50% of women, and 25% of children in the UK. Arguments about the social determinants of health have informed public health interventions targeted at the obesogenic environment, or what has more recently been called the food environment.
This signals a recognition that patterns of diet and exercise are embedded in systems of provision and in the social and material organisation of everyday life. In this paper we take this insight further, drawing on social theories of practice to conceptualise trends in obesity as outcomes of collective changes in specific practices (shopping, eating, exercise), and as consequences of how different practices connect and combine. This prompts us to consider conjunctions and emergent trends in bundles and complexes of social practice and in the material arrangements and timespaces involved. This approach generates new ways of thinking about established concepts like the 'social determinants' of public health. It also points towards new sites and forms of intervention – moving beyond the obesogenic environment in order to address the fundamental dynamics and interactions of social practice.

Wednesday 11 September 2019 at 14:35 - 15:05
Experiences of Health and Illness
PT007

Women’s experiences of early medical abortion at home

*Boydell, Nicola, Ancian J., Harden, J.*
(University of Edinburgh)

Medical abortions account for the vast majority of terminations currently performed in Scotland. Self-administration of the ‘abortion pill’ (Misoprostol) for early medical abortion at home (EMAH), when clinically appropriate, has been available to women across NHS Lothian since December 2017. It is expected that EMAH with self-administration of Misoprostol will increase access to early abortion for women, and reduce some of the stress associated with the event.

Our qualitative research, based on in-depth interviews with 20 women, investigates their reasons for choosing to access EMAH and their experiences of both self-administration of Misoprostol, and of passing the pregnancy at home. Drawing on the concept of ‘therapeutic landscapes’ (Gesler 1992) this paper explores women’s experiences of undergoing EMAH, in particular how they manage ‘intimate’ and often acute pain in the space of the home.

We focus on women's articulation of issues around privacy, de-medicalisation and 'empowerment', and attend to the ways in which they construct the 'home' as potentially therapeutic space for abortion. Preliminary analysis suggests that EMAH is perceived by women as bringing comfort and control, helping them to cope with a potentially disruptive event. Women's accounts suggest that they engage in different forms of 'preparation' within the space of the home, as they anticipate passing the pregnancy. They also indicate that one of the benefits expected with EMAH is enhanced privacy, which can mitigate exposure to other's judgments. This serves to emphasise the ways that abortion remains stigmatised, despite efforts to normalise the practice as reproductive healthcare.

Thursday 12 September 2019 at 14:35 - 15:05
Lifecourse
PX001

Using stories to connect and exclude: older adult veterans and loneliness

*Brewster, Liz*  
(University of Lancaster)

There is evidence that as veterans age, they experience declining levels of well-being. In particular the effects of loneliness, including the impacts on cognitive and physiological functioning, have been widely reported. This paper reports findings from a qualitative study working with older adult UK veterans (born before 1 January 1950) which investigated how stories of military service were told, what telling these stories did for veterans and how these stories were used. By considering military narratives told by veterans, we identify how these stories could mitigate against loneliness, but could also help to exacerbate it and isolate veterans from civilians. We used a semi-structured life-world interviewing approach to interview fifty veterans; analysis was conducted using a data-driven constant comparison approach. This paper highlights how loneliness and isolation affected older adult veterans and how they drew on fictive kinship in response. Using narratives of military experience to connect, both in the telling of a story and by having an audience for the story, was vital to overcoming loneliness. Veterans were able to access each other as a resource for listening and sharing. However, it was also exclusionary: civilians could not understand, and so could not be used as a resource.

Mental Health
PT006

When a test is more than just a test: findings from a qualitative study exploring people’s experiences of a technology to detect antidepressant medication response

*Brown, Susan, Ploeger, C., Petersen, J., Morriss, R.*  
(University of Nottingham)
Experiences of power in Mental Health Act assessments

Buckland, Rosie
(University of Bath)

Mental Health assessments have been rising year on year since 2010, giving rise to concerns about the potential overuse of the Mental Health Act. People's experiences of detention are often traumatic and serve also to reduce trust in mental health services. At the same time, mental health services are now steeped in a rhetoric of service user empowerment and recovery, giving rise to significant tensions and contradictions. This paper explores how Mental Health Act assessments, where detention in hospital under the Mental Health Act or 'Sectioning' is considered, function as a battleground for power. It briefly charts the origins of and changes to the Act over time, including the recently published Independent Review of the MHA – what is it that people want the Act to do, who do they want to have legal powers under it and where is it that people feel uncomfortable about the use of the Act? It then draws on the early stages of analysis of data collected from participants within 5 recent Mental Health Act assessments across 2 local authorities, including with the person assessed, relatives, the assessing team and other professionals. I have undertaken interviews with participants and used documents written at the time of the assessment, with a view to charting narratives and discourses of power within them. Participants have described the events of the assessment and their impacts in very different ways and I begin to explore how this might help understandings of power relations within Mental Health Act assessment contexts.
Embodiment

Visibility, passing and recognition: emplaced and embodied identities in the cystic fibrosis clinic

Buse, Christina, Nik Brown, Nettleton, S., Martin D., Lewis, A. (University of York)

The identities and experiences of people living with cystic fibrosis (CF) have been explored in relation to biographical disruption and continuity, stigma and disclosure (Lowton and Gabe 2006, Nowakowski and Sumerau 2019). By following patient pathways through hospital buildings, we examine how encounters with the built environment are entangled with bodily dys-appearance (Leder 1990), and dynamics of recognition, passing and visibility (Goffman 1963, 1969). These processes are examined drawing on data from Pathways, Practices and Architectures (PARC), an AHRC funded study comparing three CF clinics, using visual and ethnographic methods. Patients describe CF as a condition that is not visible, making it easy to ‘pass’ in public spaces and difficult to recognise others with the condition. However, interactional ‘moments’ and aspects of the building prompted an awareness of bodily impairment and sense of visibility. Experiences of visibility and stigma were triggered by movements across thresholds of public and private, front stage and back stage spaces during patient journeys. Patients developed strategies of recognising others with CF, applying ‘ways of knowing’ and ‘ways of seeing’ that draw on tacit knowledge and embodied experiences. These dynamics are situated in a context where people with CF are segregated from one another to prevent cross infection, and the ability to identify and avoid others with CF is vital to keeping ‘safe’.

Healthcare Organisation

Resources, Relationships, and Roles: The Social Organisation of Medical Work Environments

Byrne, John Paul (Royal College of Physicians of Ireland (RCPI))

Ireland faces a health workforce crisis marked by low workplace well-being and high rates of doctor emigration to the UK, Canada, and Australia. Recent studies have framed these discussions in terms of consequences for individual doctors or national health workforces. However, to address these high rates of emigration and work-strain, we need to better understand the factors and dynamics which shape doctors’ experience of the medical work environment. The paper draws on 51 semi-structured interviews with doctors who had previously worked in Ireland and are now working in Australia, to show how the social organisation of medical work environments (relational hierarchies, staffing, and governance) shapes the practices and cultures experienced by hospital doctors. Providing a sociological account of medical work in different national settings, we present a framework which identifies the key components which socially organise medical work environments and illustrates how these features permeate medical practices and cultures via the resources, relationships, and role demands which constitute doctors’ everyday experience of work. The social organisation of the hospital has implications for the well-being of both doctors and patients.

Gender

‘If You Can Change Your Body… You Can Change Your Situation’: Beefing-up, Slimming-down and the somatic self of Japanese men

Castro-Vazquez, Genaro (Kansai Gaidai University)

This paper presents data from an on-going research project on bodyweight control in contemporary Japan. Government statistics elicit the masculinisation of obesity, which has increased about 30 per cent among men aged between 40 and 60. Based on a set of two, semi-structured, individual interviews with 21 Japanese men aged between 25 and 57, from Tokyo and Osaka, this paper explores the rationale underneath their eating habits and engagement in physical exercise. Ten and eleven of the men identified themselves as ‘beefy (maccho)’ and ‘slim-muscular man (hosomaccho)’, respectively. The analysis of interview is grounded in symbolic interactionism and the construct of the somatic self—an individual thinking about, verbalising and making sense of lived embodying experiences that are socio-culturally and historically localised. ‘Biopedagogy’ (Harwood 2009), gender and emotion are three axes to grasp the participants’ embodied experiences. Biopedagogy is underpinned by the consumption of dietary supplements, the concepts of Body Fat Index and ‘healthism’ (Crawford 1980), as well as the understanding that dieting+exercise=bodyweight control. The men champion the understanding of ‘full-fledge man’ to convey a form of hegemonic masculinity underpinned by the notions of perseverance and mulishness, to help the mind have the body under control, which tends to enlarge social inequality and discrimination that an obese/overweight self endures. Embodied emotionality for these men could be referred to by the construct of the ‘male looking glass body’ which mostly entails homosocial synergy at a ‘bodybuilding habitus’ (Monaghan 2001).
Paper Abstracts

Reducing harmful drinking through a football club health initiative: offering social alternatives as a public health prevention strategy

Catterall, Emma, Larsen, J. A., Parvez, H. (Drinkaware)

Background: Alcohol consumption globally represents the fifth largest single cause of premature mortality, loss of health and disability. In the UK, rates of alcohol-related deaths remain higher than 20 years ago, and two-thirds of these are men. The 45-64 age group contains a quarter of the population but accounts for half of all alcohol-related deaths. Midlife men regularly drinking over the low risk drinking guidelines rarely recognise a need to cut down – typically 'othering' the 'problem drinker'. Innovative ways of positively engaging men in health interventions are needed. Since 2017, the charity Drinkaware has partnered with Derby County FC to deliver alcohol education through their 12-month health programme.

Method: Data was routinely collected using a harmful drinking assessment tool (AUDIT-C) at the beginning of the programme and at follow-up every 3 months. Encouraged by the extremely positive results, observations and qualitative interviews are being carried out with programme participants and programme leaders during spring/summer 2019.

Results and discussion: At the end of 2018, the health programme counted 119 participants, of which 91 joined the programme in January or February 2018. Results for these 91 participants show a clear decrease in the number of participants drinking at increasing risk levels or above from 50 (55%) at the start to only 2 (2%) at the end of the 12-month programme. Based on observations and in-depth interviews (currently ongoing), the experiences and reasons behind these results will be presented at the conference. Further potential for such alternative public health initiatives are discussed.

'Liquid life': stem cell transplants, temporality of cure and the politics of health in India

Chattoo, Sangeeta (University of York)

This paper analyses the social and ethical implications for a notion of (parental) care posed by the simultaneous framing of inherited blood disorders, within medicine and global public health policy, as both incurable and curable. Using data from a multi-sited ethnographic study of thalassaemia in India, the notion of therapeutic milieu is used to analyse how parents navigate risk and temporality of a life-saving and life-limiting regime of blood transfusions and chelation, and novel but life-threatening treatments such as stem cell transplants promising cure. A focus on families with minimal resources, against a backdrop of huge disparities in income and access to healthcare (within and between public and private sectors as well as urban and rural areas across India) poses a more serious and wider question for discussion. Hence, the paper concludes by asking: In what ways might state subsidy for expensive curative transplants (for a few) aimed at addressing such inequalities paradoxically, inscribe new (?) forms of inequities through bureaucratic norms about whose life is worth saving and who can be cured? Contrary to popular wisdom, such political/policy interventions seem less driven by a simple logic of neoliberal economy, going against the grain of the logic of more pervasive, ongoing policies aimed at prevention (carrier screening and terminations); echoing different histories of the disease linked to practices and ‘politics of life itself’.

Frailty as a biographical disruption

Cluley, Victoria, Martin, G., Radnor, Z. (City, University of London)

First conceptualised by Bury (1982), biographical disruption positions chronic illness as a major life disruption in which changes to body, self and resources occur. Since its conceptualisation, biographical disruption has been used widely in medical sociology to make sense of the experience of chronic illness. It has also been critiqued, expanded and rejected by numerous scholars. In this paper we argue that based on the developments of others, particularly Engman (2019) who refocuses biographical disruption’s modernist origins to include an embodied perspective, biographical disruption can also be used to make sense of other disruptive health related experiences across a life course and is particularly useful for making sense of the ageing process. To do this we draw on the findings of 30 situated interviews with frail older people, relating their experiences of frailty to the concept of biographical disruption. We show that while frailty is not considered an illness, it is a chronic and health related life-course disruption that shares many similarities with the experience of chronic illness. We conclude that frailty is often experienced as a disruptive life event that is very much entwined with issues of stigma, identity and self.
Exploring Stigma in the Mental Health Narratives of Autistic Young Adults
Coleman-Fountain, Edmund
(Northumbria University)

Recent social science scholarship on autism has sought to provide space in the broader field of autism research for a focus on relationality, power and inequality. This includes exploring the ways that autistic people experience social interactions, and how representations of autism shape everyday encounters. There is, in particular, growing evidence of how social interaction norms and negative representations create marginalization, societal othering, and inequalities for autistic people. Within this, there is an emerging understanding of the relationship that these experiences have to health inequalities in autism, including around mental health. Drawing on autistic young adults' mental health narratives, this paper will examine how the stigmatisation of differences related to autism shaped how the autistic young adults' reported issues of self and self-esteem. It draws on an NIHR funded study for which 19 autistic young adults aged 23 to 24 took part in in-depth qualitative interviews on managing their mental health. This paper will make deeper connections between autism research and sociology by exploring what Plummer refers to as intimate inequalities. By focusing on stratified relations of deference and disrespect as a feature of autistic people’s everyday lives, the paper will explore a sociological framing of autistic people's experiences of mental health problems.

Silos, visualised: The Tribes and Territories of Health Equity Research
Collyer, Taya
(University of Edinburgh)

Health Inequalities and Disparities Research (HIDR) is a rare example of a domain where social and natural scientists from multiple disciplines address similar scientific questions. While it is frequently asserted that public health is a multidisciplinary field, no study has systematically documented the blend of disciplines contributing to a public health specialism, and theories from SSK and STS which might illuminate the impact of disciplinary training on research about health have been scarcely applied.

I present early findings from my PhD project, which - using HIDR as a case study - aims to document disciplinary diversity and flesh out theoretical understandings of the ways in which researchers' training impacts the design, conduct and interpretation of research about health. Via bibliometric analysis (n= 29,212 papers) the field is mapped and eight discrete 'communities' detected. Disciplinary diversity is not uniform between communities, or across the field.

Qualitative interviews (n=43) with members of these communities suggests deep unity and disunity across disciplinary boundaries. Researchers express contrasting beliefs about the state of HIDR and science generally, which appear to stem from their original trainings. Tensions anticipated by the STS and SSK literatures are also evident in these data.

This research i) contributes to understandings of factors producing and sustaining academic ‘silos’ within public health ii) acts as a resource for HIDR researchers and funders wishing to diversify or expand their networks, and iii) empirically extends theoretical work asserting the powerful, enduring influence of scientific training.

Using creative writing as a method in medical sociology: Reflections from the field
Cooper, Harriet
(University of East Anglia)

In my qualitative research which seeks to characterise 'rights-based rehabilitation' from the perspective of service users with long-term physical or sensory impairments, the question of how to represent disabled people's voices is fundamental. As a social researcher with a doctorate in the humanities and an interest in life-writing, I wanted to see whether the use of creative writing as a data collection activity could both foreground the voices of the individuals who took part, and highlight something about rehabilitation experience that is not easily accessible via other qualitative methods. Could the creative writing process itself produce new insights for participants? Some researchers argue that the opportunity to write (instead of, for example, responding orally to interview questions) liberates participants from anxiously focussing on producing a 'truthful' account, allowing the meaning of an experience to emerge (see Leavy 2009; Barone and Eisner, 2012). Yet there are also questions about how to analyse the data that emerges via participants' writing.

This paper will explain how I approached these issues in my study, Rights-based Rehabilitation. The project has involved both conventional qualitative methods (semi-structured interviews and focus groups) and a creative writing group. This writing group
Paper Abstracts

included an exploratory workshop with structured writing tasks, and also a follow-up discussion meeting which was audio-recorded. Drawing on the transcripts and on my own reflective writing about the process, this paper will consider the productive possibilities of creative writing as a tool for exploring participants’ lived experiences, as well as the methodological challenges associated with it.

Wednesday 11 September 2019 at 14:35 - 15:05
Ethics
James Hall

Making ethics (at) work: Understanding the practice of organ donation after circulatory death in the UK

Cooper, Jessie
(City, University of London)

Over the last 50 years, the global demand for transplantable organs has led to diverse measures to increase supplies of these resources. One such effort has involved reviving controlled organ Donation after Circulatory Death (DCD). In the UK, DCD was reintroduced in 2008 and now makes up 39% of all deceased organ donation. Yet, despite contributing to increased donor rates, the resurgence of DCD has become the focus of bioethical controversy, since it necessitates intervening in the care of dying patients to obtain quality donor organs. Transplant policy responses to these concerns have generated legal and ethical guidelines to address uncertainties around DCD, producing claims that the UK has ‘overcome’ its ethical challenge. In contrast, using data from an ethnographic study on health professionals’ experiences of DCD, I argue that ethics in DCD go beyond abstract directives for practice and, instead, are composed and dealt with as a practical-organisational problem. To do this, I show how ethics get (re)constructed and negotiated in the course of everyday practices involved in DCD, to encompass concerns around: dignified dying, the welfare of potential donor families, organisational resourcing, and tensions between the role of caring for patients and for potential donors. In so doing, I argue for the expansion of ethics in DCD, and for acknowledgement of the work done by health professionals to ensure the process is acceptable, not only for potential donors and their families, but also for their own role in caring for patients at the end of life.

Professions
PT111

Pestle and Mortal: Re-professionalisation and the Death of Community Pharmacy in the UK

Cooper, Richard
(University of Sheffield)

Community pharmacy has been an easy target of negative sociological scrutiny over the years. Often linked to its commercial base, it has been considered an incomplete profession, without sufficient transformative control over its social object, the medicine, and threatened, like many occupations, from technological advances and de-professionalisation. However, its perceived ease of access and public visibility, has made it an enduring - if ultimately unsuccessful - focus of policy initiatives over the past half century. This paper builds on previous sociological insights and argues that these remain prescient and the future of UK community pharmacy is a bleak one. Proposals to re-professionalise community pharmacy encroach on existing health and public health roles that other health professionals already undertake; these are, however, more a desperate bid for survival, than a credible bid to challenge medical dominance. Such re-professionalisation also has spatial and clinical implications which move the community pharmacy role away from its defining place, into suggested medical practice sites and clinic-based activities, that existing ‘clinical pharmacist’ roles already occupy. The increasing corporatisation of UK community pharmacy, with post-Fordian mass dispensing processes reduces the need for patients to visit community pharmacies. Finally, new roles linked to medication reviews and adherence and health promotion interventions may be considered negatively as forms of surveillance and resisted. Community pharmacy now arguably represents a professional palimpsest, effaced with new roles that all but remove what is previously was.

Wednesday 11 September 2019 at 16:20 - 16:50
LifeCourse
PT007

Re-thinking egg donation in Europe: expanding practice, extending boundaries.
Coveney, Catherine, Hudson, N., Herbrand, C., Provoost, V., LaFuente, S., Weis, C., Pavone, V.
(Loughborough University)

The expansion of the use of donor eggs in fertility treatment has been exponential. Whilst the majority of egg donation historically took place in the US, donor eggs are used in over 56, 000 cycles of fertility treatment per year in Europe and a number of European egg donation ‘hubs’ have emerged, for example in Spain and Cyprus. Growth in the use of donor eggs in part reflects a changing profile amongst users of assisted reproductive technologies, including growing numbers of older women, male same sex couples, and those at risk from genetic conditions. An increasing number of egg donor ‘intermediaries’ such as egg banks and agencies have
also emerged in the European context, reflecting a general shift towards an increasingly commercialised landscape around fertility treatment provision. Despite these changes, few studies have specifically considered their implications.

Drawing on an ESRC-funded study on the economic, political and moral configuration of egg donation in the UK, Spain and Belgium, we suggest that changes in the ways egg donation is provided in the European context are worthy of increased attention. Data from policy mapping and interviews with policy stakeholders and professionals illustrate significant shifts in professional and commercial practice. These changes are reshaping the intersubjective, political and social boundaries involved in egg donation in novel and complex ways. We suggest that the expansion and diversification of its use has implications for the policy and regulation of egg donation the European context.

Thursday 12 September 2019 at 11:20 - 11:50
Critical Public Health
PL002

Avoiding patients' health concerns in preventative healthcare: Findings from ethnographic analysis of NHS Health Checks in general practice

Cupit, Caroline, Armstrong, N., Martin, G.
(University of Leicester)

Over recent years, general practice policymaking in England has increasingly focused on preventative care, and the problem of ‘engaging’ or ‘motivating’ patients to make changes to unhealthy behaviours. This paper is based on observations of NHS Health Checks supported by interviews with healthcare professionals and patients, conducted as part of an institutional ethnography (Smith 2005) of cardiovascular disease prevention in general practice. Using institutional ethnography's theoretical approach to analysing people's ‘work’, I highlight what happened during Health Checks. I show that, as healthcare professionals worked through the Health Check's electronic template, they both 'opened up' patients' lives and lifestyles to scrutiny, whilst also placing strict limits on the support they were able to provide and using various techniques to avoid 'social issues'. They systematically inhibited meaningful discussion of the underlying issues surfaced by lifestyle questioning, whilst focusing on quickly and efficiently diagnosing and treating risk conditions. It was healthcare professionals (not patients) who appeared to ‘disengage'.

I highlight how healthcare professionals' preventative care work (including their apparent lack of interest in patients' own health concerns) is organised within the institutional structures of preventative healthcare. Economic models, orientated towards demonstrating measurable reductions in the burden of disease, determine the length of Health Check appointments, the competencies of staff who routinely deliver them, and the types of preventative work which should be included (and omitted).

Wednesday 11 September 2019 at 15:45 - 16:15
CAMS
PL002

Translation and negotiation of complementary and alternative medicine (CAM) in the European union

Danell, Jenny-Ann
(Umeå University)

This paper focus on how complementary and alternative medicine (CAM) is translated and negotiated politically. Although CAM treatments are widely used and has gained increased acceptance they are often considered unscientific, risky, and put in contrast to established medicine. The aim of this paper is to analyze how different actors (such as politicians, interest organizations, legislators) translate and negotiate CAM in two interrelated political contexts; the European commission and the European parliament. How are boundaries of CAM established? What are defined as political problems? What goals or solutions are offered? What is mobilized and enrolled? Empirically is this paper based on written documents from the EU commission and parliament, from the early 1990s to 2018. The documents are analyzed with an actor network approach. The preliminary results indicate that CAM is established negatively, often in terms of non-conventional medicine, but that the boundaries are unclear. In the EU commission there are three main translations of CAM, focusing on public health and health prevention, professional activities, and CAM as commodities. The last translation is dominating in the EU parliament. Some of the recurrent political problems focus on unfair competition, patient security, and lack of holistic perspectives in public health care. The translations includes, to varying extent, mobilization of widespread use of CAM, ideals on free markets and individual choices, evidence based medicine, and enrolment of named researchers, specific studies, and organizations such as WHO. However, the translations also indicate controversies on scientific and professional legitimacy, as well as substantial national differences.
Who is actually ‘hard to reach’? Becoming a response-able researcher with people who use drugs

Dennis, Fay
(Goldsmiths, University of London)

'Hard to reach' is an unfortunate term that is still used in some areas of medical sociology to describe populations or participants who cannot be recruited and studied through traditional means, often due to marginalization or stigma. But rather than challenging these forces, the term implies that there is something inherently unavailable, difficult or despondent about these research subjects and perhaps, even, in some way to blame. This presentation seeks to spin this concept on its head and ask: what if it is us who are hard to reach? And thus, how can we become more approach-able or relate-able? Drawing on Donna Haraway’s (extended by Karen Barad) concept of response-ability, perhaps it is us as researchers and our current methodologies that mean we cannot respond to these (participants’) different ways of being and knowing. I will present initial findings from my current research project with people who use drugs (a so-called hard to reach population) that has experimented with method as a way of becoming more response-able to modes of being with drugs that are otherwise excluded by powerful discourses of addiction. Through creative body-mapping workshops and ethnographic work at a theatre company, I attune to bodily, affective, relational, non-verbal and non-cognitive experiences of using drugs. I will explore how making ourselves available to different ways of being can challenge and put at risk our well-trodden research practices that privilege the individual, rational and verbal, and what new kinds of relationality, care and politics it might foster.

The gender wage gap in the nursing occupations- a cohort study

Dietrich, Hans
(Institute for Employment Research (IAB))

The gender wage gap in nursing occupations is well documented (Munch/Dietrich 2019). Less addressed is the question, which mechanisms contribute to the occurrence and persistence of the gender wage gap. This paper follows graduates from nursing training in Germany, who finished their education in 2006, till 2016. In this period the gender wage gap increased from an initial wage gap of 2% immediately after graduation to 12% in 2016. We employ register data from the social security system, which cover the whole employment career and deliver daily precise information on income. We test two mechanism. A first one is the mechanism of selection of nurses into different institutions (type of hospital, region, occupational specialty). A second one is mobility of nurses within the nursing occupation. A third one addresses exit options (e.g. to health management), which improves bargaining power of nurses. These mechanisms shape the gender specific distribution of wages. The paper presents empirical evidence and discusses possible theoretical explanations.

GPs acting as street level diplomats when supporting women with FGM in the context of recent English policy

Dixon, Sharon, Hinton, L., Griffiths, F., Ziebland, S.
(Nuffield Department of Primary Care Health Sciences, University of Oxford (1), Warwick Medical School, University of Warwick (2))

Problem: Female Genital Mutilation (FGM) is all procedures which intentionally harm or alter the female genitalia for non-medical reasons. In 2015, new reporting duties were introduced, applicable to GPs in England, including a mandatory reporting duty, and an FGM Enhanced Dataset. Our PPI work identified exploring potential impacts of these duties on trust in healthcare as a research priority.

Approach: Qualitative semi-structured interview study with GPs using a fictional scenario about managing FGM. We spoke to 17 GPs, from five cities, including those who saw FGM often, rarely or never.

Findings: Drawing on the concepts of street-level bureaucracy (Lipsky 2010) and street-level diplomacy (Gale 2017), we consider the tensions that GPs experience when caring for women with FGM, and the strategies they adopted to manage these. Consultations with women with FGM were experienced as complex, potentially stressful, and relatively unfamiliar. Challenges GPs identified included how to raise the topic of FGM, balancing caring for the woman with the needs of her family, coding FGM into GP records and managing their reporting requirements. These tensions can be understood in the context of Lipsky’s “essential paradox” where front-line practitioners must balance delivering policy requirements and individualised care. Strategies GPs identified to manage these tensions, included "diplomatic" skills to develop trusting relationships.
Consequences: Relationships with GPs are challenged by mandated reporting requirements, including for behaviours with the potential for harm. The tensions evident around FGM are likely to affect other areas of current and proposed mandated reporting, with consequences for trust in healthcare.

Thursday 12 September 2019 at 15:10 - 15:40
Methods
PT111

Public and private accounts of help-seeking: a challenge to our beliefs about research methods suited to the investigation of sensitive topics

Dobson, Christina, Russell, A., Brown, S., Rubin, G. (Newcastle University)

Drawing upon research into the symptomatic experiences and consultation behaviours of people with symptoms of cancer, we consider the role of two research methods in the presentation of people's accounts of help-seeking. This study found consistent discrepancies in the length of the patient interval (time from symptom onset to first consultation), as presented by participants in questionnaire and interview accounts. We initially expected the interviewees to present more socially acceptable accounts of 'early presentation', because of social deference, and for questionnaire respondents to report longer accounts of help-seeking, because of the security of anonymity afforded through the questionnaire. However, our data showed the opposite to be the case. We draw upon the concepts of 'public and private accounts' and 'frontstage and backstage performances' to explain these discrepant accounts and consider the implications of this finding for help-seeking research.

Thursday 12 September 2019 at 11:55 - 12:25
STS
PL005

Emergence, governance and ownership: shaping the experimental space of 3D bioprinting

Faulkner, Alex, Bicudo, E., Li, P. (University of Sussex)

The governance of emerging scientific and technological fields remains a perennial policy problem. Examples of 'regulatory lag' abound, countered by attempts at 'anticipatory regulation' and a growing interest in 'adaptive governance'. In this context, we outline recent and current developments in the field of 3D bioprinting – the use of 3D printers to engineer living tissues with potential therapeutic properties. We demonstrate the early emergence of the technology, investigating both the hardware of printers, software applications for the process, biomaterials developments, and the clinical applications envisaged. We contrast on the one hand ownership and value dynamics of commercialisation and standardisation, set against on the other hand inventive experimentation and open source licensing amongst the multidisciplinary research teams involving themselves in the field. We present anticipatory analysis of governance issues such as the interface of medical device and Advanced Therapy Medicinal Product regulatory regimes (in the EU/UK) and consider liability governance issues for healthcare systems and their actors. The paper draws on a range of ESRC and Leverhulme Trust projects and other research, basing the presentation on quantitative trend and content analysis of publications in international bibliographic databases, fieldwork interviews in research centres in Brazil and the UK in both entrepreneurial and academic institutional settings, and associated legal/regulatory analysis of this apparently emerging field.

Thursday 12 September 2019 at 11:55 - 12:25
Health Policy
PT103

The rise of system leadership discourse: the case of Health and Wellbeing Boards in UK public health

Finn, Rachael, Hunter, D., Visram, S., Perkins, N., Forrester, A., Adams, L., Gosling, J. (University of Sheffield)

Recent health policy discourse positions leadership as a panacea for addressing the complex challenges of health care organisation, its performative effects extending to an increasing proportion of staff as agents of policy within distributed, collective models (Martin and Learmonth, 2012; Martin et al, 2015). Building on these arguments, we examine the ascendance of system leadership within health policy discourse (Kings Fund, 2015), aligned with government agendas for system reconfiguration to overcome institutional fragmentation through emphasis on collective agency and identification with 'the health of the whole' (Senge et al, 2015). Moving beyond romanticised rhetoric to examine the realities of system leadership, we focus on Health and Wellbeing Boards (HWBs) - key element of public health reform (Health and Social Care Act, 2012) – as illuminative. Positioned as system leaders, HWBs are charged with integrated working across organisational boundaries to reducing health inequalities and improving population health. Drawing on in-depth qualitative interviews with members within four HWBs, our findings point to varied local negotiation and enactment of the system leadership role against a backdrop of austerity and wider, competing institutional mandates. These responses have different but ultimately limited effects on the salience of organisational interests, dominance of NHS agendas and associated medicalised
constructions of notions of 'public health'. We argue that without an associated shift in resource and alignment of wider policy to support HWBs, their role as system leaders is limited to a discursive appeal and their potential for transformative effects on population health not realised.

Thursday 12 September 2019 at 14:00 - 14:30
STS
PL005

‘Ingestible Event Markers’ and Relationships of Care in the Era of Digital Mental Health

Flore, Jacinthe
(RMIT University)

In November 2017, the Federal Drugs Administration in the United States approved Abilify MyCite (aripiprazole), the first pharmaceutical embedded with a digital ingestion tracking system, also known as an ‘Ingestible Event Marker’. Abilify MyCite marks a profound turn in digital mental health. In addition to the chemical compound swallowed as part of treatment for a mental illness diagnosis, the person now ingests a sensor, wears a patch, has access to an app on a smartphone, and has the option to connect supporters and health practitioners to an online website. Treatment, in other words, is part of an intricate network of chemicals, technology, apps, and non-human and human actors. It enacts a complex web of socio-material and socio-technical relations. The approval of the first ‘digital antipsychotic’ signals a new era of digital mental health which promises to change in unpredictable ways how we understand diagnosis, treatment, monitoring and recovery, as well as ideas of individual responsibility, subjectivity and indeed mental health itself. Using Abilify MyCite as a case study, this paper explores how digital technology can potentially transform relationships of care between psychiatrists and other mental health practitioners and mental health service users. Deploying a framework that draws from science and technology studies, the paper more broadly examines the questions raised by digital mental health, particularly in relation to technology, care and subjectivity. Dr Jacinthe Flore is a Vice-Chancellor's Postdoctoral Research Fellow at RMIT University, Melbourne, Australia. Her first monograph ‘A genealogy of sexuality in Western psychiatry’ is forthcoming with Palgrave Macmillan.

Thursday 12 September 2019 at 14:35 - 15:05
Theory
PL002

Health, class and matter: the materiality of health disparities

Fox, Nick
(University of Huddersfield)

The materialist thread within health sociology represented by authors including Peter Townsend, Vicente Navarro, Lesley Doyal suggested a powerful social class gradient on a range of health measures (Scambler, 2012). More recently, Bourdieu’s post-Weberian approach to social class has become prominent in sociology. He complemented the 'economic capital' of Marxist analysis with 'symbolic' capitals such as ‘social’ and ‘cultural’. This scholarship spawned studies such as the BBC Great British Class Survey (Savage et al, 2013), which generated inductively seven social classes defined by volumes and combinations of economic and symbolic capitals. However, studies that explore associations between such groupings and health inequalities paint a contradictory picture of the effects of symbolic capital upon health (Abel and Frolich, 2012; Christensen and Carpiano, 2014; Villalonga-Olive and Kawachi, 2017). In this paper I shall suggest that this emphasis upon symbolic capital has regrettably shifted attention away from the effects of materiality upon health. Rather than asserting a return to a historical materialist sociology of class, I argue for a new materialist re-focusing upon the interactions between humans and a very wide range of non-human matter, including the natural and built environment, workplaces, schools, hospitals and other institutions, public and private transport, consumer goods, animals, food and technologies. I will illustrate the impacts of non-human matter upon health in different class positionings. This analysis suggests that materiality rather than symbolic capitals are of greater significance in the production of both social class divisions and health disparities.

Friday 13 September 2019 at 10:10 - 10:40
STS
PL005

Users in the NHS

Fuzesi, Peter
(Lancaster University)

Since the early 2000's there have been increasingly loud voices calling for technologies specifically designed for elderly and disabled people. Underpinning these discourses, on the one hand, the image of accelerating technological change that often affords transformative power for technological artefacts. On the other, demographical changes and service provision for groups of elderly and disabled people are increasingly framed as an additional challenge for the welfare state. In a fantasy of a perfect fix, these discourses coalesce into the twin figures of health/care technologies and patient/users.
My presentation looks at a partial aspect of technology use, to trace how design, use and technological devices transform when they settle into practices in the National Health Service. I draw on ethnographic fieldwork material at a Specialised Assistive Technology Centre in the North of England to explore a number of design practices and services aimed at accommodating a wide range of differently abled users.

Following use and technologies highlight how implicit assumptions and expectations about users are unsettled and transform at these new contexts, and queries what relations held them in place at other sites. I focus on two types of displacements: first, those that concern the nondisabled individual subject, a figure that NHS patients are increasingly expected to inhabit in imagined public health futures. Second, I attend to the ways the figures of users and devices, initially rooted in imaginaries of acceleration, progress and markets, are to be re-imagined in contexts of public health provision and ongoing care.

Friday 13 September 2019 at 11:55 - 12:25
Experiences
PT006

‘Prep Is A Chemical Condom’: Narratives Of Pre-Exposure Prophylaxis For HIV Among Barebackers And Bugchasers

Garcia Iglesias, Jaime
(The University of Manchester)

PrEP, a daily drug regime which helps prevent HIV infection even if exposed to the virus, has caused a cultural groundswell in the gay community with its potential to prevent HIV and its problematic medicalization of the HIV-negative body (Dean 2015, Feliciantonio 2017). This paper looks at the impact of PrEP among barebackers, who fetishize unprotected sex, and bugchasers, who fetishize HIV infection. While PrEP has been conceptualized as an effective HIV-prevention tool by mainstream media and the ‘gay community’, little to no empirical work is available on how barebackers and bugchasers use PrEP and interact with the medical authorities providing it. Over the past year, I have conducted over fifteen in-depth interviews with barebackers bugchasers and analysed hundreds of online messages to explore how these men access, consume or reject PrEP. This paper sustains that barebackers’ and bugchasers’ perceptions of PrEP are fluid and varied: whereas some see it as a last-barrier against HIV infection, others consider it to be an obstacle for intimacy. Even more so, whereas current research focuses on the process of starting PrEP, participants in my research found abandoning PrEP to be a much more symbolic act, whereby they would be truly experiencing freedom from medicalized sex. Overall, this paper theorises these narratives and contextualises them within larger dynamics of sexual and public health, presenting alternative significations and challenging stable narratives of PrEP. In so doing, I open new avenues for research regarding PrEP and proposes points of action for future public health interventions.

Thursday 12 September 2019 at 10:10 - 10:40
Citizenship
PT006

‘….Definitely me against big brother’: Promoting collective critical reflection on public involvement as a 'knowledge space'.

Gibson, Andrew, Welsman, J.
(University of West England)

Increasingly, citizens are challenging scientific expertise relating to health. In the resulting interactions between scientific, professional and ‘lay’ knowledge, traditional boundaries of expertise blur and new ‘knowledge spaces’ are formed. These interactions are frequently fractious but, using the example of public involvement in health research as our example, we suggest that these knowledge spaces have the potential to provide a more holistic perspective on complex problems. Drawing on sociological theory we previously proposed a theoretical framework for analysing the nature of knowledge spaces. In this paper we apply the framework to an analysis of public involvement in health research agenda setting.

Traditionally, research agendas have been set by academics and only fairly recently has the importance of involving the public been recognised. The NIHR Peninsula CLAHRC has helped to pioneer involvement in research agenda setting. On two occasions, two years apart, the authors ran and subsequently evaluated public involvement in the research prioritisation process, using a participatory workshop, as described by Gibson et al., (2017). Our key findings were that: 1) improving the ‘quality’ of public involvement did not necessarily improve participants’ experience of the process 2) over the two years public contributors became more divergent in their views of their experience 3) participants appeared to become more aware of the forces influencing the setting of research agendas. We conclude that the workshops created an opportunity for public contributors and involvement practitioners to reflect on their work and question the boundaries of the knowledge space they operate within.
Paper Abstracts

Gibson, Barry, G, Lowery, M. Flinders, (University of Sheffield)
Public health has been criticised for acting as a new form of technocratic control (Porter, 2006). This paper seeks to examine such claims through a theoretically informed discussion of changes in the status of Public Health in England since 2010. The role of Public Health in England has been transformed to the extent that in some localities there is now an incipient ‘public health insurgency’ against the social determinants of health. Scientific knowledge is being mobilised within local decision making bodies for population health, with resulting implications for the relationship between public health, science and democracy. This paper will compare and contrast two case studies of public health policy formation (obesity in children and water fluoridation) within this new configuration. The paper asks if Luhmann's theory of social systems can help make sense of the emerging relationship between localised policy networks, science, politics and democracy. The paper explores the dynamics at work in the policy development process, suggesting that the location of public health in local politics may overcome the democratic deficit associated with public health in functionally differentiated societies. In such arrangements the efficiency of public administration can be tempered with interactions between elected officials in local governance networks and public health networks. The paper explores the degree to which such arrangements might be tested when universalist policies such as water fluoridation are pursued and suggests potential remedies to overcome resulting deficits.

Thursday 12 September 2019 at 09:35 - 10:05
Inequalities
PL001
Life form and health inequalities
Gjernes, Trude
(Nord university)
Finnmark county in northern Norway has been overrepresented with health problems for many years. Mortality and morbidity rates have been higher compared to the rest of Norway. Differences also exist within the county. In a Sami inland municipality women live longer than Norwegian women in general and in a coastal municipality with mostly Norwegian inhabitants, males live shorter than Norwegian men in general. Earlier research has indicated that the population in Finnmark had more and more serious health problems than the rest of the country because of their ways of living. They had more social problems, less healthy diets, smoked more, and exercised less. The population in Finnmark is now more similar to the rest of the population in the country with regard to risk behavior; nevertheless, the difference in health remains. In this paper we use a qualitative approach to explore inhabitants' involvement in construction and reconstruction of life forms and living conditions with a potential to affect their health conditions. We focus on to what degree the population are concerned about the differences in health, and what they do to change their situation. The study focuses on medically known risk factors, and on contextual and structural factors, such as material conditions, work conditions, cultural dispositions, and social integration that may cause or influence these inequalities. Data come from ethnographic fieldwork in three municipalities. The theoretical framework is influenced by pragmatist approaches. This is a work in progress.

Thursday 12 September 2019 at 09:00 - 09:30
Pharmaceuticals
PL006
Using Burden of Treatment Theory to explore the ‘medicines work’ of people with complex polypharmacy regimes
Grant, Aileen, MacLure K, Gallacher K, Dreischulte T, Mair A, Stewart D
(Robert Gordon University)
With an aging population there are increasing numbers of people self-managing multiple morbidities, their healthcare and complex medication regimes (polypharmacy). The more conditions a person has the more medications they are likely to be prescribed, medications can interact creating side-effects and more medications are then prescribed for those interactions resulting in increased 'medicines work'. The risk of medication-related problems increases with each drug prescribed and those with more conditions experience more treatment burden and lower quality of life. People with multiple morbidities receiving complex polypharmacy regimes (defined as 10 or more medicines) are often elderly and frail. The physical and emotional impacts of their diseases and the side-effects of medications can impact on their functioning, well-being and ability to effectively self-manage their 'medicines work'. So managing their polypharmacy can often be extended to their family and social networks.

The dimensions of patient's work in managing multiple morbidities is increasingly being investigated with research to-date identifying polypharmacy as an onerous burden. Yet the work for patients in self-managing their complex polypharmacy has yet to receive much sociological attention. Attention to the 'medicines work' of self-managing complex polypharmacy is needed to better understand how
the burden impacts on patients’ everyday life, their agency and capacity to self-manage, the resources and support networks they utilise and their strategies for (un)intentional non-adherence and (non-)compliance. This paper will present the findings from longitudinal diary interviews with 10 patients with complex polypharmacy exploring their experiences of self-managing their ‘medicines work’ using Burden of Treatment theory.

Thursday 12 September 2019 at 11:20 - 11:50
Screening and Diagnosis
James Hall

Political sociology and healthcare reorganization: a tale of four major healthcare reforms.

Greener, Ian
(University of Strathclyde)

This paper compares, using the strategic-relational view of politics (Hay, 2002, Jessop, 2008, 2015), four major healthcare reforms in the US and UK, to explore what they tell us about social relations, power and health policy change. Comparing the cases of the failed attempt to reform healthcare in the US under the Clinton administration, and the more successful attempt by Obama, it considers the relationship between key policy actors in the US and the form of government there to explore why Obama succeeded where Clinton did not (Gordon, 2009, Skocpol, 1997, Tuohy, 1999, 2018). It then moves to England, comparing the 1989 and 2010 government's attempts at putting in place market-based reorganisation in the UK, where both sets of changes (eventually) became law, but both also appear to have struggled significantly in implementation (Timmins, 2012, Tuohy, 2018). It asks what these two reorganisation attempts, surely the most significant since the founding of the NHS in 1948, tell us about health care reorganisation in the UK. Finally, the lessons from each pair of case studies are compared, in their respective contexts, to see what they can tell us about the balance between policymakers, the medical profession, the private sector, the public and the general form of policymaking in each country.

Thursday 12 September 2019 at 11:55 - 12:25
Lifecourse (Pecha Kucha)
PT007

Big Birthas: unpacking ‘choice’ for pregnant women with a high-BMI

Greenfield, Mari, Marshal, A.
(University of Hull)

What does it mean to be labelled as having a high-BMI whilst pregnant? How does this label affect women's experiences of navigating maternity services? This presentation is based on a novel user-led Citizen Science collaboration between Big Birthas (peer information and support service) and Parenting Science Gang (Wellcome Trust funded user-led citizen science project). 161 parents designed, undertook and analysed the research, examining the experiences of women who had given birth in the UK at least twice, with the most recent birth being within the previous three years, and whose recorded booking-in BMI was >29. Semi-structured surveys were returned from 20 participants, and were thematically analysed. The results described complex journeys, where interactions with healthcare professionals revolved around conversations of BMI-related risks to the exclusion of other factors, and ignored other events of the pregnancies. Women experienced these conversations as a tool used to enforce their compliance with a medicalised labour and birth, rather than an experience of being given information to enable the woman to make choices. The most commonly reported risk discussion was manual handling, irrespective of woman’s actual weight. Women also reported disrespectful and shaming language from healthcare professionals, and conflict if they asserted a decision that was not in line with the healthcare professional's views. This led some women to decline care that they actually wanted, or avoid attending appointments, to avoid conflict or denial of choice; a consequence which was particularly apparent when we examined how those women chose to approach their second pregnancies.

Thursday 12 September 2019 at 10:10 - 10:40
Screening and Diagnosis
James Hall

Biological citizenship and Sexual health: Exploring Self-testing knowledge, attitudes and practices among the LGBT+ Community in Greater Manchester.

Hammond, Natalie, Duffy, D.
(Manchester Metropolitan University)

Self-testing for sexual health is a practice of biological citizenship and it is argued there is now a moral obligation to protect oneself and wider society (Banda, 2015). Sexual health self-testing is increasingly being utilised for sexual health screening alongside other more traditional methods of clinic-based screening and diagnosis. HIV screening specifically is being hailed as part of efforts to tackle the persistent number of new HIV diagnoses and to assist with ending ongoing transmissions. This paper reports on a ‘work in progress’ study focused on self-testing and the LGBT+ community in Greater Manchester (in collaboration with the LGBT Foundation).
Data generated thus far indicates a gap between knowledge of self-testing and engagement. This presentation will discuss our emerging findings in relation to broader debates about intimacies of care, the feel of technologies in sexual health self-testing and biological citizenship (Rose, 2007; Rose and Novas, 2003).

**Thursday 12 September 2019 at 11:55 - 12:25**

Critical Public Health

PL002

**Unruly Bodies: Examining resistant bodies and hysteresis in health interventions**

Hanckel, Benjamin, Milton, S., Judith Green, J.

(King's College London)

In this paper we bring together two diverse case studies of complex health interventions in England to examine how resistant bodies are conceptualised and made through professional practices within those interventions. The first case study is of The Daily Mile, an intervention delivered by teachers aiming to increase physical activity in schools. The second is an intervention aiming to increase the accuracy of referral for developmental dysplasia of the hip in infants in primary care. Drawing on observations, field notes, and narratives from participants of the interventions, we focus on how resistance to the interventions surfaces and is conceptualised. Discursively evoked, these include: teachers who do not participate in implementation framed as having particular types of resistant, un-moving reluctant bodies; and, in the second case study, the GPs' imagination of the infant body as multifaceted and relational, versus the orthopaedic infant body (discrete, anatomical parts), framed as resistant to the intervention. We show how discourses of resistance are framed through the imagination of different, 'right' and/or 'wrong' bodies. Our findings show how boundaries of body possibilities are framed through the intervention, and the professional fields in which bodies are located. Using the Bourdieusian concept of hysteresis, we show how health interventions draw attention to and shape the changing nature of, and interaction between, professional fields and bodies. Health interventions are important spaces in which to explore the hysteresis effect, to better understand resistance and its productive potential, and to critically explore the role health interventions play in marginalising particular bodies.

**Friday 13 September 2019 at 12:30 - 13:00**

Health Service Delivery

PL001

**Considerations of dignity and the medical waste stockpiling scandal**

Hanna, Esmee, Robert, G.

(De Montfort University)

In light of the recent UK controversy regarding failures in medical waste disposal and the stockpiling of waste, including body parts, the appropriate handling of human tissue has been subject to increased scrutiny (Carding et al., 2018). Whilst this scandal has evoked concern regarding procurement and supply chain issues within the NHS, as well as possible health and safety risks from such a 'stockpile', the dignity of those patients' whose body parts who are implicated in this controversy have been less widely considered (Hanna, 2018). In this paper we utilise the concept of dignity to consider the ethics of disposal of amputated limbs. Limbs provide a useful case study for exploration of this topic, as whilst the management and disposal of human tissue has been subject to greater scrutiny and discussion in recent years, the disposal of limbs often remains absent from such discourses.

We draw on Foster's (2014) work on dignity, in order to argue that a dignity framework provides a useful means for the consideration of the disposal of limbs after amputation. Such a framework may, we contend, be difficult to reconcile with the logic of business and the 'biovalue' of medical waste in an era of increasing privatisation of services and highly competitive tendering processes. However, utilising dignity as a concept within our understandings of medical waste could facilitate a more patient centred approach towards disposal in the case of amputated limbs and herald better practices to help mitigate future stockpiling incidences.

**Friday 13 September 2019 at 12:30 - 13:00**

Risk

PL002

**Emotional responses and professional consequences: Perceptions of uncertainty and risk amongst care home staff involved in the ‘risk work’ of resident hospital transfers**

Harrad, Fawn, Armstrong, N., Williams, C.

(University of Leicester)

For some care home residents a transfer to hospital carries limited benefit yet significant risk of iatrogenic illness, physical and cognitive decline. International literature suggests that some transfers may be initiated ‘inappropriately’, without the expectation of an improved quality of life or clinical outcome (Arendts et al., 2013). For example, where transfers are initiated to avoid litigation (Dwyer et al., 2015). A sociological understanding of this complex phenomenon could shape better services for care home residents and reduce the number of 'inappropriate' transfers.
Semi-structured interviews were carried out with 30 members of care home staff across six theoretically sampled care homes. Discussions covered personal experience of being involved in resident transfers and reflection on a number of vignettes. Interviews were transcribed and analysed using the constant comparative method.

The complex and multifaceted decision-making process was often surrounded by uncertainty and could be conceptualised as ‘risk work’ (Gale et al., 2016). Risk work comprises three interwoven components; risk knowledge, risk interventions, and social relations (Brown and Gale, 2018). Therefore, consideration will be given to how staff assess and conceptualise risk during transfer decisions, the practices that staff undertake to minimize and mitigate against different forms of risk and the way in which staff care for residents within situations that are laden with risk and uncertainty.

The results provide a novel contribution to research surrounding hospital transfers from care homes by drawing on the sociological concept of risk work to understand the experiences of care home staff involved in transfer decisions.

Thursday 12 September 2019 at 15:10 - 15:40
Health Care Organisations
James Hall

Patient and public engagement and involvement in clinical commissioning; socio-material pedagogies of partnership
Hatfield, Debbie, Ferns, G., Aranda, K., Flaherty, B.
(Brighton and Sussex Medical School)

Clinical Commissioning Groups (CCGs) are now required to involve service users (patients and carers) and the public. Engagement and partnership working with service users is an imperative for health care organisations and the evolving Sustainability and Transformation Partnerships (STPs).

Two CCGs were studied using a focused ethnography to explore service user engagement practices in the process of strategic clinical commissioning. Research questions related to working in partnership and engagement and involvement practices. Focus groups, observations, artefacts and face-to-face interviews involved service users, lay representatives on CCG Governing Bodies and GP clinical commissioning Leads.

Four sets of situated learning practices were identified as CCGs evolved to align with partnership working requirements for commissioning; trust, leadership, learning and partnership. A practice theory lens offered new insights with respect to the socio-material aspects of the situated learning. Wenger’s work on communities/landscapes of practice enabled a deeper analysis of the data examining participation, materiality, competence, boundary encounters and meanings; and clarified the visible and hidden practices shaping patient and public engagement and involvement (PPEI) in two CCGs.

Research on PPEI in commissioning is very limited, and particularly its associated socio-material context. The entangled and distributed quality of PPEI was found to be influenced by identification with present and past communities of practice and specific boundary encounters. Enablers, constrainers and pre-requisites for PPEI in clinical commissioning were identified and a conceptual map devised for both examining and developing learning and practice.

Thursday 12 September 2019 at 14:00 - 14:30
Health Care Organisations
James Hall

Patients’ conceptualisations of responsibility for healthcare: A typology for understanding differing attributions in the context of patient safety
Heavey, Emily, Waring, J., Aoife De Brún, A., Dawson, P., Scott, J.
(University of Huddersfield)

Despite the ongoing emphasis in medical sociology on patient experience, there is little understanding of how they experience and conceptualise responsibility in care settings. This absence is striking, given the current emphasis on engaging patients as active participants in their own healthcare. Understanding whether and how patients perceive and accept this responsibility is a vital step in encouraging engagement and - of equal importance - mitigating an absence of engagement.

This paper examines how patients conceptualise responsibility for their healthcare and make sense of the complex boundaries between patient and professional roles. Focusing on the specific case of patient safety, narrative methods were used to analyse semi-structured interviews with 28 patients recently discharged from hospital in England. Patients told stories about their own and others’ experiences in the hospital setting, including experiences of being or feeling safe and experiences of harm or risk. These stories variously attributed responsibility to staff, to patients, and to both groups.

We present a typology of attribution, which demonstrates that these attributions are informed by two dimensions of responsibility: basis and contingency. The basis of responsibility is the reason for holding an individual or group responsible. The contingency of responsibility is the extent to which that attribution is contextually situated. The paper contributes to knowledge about responsibility in complex organisational environments, and offers a set of conceptual tools for exploring patients’ understanding of responsibility in such contexts. There are implications for addressing patient engagement in care, within and beyond the field of patient safety.
Paper Abstracts

Wednesday 11 September 2019 at 14:35 - 15:05
Lifecourse
PX001

'Ve were able to keep her at home and we weren't scared of uncontrollable pain'; carer administered medications in the last days of life.

Hendry, Annie, Wright, S., Hiscock, J., Poolman, M., Roberts, J., Wilkinson, C. (Bangor University)

This paper explores the accounts of lay carers who have cared for a loved one at home during the last days of life. Many people nearing the end of life express a wish to die at home; the fulfilment of these wishes often depends on the ability of a lay carer to support them at home during this difficult and emotional time. Healthcare professionals are often required to visit those dying at home to give medications for pain, agitation, and noisy breathing. The waiting times for healthcare professionals to arrive, particularly out of hours, may be long and distressing for those involved.

In this study, lay carers were trained to give medications to their loved ones at the end of life. In depth interviews were conducted with carers in their homes and analysed using Interpretive Phenomenological Analysis.

The rich and detailed accounts of carers in this study reveal the complexity of caring for a loved one during the last days of life and are intrinsically bound with the desire to fulfil wishes, alleviate pain and suffering and to contribute actively towards care. However, these factors are further intertwined with concerns regarding lay/professional boundaries, carer burden and the potential for hastening death. This paper will shed light on the lived experiences of carers caring for a loved one in the last days of life and the ways in which they are able to navigate their way through this challenging time.

Friday 13 September 2019 at 11:55 - 12:25
Professions
PT111

Certain uncertainty: An analysis of the constraints and possibilities of gendered medical professionalism as taught to and understood by trainee doctors in the UK

Heney, Veronica
(University of Exeter)

Medical professionalism is a highly contested concept, which holds particular relevance amid a context of an increasingly privatised, neoliberal NHS, an embattled medical profession, and a continued media focus on high-profile failures of care. In addition to well-established sociological and activist critiques of professional status and dominance, feminist writing contends that professionalism is grounded in exclusionary masculine norms. However, recent reassessments of medical professionalism and calls for its continued utility have not included gender in their analysis. This project, a small qualitative interview study with medical students and junior doctors (n=11), explores the ways in which those entering into a medical career understand their roles and responsibilities and respond to the implicitly gendered understandings of medical professionalism with which they are presented in their education and work. Considering themes of communication, dress codes, and systemic failings in healthcare suggests the ability of medical students and junior doctors to assess and reject established gendered norms, and the possibility of a reconceptualised professionalism which refuses masculine norms of mastery, control, and detachment and instead centres human connection, embodiment, and the collective disruption of dangerous systems. Such a shift in conceptualisation has significant implications for both women’s participation in medical workplaces and for patient care and experience. Through engagement with the understandings and experiences of medical students and junior doctors this paper engages in speculative and explorative thinking grounded in gender and disability theory to imagine a more meaningfully reconfigured professionalism and the future healthcare that such a reconfiguration might make possible.

Wednesday 11 September 2019 at 14:00 - 14:30
Ethics
James Hall

The Vulnerable and Consenting Subject: Reimagining Informed Consent

Hewer, Rebecca
(University of Edinburgh)

The problem with informed consent (IC) is that it is premised on the politically fictitious subject of liberalism. Frames of the subject as disembodied, atomistic and asocial legitimise a bioethical orthodoxy organised around individualism and ‘respect for autonomy’. Consequently, they erase the embodied and relational dimensions of existence, whilst justifying neglect of more ambitious bioethical imperatives (e.g. structural reform). This paper draws on feminist theories of vulnerability to a) problematize the use of IC in health research and b) propose an alternative model of ‘vulnerable consent’ (VC). Influenced by the work of Butler and Fineman, VC eschews the reductive proceduralism endemic to IC and attends to the fundamentally social and substantive dimensions of subjecthood. Accordingly, it demands consent be sought in deference, not to autonomy, but to the epistemic value of situated, embodied and affective knowledge. Moreover, VC demands recognition of the mutually constitutive dependencies existing between the self and
society, and subsequently frames consent as a necessary but not sufficient condition of appropriate bioethical practice. Plainly, VC posits that - insofar as the subject contributes to society (e.g. through tissue donation) - society has a positive obligation to secure the wellbeing of the subject, e.g. through structural reform.

"If you wear a uniform you're a nurse. I don't" Boundary spanning and identity work in the clinical research workforce; a qualitative study of research nurses, midwives and allied health professionals.

Hinton, Lisa, A. McNiven, L. Locock.
(Oxford University)

Research nurses, midwives and allied health professionals (RNMAHPs) are at the heart of delivering clinical research in the UK. They operate in a constantly unfolding policy context regarding health research workforce, and are the focus of significant National Institute of Health Research strategy and leadership investment. There is a growing literature on the experiences of the health research workforce, including that of nurses, midwives and allied health professionals. Our study adds to this emerging literature.

In-depth interviews were conducted with a maximum variation sample of RNMAHPs (n=46) with experiences ranging from a few months to over 25 years. Interviews were audio and video recorded (with consent) and transcribed. A thematic analysis was undertaken using a modified grounded theory approach.

Interviews were wide ranging and revealed a range of tensions; practical, ethical and emotional. Barriers can be structural, physical and cultural, ranging from lack of available rooms to see potential participants when discussing sensitive issues to unclear career structures and progression. Participants used formal and informal strategies to navigate the potential inhibitors to research activity, sometimes in subversive ways and/or using creativity and reward-based systems. There were a range of challenges to professional-personal identities and challenges to those identities in the transition to research jobs that were surfaced. Signifiers, such as uniforms and badges, became key symbols of these tensions. We discuss these findings in the wider context of the invisible work of nursing (Allen 2004), identity work and status identity (Gill 2013) and the sociology of the professions (Freidson 1984).

Leaving the digital platform to embark on the health practices journey: a dynamic model of patient trajectory, sociohistorical context and capitals

Hope, Jo,
(University of Southampton)

Critical digital health studies calls for greater use of sociocultural perspectives, but has tended to focus on the application of science and technology studies (STS) theory to health. This paper argues for a conceptual shift, exploring digital health work through the lens of medical sociology. The example of digital health information and support seeking is explored. The existing literature tends to use snapshots of the affordances and limitations of different digital platforms rather than exploring digital information seeking within the wider health work accomplished across a carer or patient trajectory.

This paper uses data from a mixed methods study into the role of online support and information for parents of people with a rare syndrome (Rett syndrome) including a survey (n=190) and interviews with diaries (n=20). A novel model is presented that conceptualises the use of digital health information and support as driven by carer and patient trajectories. These trajectories involve the accomplishment of pertinent health work tasks (such as navigating biographical disruption, developing new social networks and building relevant health expertise). This is a dynamic process that occurs across time, within shifting sociohistorical contexts with differing states of health knowledge and research, technologies and communication media. The access to and use of digital health information and support is constrained by contemporaneous access to relevant capitals when accomplishing this health work.

This paper demonstrates how sociological theories and concepts can be used to reframe our understanding of the embedded but unequal use of digital technologies in everyday life.

Healthcare provision and regulation beyond the state: evidence from Maharashtra, India

Hunter, Benjamin, Susan Fairley Murray
(University of Sussex; King's College London)
Paper Abstracts

Scholarship on regulation in healthcare has failed to keep up with a rapidly changing landscape for healthcare provisioning and financing in which the historical prominence of government legislation and professional self-censure takes a back-seat to other imperatives. Healthcare is, as Mary Dixon-Woods recently noted, a ‘polycentric’ regime involving multiple agencies and actors. In the context of middle-income countries such as India, this includes regulators, commissioners, insurers, owners of private facilities, investors, medical professionals, consultancy organisations, charities, online platforms and booking portals, and patients and their advocates.

Here we argue that behaviours in the Indian healthcare sector increasingly reflect these competing concerns. We present findings from qualitative research in Maharashtra. Semi-structured interviews were conducted with healthcare professionals, user groups and representatives from healthcare industries and government, plus three ‘witness seminars’ with representatives from the above groups. These covered topics of healthcare transformation and government regulation. Transcripts from interviews and witness seminars have been analysed using a framework approach.

Findings point to the growing range of imperatives that varyingly compete and intersect in healthcare practice. In addition to legislation and professional codes of conduct, there are pressures to hit income targets set by corporate hospital management, bolstered by middle-class and wealthy user demands for high-technology and hotel-style facilities, but also tempered by requirements to conform to the treatment and informational protocols of insurers and their third-party agents. The paper discusses the implications of these findings for governance in the health sector.

Wednesday 11 September 2019 at 14:35 - 15:05
Mental Health
PT006

“You're young, it's gonna happen, you'll grow out of it”: Exploring how young people make sense of depression among conflicting discourses surrounding ‘youth’

Hyde, Emma
(University of Oxford)

Depression is one of the leading global causes of illness and disability among young people, however existing research finds clinicians are often reluctant to diagnose depression in this group through fear of over-diagnosis and ‘medicalising moodiness’. Depressed mood is largely perceived as ‘part’ of growing up, blurring boundaries between normality and pathology. Interlinked is a familiar discourse of ‘mood-swings’, ‘hormone imbalances’ and ‘difficult phases’ attributed to youth transitions. Despite increasing interest in conceptualisations of mental illness, research into young people's experiences of depression is relatively lacking. This paper presents a secondary thematic analysis of 25 qualitative interviews from 4 projects held in the Healthtalk data archive and asks new questions of existing data on youth experiences of depression. Early analysis identifies two contrasting yet interlinked conceptualisations: the normalisation of depression as common and inevitable for young people, and the dismissal of ‘real’ depression by virtue of being young. In this conflicting landscape, I explore how young people aged 16-27 make sense of depression in the context of what it means to be ‘young’; situating experiences within wider discourses and assumptions surrounding ‘youth’. Theoretically grounded in symbolic interactionism, I seek to understand how young people develop and negotiate a depressed ‘self’ through an interpretive process shaped by interaction with their social environment. Both normalising and dismissive attitudes from parents, professionals, and young people themselves may influence the perceived seriousness attributed to low mood. Therefore, I also consider how conflicting discourses surrounding ‘youth’ may shape or disrupt pathways to mental health support.

Thursday 12 September 2019 at 10:45 - 11:15
Citizenship
PT006l

Managing risk versus choice: The case of fetal heart monitoring in midwifery-led care

Jackson, Clare, Annandale, E., Baston, H., Beynon-Jones, S., Brierly-Jones, L., Brodrick, A., Land, V.
(University of York)

Potential tensions between guideline-driven care (Kotaska, 2011) and personalised care - the risk-choice paradox (Symon, 2006) – are particularly relevant in the context of childbirth; a site of a longstanding debate about the erosion of choice by the medicalisation of practice. However, little is known about how this apparent paradox is managed in real-time during labour. In this paper, based on NIHR funded conversation analysis of 23 video/audio recordings of intrapartum care in two UK midwifery-led units, we take fetal heart monitoring (FHM) as a case study to examine if and how risk and choice are oriented to in interaction between a woman and her carer. NICE guidelines state that women at low risk of complications in established labour should be offered intermittent fetal monitoring and that this should be conducted every fifteen minutes during the active first stage of labour. Guidelines also state that such monitoring can be conducted via Pinard stethoscope or Doppler ultrasound. However, in our data, there is only one instance of Pinard use and there is no discussion about the two different technologies. Our findings demonstrate the normalisation of Doppler ultrasound and its apparently non-optional status vis-a-vis labouring women. Occasionally, data show midwives conducting monitoring without verbal discussion. More commonly, midwives state their intentions to monitor in ways that expect agreement. When women (rarely) resist such moves, midwives orient to risk in pursuit of agreement. Far from a risk-choice paradox, the practices of FHM enact this as a routine technique of risk management during labour.
Please call my daughter: Affective Ethics in Dementia

Jeong, Jong-Mim
(University of Manchester)

If your mother with dementia wanted to call her daughter at twenty past five on an early autumn morning, what you ‘should’ you do as researchers, staff, and family members? Should ethics come before research, care practice and ontology? Should we stand against ethics which assumes that ethical problems can be treated by implementing pre-defined rules and regulations, and by applying rationalist frameworks such as utilitarianism, deontology and virtue ethics? Should we perceive her utterance and behavior as a wandering and anxiety disorder? Alternatively, in this article I aim to extend the ways we perceive and understand such bodily movements as affectively enmeshed ethical endeavors by turning these matters into a cartographic ethnography, focusing particularly on affectively embedded and embodied bodily practices in ordinary ethics. Critically developing Deleuze, Guattari and Deligny’s cartographic approach, I demonstrate the ways in which people involved articulate affective ethics and ethical responsibility, commitment, and obligation towards others, highlighting affectively underpinned encounters and relationality in the condition of co-dwelling. Accordingly, I argue that affect is an integral constitutive of ordinary ethics and the affective dimension of ethics should be accounted for in any framework of ethics.

A morally individualised death? Dying in private residential care

Johnson, Eleanor
(University of Bristol)

In this presentation, I report on an ethnography of care work in one high-cost and one low-cost private residential care home for older people. Specifically, I explore the symbolic work undertaken by care workers with respect to the dying and death of residents. Informed by the work of Durkheim, Douglas, and others, I identify how care workers’ routines and rituals surrounding dying and death function to either show honour or disregard for residents. In the high-cost home, for instance, a series of rituals were undertaken to ensure the 'sacredness' of dying residents, such as one-to-one care, inclusion in the home's collective life, and attending to individual preferences for end-of-life care. This involved framing the hospitalisation of dying persons as harmful and as preventing a 'good death'. In the low-cost home, however, similar symbolic rituals did not emerge and there was no distinction established between 'end-of-life' care and ordinary caregiving. Here, residents were framed as 'non-persons', which allowed care workers to view dying residents as inefficiencies which disrupted the usual pattern of work in the home. Indeed, the hospitalisation/medicalisation of residents was encouraged, if not celebrated, by workers in the low-cost home. In this presentation, thus, I identify the symbolic resources – beliefs, rituals, vocabularies – available to care workers and what implications the presence or absence of these resources has for the care provided to older people before and after they die.

Reflective practice in acute care settings: is it always good for staff and good for patients?

Jones, Jennifer, Brown, C., Bion, J., Brookes, O., Willars, J., Tarant C.
(University of Leicester)

Patient experience is identified by NHS England as a key component in improving care quality but staff may lack insight into how their behaviour may be detrimental to the patient experience. One technique for gaining insight is reflective practice. Much research has focussed on how reflective practice is taught but comparatively little is known about how reflection takes place in acute care settings. We conducted around 150 hours of observations and 45 interviews with a purposive sample of healthcare staff in Intensive Care Units and Acute Medical Units in three NHS hospital sites. Staff described a variety of triggers which prompted reflection, but struggled to identify examples when reflection changed behaviour and improved patient experience. We identified three types of reflection: ‘stress relieving reflection’ with colleagues, which provided an outlet to release emotions, but did not necessarily result in changes in attitudes or practice; ‘critical reflection’ which led to insight and a change in attitudes and practice, or a reassurance that the staff’s behaviour did not need changing; and individual ‘rumination’ which was unproductive and potentially damaging to the staff member. We suggest that while ‘stress relieving reflection’ may buttress staff resilience, it fails to address underlying problems. Critical reflection is likely more creative and should be encouraged and supported to facilitate positive behaviour change in staff interactions with patients. Rumination should be avoided, and may be a marker for insufficient organisational support for staff well-being. Interventions to promote reflection in practice should account for these different types of reflection.
Exploring the role of medical directors in healthcare governance

Jones, Lorelei, Fulop, N.
(Bangor University)

Sociological scholarship has positioned medical directors within the restratification of the profession (Friedson 1985, Waring 2014). Medical directors are a form of 'managerial elite' (2014), reflecting the pervasive influence of managerial ideas on professional work. Such professional-managerial 'hybrids' bring together what are often seen as contradictory logics, for example, a professional concern with quality and humanity with a managerial concern for efficiency and profitability. Recently Noordegraaf (2015) has argued that changes in the societal and organisational context of medical work have resulted in professional identities that have moved 'beyond hybridisation'. Medical professionals must now implement innovation, cooperate with other team members, and, as their careers progress, develop services with strategic and budgetary constraints in mind, all the while accounting to external stakeholders. In the process, 'organizing' has become an integral and 'natural' part of professional action and professional identity. Others have suggested that it is the very 'naturalness' of this professional identity that makes it a potentially effective conduit for government. Martin and Learmonth (2012), for example, suggest that it is partly through these new subjectivities of 'clinical leaders' that governmental objectives are accomplished. While there is a considerable literature on professional-managerial hybrids, this has, to date, focused on lower tiers of hospital management, and on the implication for professional autonomy and influence. This paper presents preliminary findings from an ethnographic study exploring the 'work' (Strauss et al 1985) of medical directors, both within and outwith their organization.

Structure and identity. The importance of the sociocultural context in examining the excess psychosis risk in ethnic minorities.

Jongsma, Hannah
(UCL Division of Psychiatry)

Psychotic disorders are more common in certain ethnic minority groups in Western countries. Despite the well-established nature of this epidemiological finding and nearly a century of research into it, no satisfactory explanation is offered. There is no evidence to suggest that increases rates are entirely due to sociodemographic artefacts, or that certain ethnic groups are 'inherently' at increased risk. A hypothetical 'unhealthy migrant' effect is also not borne out by empirical data, and traumatic (pre-) migratory circumstances appear to play a role but fail to explain excess risk in second and later generations of migrants. The post-migratory social context appears to be a crucial causal candidate and this paper examines how an understanding of ethnicity as structure and as identity can provide an explanatory framework. The structural nature of social gradient in health has not been researched in the context of psychosis, but is applicable here: many risk factors for psychosis are variants of being 'worse off' in society, a life-course perspective is crucial in understanding psychosis and there is a possible biological mechanism to link the two. Ethnic minority groups are disproportionately often socioeconomically disadvantaged and this structural element might contribute to their excess psychosis risk. This can however not be a full explanation, as an excess risk remains after adjusting for socioeconomic status. Ethnicity is often used by the majority as a divisive identity: the plurality of identities within ethnic minority groups is disregarded and ethnic identity becomes a tool for othering and exclusion. This paper will explore how understanding both the structural and this identity element of ethnicity is crucial for our understanding of excess psychosis risk in ethnic minorities.

Opening the pedagogic space of sexual and reproductive health: how can we re balance our knowledge ecology?

Keogh, Peter
(The Open University)

Assessment mechanisms such as the REF, KEF and TEF as well as the restructuring of funding councils to align with the UK industrial strategy can be seen as examples of moves to bureaucratise knowledge production in universities aligning it with governmental and economic imperatives within a marketized knowledge economy.

Drawing on examples from across the sexual and reproductive health (SRH) field, I will argue that the bureaucratisation of knowledge is contributing to a problematic imbalance in the SRH knowledge ecology. Experimental and technical forms of knowledge consistent with biomedical and epidemiological epistemic paradigms fare well within this new system and are thus coming to dominate in all
areas of SRH. However, when we consider the urgent challenges we are facing in SRH (for example, the global gag, contested abortion provision, a crisis in SRE in our schools, the rise of gender essentialism), these forms of knowledge on their own have little to offer. Moreover, this bureaucratised and technologised pedagogic space is evacuated of political meaning and potential.

In this talk I will consider ways of re-balancing the knowledge ecology around SRH in the university. Taking the Open University as an example, I will make some concrete proposals for reviving academic knowledge production and deployment around political, embodied and affective responses to SRH challenges. These strategies require us to consider better ways of making the ‘pedagogical space’ of the university more ‘open’.

Friday 13 September 2019 at 11:20 - 11:50
Experiences of Health and Illness
PT006

How the beliefs of African Caribbean men in TT contribute to delays in diagnosis of prostate cancer
King-Okoye, Michelle, Dr Anne Arber, Professor Sara Faithfull
(University of Surrey)

Background - Black African Caribbean men in Trinidad and Tobago (TT) have the highest prostate cancer mortality rates in the world. As TT is a multicultural, multi religious and multiethnic nation it is important to explore how beliefs impact on men's experiences of routes to diagnosis for prostate cancer. This paper reports on TT men's pre-diagnosis journey and how their beliefs contribute to delays to diagnosis of prostate cancer.

Methods - Men recently diagnosed with prostate cancer were recruited from four centres in TT. Semi-structured interviews were conducted with Black Caribbean men (N=51) from TT following the principles of Grounded Theory.

Results - TT men reported major barriers to medical help seeking. These were lack of knowledge and awareness of the prostate gland and symptoms of prostate cancer and where to seek help for prostate concerns. Men's hegemonic masculinity norms and cultural and religious beliefs influenced their decision to delay seeking medical help. Consulting with traditional healers and pharmacists were also found to contribute to increased time to diagnosis.

Conclusion - It was important to unearth barriers and facilitators to prostate cancer care in TT in which culture; traditional health practices and religious beliefs play major roles. These findings will direct specific health messages to enable and empower men to seek help for early symptoms of prostate cancer.

Wednesday 11 September 2019 at 15:45 - 16:15
Patient – Professional Interaction
PL005

Moderators of emotional labour in the emergency department.
Kirk, Kate
(University of Nottingham Business School)

It is undeniable that challenges facing the NHS have implications for staff tasked with delivering care. Low rates of well-being have a direct impact on the quality of care delivered (Boorman, 2009). Despite evidence showing the importance of positive nurse well-being, the emotional component of the role (a great influencer in well-being) (Warren, 2016), is overlooked (Smith, 2012). An integral part of nursing is often neglected: the emotional labour of nursing.

I have applied Hochschild's theory of emotional labour to a previously unexplored clinical speciality: emergency care. In spite of the challenges facing ED, and their distinctive nature, an exploration of ED nurses' emotional labour is missing - we know little of how the ED environment influences the management of emotion.

Ethnography, enabled immersion in the ED setting, gathering the lived experiences and narratives of the ED nursing team. This allowed room for the dynamism of the setting, workload and pace. I used two departments for a rich and illuminative dataset.

I aimed to understand how the environmental, institutional and organisational dynamics of the ED instrumented the emotional labour. I found that elements of time and space were 'moderators' of ED nurses' emotional labour – in essence, understanding these moderators' integrated relevance offers a contribution to knowledge. Understanding the moderators of emotional labour from an organisational 'meso-level' perspective, in addition to the study of the more familiar micro level exploration is of interest to those outside of the case study. In particular, those studying organisational behaviour and sociology.

Wednesday 11 September 2019 at 14:00 - 14:30
Health Service Delivery
PL006

Making New Health Services Work: An ethnographic study of community nurses' contribution to service development.
Paper Abstracts

Kise Hjertstrøm, Helle, Norbye B., Obstfelder, A.
(Telemark Research Institute)

Norway, as many European countries, faces challenges in the delivery and organization of healthcare, leading to increased demands for service development and innovation. The health policy in Norway aims to achieve better and more effective healthcare for individual patients by transferring several tasks and responsibilities from hospitals to municipalities. Consequently, community nurses get more responsibility and perform additional new tasks. This study explores nurse’s contribution to the development of a new politically initiated emergency ward in an already existing emergency service and what competencies guided the nurse’s work. The study applies an ethnographic approach to the data collection by combining observations and interviews with nurses in a rural emergency health service. In our analysis, we draw on the theory of the social organization of healthcare work, particularly the concepts ‘organizing work’ and ‘articulation work.’ The analysis demonstrates how the nurses navigate in their everyday work, especially their contribution in ‘filling the gap’ between the political intentions, professional standards and what the service could be within the local health care setting. The nurses continuously shifted their attention from the individual patient to the organization of patient work. In the development of the emergency ward, the nurse’s focused on individual patients’ potential caring needs, the overall care arrangements, organizational relationships, and the necessary supporting resources. We argue that nurse’s ‘organizing work’ is a necessary contribution to the local development and implementation of abstract and general political initiatives, and contributes to ensuring that new emergency ward is considered comprehensive services for individual patients.

Wednesday 11 September 2019 at 16:20 - 16:50
Ethics
James Hall

The stigma of a special hospital wristband: The ethical problems with visual identification for hospitalised people with dementia

Kuberska, Karolina
(University of Cambridge)

A significant proportion of hospitalised elderly patients also have dementia and may wander, which makes their care more challenging to clinical staff. Many hospitals have systems of visual identification for such patients in the form of e.g. stickers placed above their beds. These visual identifiers, while useful, do not help to prevent problems arising when patients with dementia walk about the hospital and become lost. One of the design interventions proposed to address this particular issue was using visual identifiers that can be placed on the patient, such as blue hospital wristbands. Similar interventions have been rolled out in a number of NHS trusts in England although they are not routine everywhere. Some concerns have been raised about wristbands of this kind having the potential to stigmatise patients with dementia by revealing their condition to those who can interpret the identifier, evoking the notion of a badge of shame. The goal of this paper is to explore the stigmatising potential of a hospital wristband for patients with dementia in two contexts. The first includes a comparison with other visual identifier systems used in hospital settings that do not raise such criticisms. The second concerns broader understandings of living with dementia that de-emphasise medicalisation of processes typical of old age. By exploring the stigmatising potential of a hospital wristband it is possible to reveal the frictions at the intersection of various agendas that simultaneously normalise and denormalise dementia in pursuit of better care for people with dementia.

Thursday 12 September 2019 at 11:55 - 12:25
Inequalities
PL001

‘Indicatorising’ social inequality within health inequalities research: a case study of the Japanese Small Area Deprivation Index

Leppold, Claire
(University of Edinburgh)

Despite emphasis that health inequalities occur along the axes of social inequalities, there has been limited attention to the ways in which social inequality is considered and operationalised in health inequalities research. Social indicators are constructed in specific, predominantly Western, contexts and then applied in research internationally. However, there has been a lack of research on the ways in which forms of social inequality, and their connections to health, may differ by context. The implications for what can be captured by existing indicators, and thus ‘found’ in health inequalities research, is an area in need of investigation.

This paper presents a critical appraisal of one indicator used in health inequalities research: the Japanese Small Area Deprivation Index (JSADI). First, the JSADI is operationalised in attempt to study health inequalities by small area deprivation in the Soma Region of Japan through quantitative multi-level analysis. This operationalisation of the JSADI itself is then examined, alongside the ways in which health inequalities may or may not be captured by its use in the Soma Region, through qualitative interviews with 16 social inequality and health inequality researchers in Japan, and 41 local Soma Region residents. Focal points of this investigation include the origins of the JSADI, the ways in which area deprivation is conceptualised and measured by researchers through use of the JSADI, as well as ‘on the ground’ understandings and experiences of area inequalities by local residents.
Trust in Healthcare in Superdiverse Environments

Lindenmeyer, Antje, Phillimore, J., Kokab, F., Brand, T. (University of Birmingham)

Poor health outcomes have been a concern in diverse communities for decades; while structural drivers have been identified, a lack of trust has also been implicated as a barrier to access to care especially for migrants. While survey-based studies link trust in healthcare with current health status, there is a need for more nuanced understandings of trust from a sociological perspective. Development of trust needs to be seen within the context both of the ‘health ecosystem’ of individual neighbourhoods and the local, national and international networks of healthcare seekers. Especially superdiverse areas—characterised by very high levels of diversity and a highly mobile population of recent migrants—pose challenges to the development of trust as long established relationships between health providers and minority communities are waning. However, superdiverse neighbourhoods also provide resources as new networks between migrants from different backgrounds develop. Residents can also access practitioners and shops offering treatments based on a range of cultural traditions.

For this presentation, we will draw on our work with residents in superdiverse areas in Birmingham (UK) and Bremen (Germany). We will explore how trust may be gained or lost in individual health encounters and how particular environments shape this process. In particular, we will address the following questions:

1. How does the complex environment of the superdiverse neighbourhood influence how trust is developed or lost?
2. Are there any individuals whose demographics or experiences make them particularly vulnerable to loss of trust?
3. Which critical factors and moments can lead to mistrust?

‘Not just a talking shop’: Justifying LGBT+ staff networks within the NHS

Lockyer, Bridget, Einarsdóttir, A., Mumford, M., Sayli, M. (University of York)

Staff networks have become a standard part of large organisational life, and are present and celebrated within many NHS organisations. They are seen as an important vehicle for increasing the visibility of certain groups of workers and offering voice mechanisms for otherwise silenced minorities. On an individual level, networks are considered to provide a safe space for members to share personal experiences and to help advance their careers through greater access to senior staff via the network and attached mentoring schemes. They are also regarded as a key element of the equality, diversity and inclusion strategy or ‘package’ of organisations, signalling a commitment to creating inclusive workplaces and opening up possibilities for networks to advise and input into their organisations’ equality and diversity policies. Critiques of staff networks have questioned networks’ capacity to fulfil their aims and objectives without real institutional power and resources (Dennissen, Benschop, & den Brink, 2018). This paper draws on a large ESRC funded study into LGBT+ networks operating within the NHS, to explore how the function, activities and atmosphere of staff networks is influenced by their location within healthcare settings. Our data collection involved observations at 45 LGBT+ network meetings and events, and 63 interviews with network members, equality and diversity leads as well as the chief executives from nine case study organisations. Our findings showed that in a within a highly pressurised and under-resourced health service, network members were concerned with networks appearing legitimate (to senior management and other colleagues) and eager to demonstrate that they were not simply ‘talking shops’. These concerns, we argue, coincided with the pervasive managerialism of the NHS to produce network meetings which were mostly bureaucratic and dominated by an agenda. This left limited time for personal experiences to be shared, and created an environment where the professional identities of members, their job roles and departments, subsumed other identities, including their gender and sexual identities. At meetings, discussion often revolved around the time spent away from work to attend meetings, the need to justify this time and, in the case of patient-facing staff, the organisation of cover. We maintain that these discourses and conversations around the lack of financial resources more generally meant the networks prioritised outward-facing activities which would appear less ‘self-indulgent’, such as awareness raising, policy contribution and publicity for the trust, to the detriment of creating spaces for LGBT+ staff to be supported. The study also showed that members found it easier to justify network activities that contributed to better care of LGBT+ patients and service users, instead of staff, corresponding to the ‘patient first’ ethos of the NHS. This paper contributes not only to our, until now, limited understanding of what staff networks do, but how they are impacted by the context in which they are located and how management measures to reduce staff inequalities within healthcare settings are stymied by the (both perceived and real) need to justify their existence within these highly pressured and overstretched organisations.
Still slaves and soldiers? Conceptualising the scars of organ transplantation
Lowton, Karen
(University of Sussex)

For sociological and anthropological scholars, the body is both a physical and social entity and a project to be worked on by the self and others. In the context of organ transplantation, these concepts unfold alongside conflicting notions of transfer of donor personality with body organs and commodification of body parts. Of note, these scholars’ conceptual work in organ transplantation and the body has overlooked surgical scars, yet these are borne by all transplant recipients and signify both vulnerability and resilience. For example, in understanding biomedicine’s intervention in the body through the skin Shildrick (2008) uses the term ‘corporeal cut’ conceptually rather than focus on the flesh that is incised and the scar that forms subsequently. In this way body flesh has become abstract; cut but unmarked, with transplantation scars being an ‘absent presence’ in these disciplines’ thinking. In this paper I develop a more nuanced understanding of how organ transplantation shapes the corporeality of the body and the embodiment of the self through considering the concept of a transplant scar in three ways. First, through transplantation scars’ dynamic physical appearance across their lifecourse and the construction of their symbolic meaning for their bearer. Second, through the management of scars’ display and the use of the scarred body in storytelling; and third, how scars’ coded messages are framed and interpreted by audience understandings of biomedicine’s reach. I draw on interview data from 27 adult survivors of childhood liver transplant, who bear either ‘Lexus’ or ‘Mercedes’ transplantation scars, to illustrate these concepts.

Photo elicitation and food insecurity
Machray, Kathryn
(University of Glasgow)

This presentation will provide a discussion of the use of narrative photo elicitation interviews in exploring men's experiences of food insecurity. This study is examining how, aside from foodbank use, single or ‘vulnerable’ men mitigate, or cope with, food insecurity and what are the impacts on their social participation and networks.

With recruitment just beginning this PhD is a work in progress. The presentation will aim to discuss the use of visual methods in relation to food insecurity and single men. This presentation will also discuss the positives and difficulties of using this method, how it has worked in practice and the ideology underpinning its selection.

Supporting safe birth: flows of public health information, responsible subjeckthood and the logics of maternity care
Mackintosh, Nicola, Shaw, E., Czyznikowska, B., Miah, N., Dunn, L.
(University of Leicester)

This paper reports on an arts-science research collaboration which used animated film to further understandings about constructions of safe birth. We used the arts both as product (knowledge production) and process (enabling involvement) to explore the ‘micro politics of knowledge’ at play. We examine how maternal health and notions of safety are constructed through sources of public health information, and the alignment of these with broader social and cultural configurations of reproductive subjecthood.

We draw on data from focus groups and individual interviews with pregnant women and community leads recruited via Indian, Bangladeshi and Pakistani community / faith based networks where we used the animation as a focus to explore participants’ understandings of safety in pregnancy and birth. An artist produced visual minutes during the focus groups and developed artwork from the narratives representing key themes which we then took back to the community centres to foster further dialogue around the key themes.

We report on tensions around the ‘distillation’ of complex social issues in the knowledge translation process, production and flow of public health information. Health imperatives embedded within visual and textual sources of information link with imagined futures for both mother and baby, and notions of responsibilisation and good mothering. Women's embodied ways of knowing and situated understandings of safety are shaped by relational elements of surveillance associated with these health imperatives, and community and social networks. We explore the alignment of these situated knowledges with broader discourses regarding the logics of choice and care in maternal services.
My BlueHealth: Developing a citizen research agenda for environment society and health.

Maguire, Kath, Garside, R., Guell, C., Health and Environment Public Engagement Group
(University of Exeter)

This presentation outlines a case study about community involvement in research about Environment Health and Society.

Elliot and Williams suggested sociologists have a unique role in developing ‘knowledge spaces’. These are interdisciplinary, cross-sectoral and publicly accessible spaces in which different types of knowledge are shared and new knowledge is created. Within these arenas socially accepted truths, those which Jasanoff has described as 'Civic Epistemology’, are negotiated. In previous papers we have characterised these spaces as liminal, between what Habermas describes as the ‘lifeworld’ of personal, familial and cultural relations and the instrumentally driven ‘system’ of economic and scientific logic.

In preparation for the EU funded BlueHealth2020 trans-national survey on access to water-based environments and health, researchers consulted the Health and Environment Public Engagement (HEPE) group about the appropriateness and comprehensibility of a questionnaire. As well as the requested feedback, HEPE also suggested that while the questionnaire could explore activities undertaken in these environments, it could not uncover what meaning is ascribed to these experiences nor why people value these places.

Working with qualitative researchers HEPE members designed their own project exploring these meanings. They submitted their own stories, poetry and photographs about why access to water-based environments is important to them. Through a series of workshops they identified and analysed themes within these data.

This presentation will outline our methodology and explore the theoretical implications for this as a method to support the democratisation of Civic Epistemology in the field of Environment Health and Society.

Okay, there are some appropriate emotional coping mechanisms or whatever: packaging and unwrapping of emotion in narratives of traumatic brain injury

Makela, Petra.
(University of Westminster)

The silencing of emotion in western modernity in general, and in clinical medicine in particular, seeps into health research inquiry (even) through qualitative methodologies. In both clinical and research interaction, we undertake emotional work to suppress awkwardness and to maintain our “status shields” (Hochschild, 1983.). An ‘epistemology of emotion’ integrates emotion within the research process, intending to contribute to understanding (Holstein and Gubrium, 2003). When undertaking narrative inquiry with people living with traumatic brain injury, emotion is intimately implicated in concepts I explore: identity, sense of self, kinship, normativity, legitimation and interaction. I wish to expose two faces of emotion within my narrative encounter. Here, the ‘unwrapping’ of a vague feeling as an emotion might bring deeper insights to my interpretations, making visible some of the taken-for-granted. I draw on two case examples from a larger study in which I used narrative inquiry to explore ‘self-management’ after traumatic brain injury. I apply Bamberg’s ‘small story’ approach to narrative analysis of dyadic, longitudinal interview data. I compare ‘packaged’ talked-about emotion with ‘unwrapped’ emotion in-interaction. My first case demonstrates clinical discourse that infuses and frustrates one lady’s attempts to make sense of her emotions after traumatic brain injury. Through the second example, I consider tacit significance of embodied emotion within an interview, and when subsequently interpreting navigation of sense of self.

The transformation of clinical consultations: Experiences of technologically-mediated consultations in HIV care

Marent, Benjamin Henwood, F., Mary Darking, M.
(University of Brighton)

Healthcare services are increasingly utilising digital technologies to facilitate mediated forms of doctor-patient interactions that fully or partially replace face-to-face consultations. Because theories of the ‘interaction order’ (Goffman) have been largely focused on the physical co-presence of interlocutors, less conceptual repertoire has been developed to analyse technologically-mediated interactions and to understand their different affordances that frame the possibilities of agentic action.
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This paper compares the affordances of face-to-face and technologically-mediated forms of doctor-patient consultations that have been introduced to follow-up stable HIV patients in five clinical sites (Antwerp, Barcelona, Brighton, Lisbon and Zagreb). As part of a sociotechnical evaluation of a newly introduced mHealth platform we conducted 8 co-design workshops and 66 interviews with 72 HIV patients and 32 clinicians to understand how the new technology reconfigured practices of care. Particularly, patients and clinicians were prompted to consider the differences of routine consultations being performed face-to-face (all five sites), by audio-video interfaces (Barcelona), by telephone (Zagreb), by email (Brighton), and through the newly introduced mHealth platform (all five sites).

Our data offers concrete examples of how different modes of interaction gradually dislocate, dissynchronize and standardise the clinical encounter and how these functional aspects enable and constrain medical examination, dialogue, patients' reassurance and the 'normalisation of HIV'. Understanding these functional affordances, we will outline what different forms of doctor-patient interaction mean for people in different situations. Our empirical evidence of technologically-mediated interactions challenges classic theoretical assumptions of co-presence through physical proximity and offers new avenues to reconceptualise the interaction order.

Wednesday 11 September 2019 at 15:10 - 15:40
CAMS
PL002

Death and the contemporary shamanic practitioner – findings from an empirical study
Marrable, Tish,
(University of Sussex)

For those facing the end of their lives or the death of someone close to them, spirituality has long been a source of comfort, whether through religion or through personal beliefs. In recent years in the UK we have seen a rise in interest in alternative spiritualities and healing methods, and different forms of ‘shamanic practice’ have been amongst these. While ‘shaman’ is a generalised term for what many consider the oldest healing and spiritual practices of humanity, contemporary understandings of this vary from still indigenous populations with long lineage to Western practitioners with new or ‘remembered’ ways of working.

This paper reports the findings from an empirical study exploring contemporary shamanic practitioners' understandings of their work with the dying, the bereaved, and the dead. It draws from 184 responses to a qualitative online survey, and a small number of semi-structured interviews with established shamans working from a number of different traditions. Responses from 22 countries demonstrate the wide range of understandings of shamanic death work, from helping those in hospices or at the end of their life to become more at peace with their impending death, to assisting the spirits of the dead to ‘pass on their way’ and detach from this world. Work with those bereaved may explore a healthy ongoing relationship with loved ones, or help to severe ties where a relationship was less comfortable. The paper will draw on the literature of ‘continuing bonds’ in grief work to help explore these connections.

Thursday 12 September 2019 at 11:20 - 11:50
Pharmaceuticals
PL006

Pharmaceuticalisation 2.0: the changing technology, politics and economics of the biopharmaceutical industry
Martin, Paul
(University of Sheffield)

 Fundamental changes are underway in the global biopharmaceutical industry as a result of major shifts in its core technologies, products and markets. In the wake of the productivity crisis that has dogged the sector a new wave of innovation is now driving drug discovery and development. This includes biological therapies (gene therapy, therapeutic proteins and monoclonal antibodies) and new classes of highly targeted small molecule drugs. At the same time, there has been a significant expansion in disease stratification and companion diagnostics. These have been translated into a raft of new products that are increasingly dominating the industry: 7 of the top 10 best-selling drugs are now biologicals; nearly 25% of all drugs sold have orphan status for small patient populations; 40% of products in company pipelines are based on these new therapies. These changes coincide with a strategic shift away from blockbuster markets based on common diseases to niche markets, high cost therapies and the treatment of rare diseases. Geographically, whilst globalisation has seen the expansion of the biopharmaceutical sector into China, East Asia and emerging markets, the highest sales growth continues to be in the USA. The industry has also been very successful in enrolling the support of patient groups for this new focus. Drawing on initial pilot work this paper will chart the contemporary transformation of the political economy of the biopharmaceutical industry, the emergence of this new sociotechnical regime and the major implications this has for patient, professionals and policy.
Thursday 12 September 2019 at 14:00 - 14:30  
Citizenship  
PL006

What can older veterans' experiences of military service tell us about wellbeing?

McWade, Brigit, Brewster, L., Clark, S., Giga, S., Fletcher, I.  
(Lancaster University)

This paper presents early findings from a project exploring the health and well-being needs of older British military veterans, funded by the Ministry of Defence's Aged Veterans Fund (AVF). This funding stream forms part of a wider social policy and government strategy drive to better recognise and reward the contribution of the armed forces to society. Drawing on the autobiographical accounts of older veterans' military experience, this paper questions whether the needs of this population are distinct from civilians and in what ways. It challenges the assumption that military service necessarily disadvantages service personnel in terms of health and well-being, revealing how military service was often described by our participants as the best days of their lives. In examining what constituted the 'best days' of our participants lives, we offer critical assessment of the policies and strategies that aim classify and mark-out veterans as "in need" of special treatment. Instead, we explore what lessons can be learned from veterans' life stories about the social and material aspects of well-being.

Thursday 12 September 2019 at 09:35 - 10:05  
Methods  
PT111

Was it autoethnography? The classificatory, confessional and mad politics of lived experience in sociological research

McWade, Brigit  
(Lancaster University)

This paper will consider the history and politics of autoethnography in relation to the activist scholarship of Mad Studies. As part of ethnographic research about 'recovery in/from serious mental health problems' in the UK, I accessed an NHS community ‘arts for mental health’ service as a service-user would do, situating this data in broader socio-political debates concerning the meaning, management and lived experience of madness and distress. This paper examines the framing of this research as autoethnographic and the relationship of personal and/or lived experience to the knowledge produced. I explore the classificatory, confessional and Mad politics of experience, identity and identification, and embodiment for research subjectivities. Employing autoethnographic means, I consider the ways in which I situate myself, and am situated by others, in relation to my research; evaluating the methodological implications of the crisis of representation in anthropology, and the post-structuralist criticism of identity politics. Through an engagement Mad Studies, I seek to move beyond these two established responses to the use of personal experience and autobiography in research.

Thursday 12 September 2019 at 10:45 - 11:15  
Pharmaceuticals  
PL006

Inclusive Digital Healthy Ageing: initial exploration and future directions

Meersohn, Cynthia, Moreira, T.  
(Durham University)

The rapid expansion of quantified-self (QS) technologies alongside variation of digital access and literacy, plays out across the intersection of age, class, and characteristics of individuals' social networks. Research about the digital literacy of older adults is shifting from a purely age based approach to an intersectional one, which considers the combined effects of socioeconomic status, autonomy of use, education, and accessibility alongside age in explaining different levels of digital savviness (Hunsaker and Hargittai, 2018). The complex relationship between health and broader dimensions of Quality of Life (QoL) has led to mismatch between QS technologies users’ expectations and existing technologies designed with a top-down approach. We explored the European QoL Survey (EQOLS) 2016 for associations between self-rated health and the broader social context of Europeans over 50 years old. Self-rated health is significantly and independently associated with specific health problems, changes in functional, status, mortality, and sociodemographic characteristics of respondents. We found that, among the European population over 50 years old, internet use was correlated with self-rated health (as a measure of QoL and well-being), but mediated by social participation and deprivation. Given these results, our working hypothesis is that different population needs demand different technology. Our analysis also indicates that the population 50+ is differentiated, but we do not know the composition of these groups. Following this hypothesis, our aim is identifying clusters of social, health, and digital exclusion across Europe, using a combination of quantitative case modelling, qualitative methods, and participatory design.
Informed and voluntary consent to children's heart surgery: What really matters to children, young people and their parents?

*Mendizabal-Espinosa, Rosa Maria., Alderson, P., Sutcliffe. K. (University College London)*

Consent to treatment for minors involves complicated three-way relationships between doctors, children and parents. The 1985 Gillick case respected the consent of children aged under-16 in English law. European-influenced law and recent commentaries accept US standards of children's 'assent'; these bypass the views of minors aged under-18. A renewed debate about how much and to what degree children and young people ought to be and want to be involved in informed consent to complex interventions is needed.

Trust is at the heart of consent. Yet it is invisible and can only be implied when patients or their parents sign a legal form. It might be better understood at three different levels through: the empirical ways in which people feel, think and talk about it; the actual nature of trusting or mistrustful relationships, interactions, discussions and rituals inside and outside medical-family encounters; and the real, powerful unseen forces, social, cultural, political and economic, which influence people's beliefs and behaviours related to trust. Trust can also be understood in its absence, such as in acts of manipulation, deception or abuse of power.

Critical realism offers useful ways to research consent and trust in medical settings. It recognises absence and unseen influences as essential to understanding social problems and identifying possibilities for change. We describe our social research in two London hospitals and discuss how critical realism might underpin an in-depth, three-level analysis that might lead to a better understanding of what 'really' matters to people in the process of giving consent.

Dialectical thinking and the “economic determinants” of performance: What Marxism can contribute to health services research in an age of complexity

*Mills, Thomas (Bradford Institute for Health Research)*

Health services researchers are increasingly urged to contextualise problems in a “multi-layered reality” of inter-related micro-, meso- and macro-level factors. Yet what is in the remit of the macro, and how macro-factors relate to micro- and meso-factors, is unclear. This presentation argues that Marxism can contribute here, both methodologically through dialectical thinking and in terms of substantive insights regarding the dynamics of capitalism which shape health service environments. A process evaluation informed by complexity science was undertaken of a two-year HS&DR funded study which sought to develop and test ways of helping Healthcare Professionals (HCPs) to improve patient experience. Severe staff and service pressures were encountered on the 6 wards involved, prompting the question of how and at what level (micro, meso or macro) the pressures should be theorised. Applying Marxist dialectics was found to enrich understanding of the macro-level, set by an on-going macroeconomic shift from embedded liberalism to neoliberalism and the constraints on public resources implied by the latter. Furthermore, while staff engagement and culture were identified as being significant micro- and meso-level factors in the study, the Marxist concept of alienation suggests these are shaped by HCPs' (lack of) autonomy over their work process, increasingly affected by capitalist forms of production and exchange despite the NHS being a public service. In summary, Marxist insights can enrich complexity-minded health services research. Marxism poses the question of the macro-economic climate, resource levels and governance arrangements that would provide a receptive context in the NHS for research and improvement work.

Wild Data: How Frontline Hospital Staff Make Sense of Patients' Experiences

*Montgomery, Catherine, Chisholm, A., Locock, L., Parkin, S. (University of Oxford)*

Patient-centred care has become the touchstone of healthcare policy in developed healthcare systems around the world. The ensuing commodification of patients’ experiences within what are widely regarded to be new logics of accounting and accountability has resulted in a mass of data but little sense of whether and how such data are used. Our research sought to understand how frontline staff use patient experience data for quality improvement in the NHS. We conducted ethnographic case study evaluation of improvement projects in six NHS hospitals in England over a 12 month period. The data drawn on here consist of 95 in-depth interviews with frontline staff and senior managers, and almost 300 hours of observation. Frontline staff worked with a notion of data as interpersonal and embodied. In addition to consulting organizationally-sanctioned forms of data collected at organisational level,
staff used their own embodied interactions with patients, carers, other staff and the ward environment to shape improvements. The kinds of data staff found useful involved face-to-face interaction and dialogue; were visual, emotive, and allowed for immediate action. We draw on de Certeau to re-conceptualise this as ‘wild data’. We conclude that patient experience data are relational, and have material, social, and affective dimensions, which have been elided in the literature to date. Moving from ‘patient experience’ as a disembodied tool of managerialism to an embedded part of healthcare staff professionalism can lead to positive change.

**Towards a Sociology of Lewy-Body Dementia**

*Moreira, Tiago (Durham University)*

Lewy Body Dementia (LBD) is an umbrella diagnostic label which includes both Dementia with Lewy Bodies and Parkinson's Disease Dementia. Distinctive features of the condition - cognitive fluctuations and hallucinations - set it apart from more common dementia forms. Existing research on this condition has overwhelmingly adopted a clinical or health services perspective. We suggest that LBD provides a unique opportunity to combine a conventional social science approach to illness with research that is 'interested in the dialectic interaction between social life and specific diseases' (Timmermans and Hass, 2008: 661). In this paper, we present a structured review of existing social science research on LBD on three interrelated domains: making, managing and living with LBD. We map the social arena of research on Lewy Body Dementia and its relationship with the fields of Alzheimer's and Parkinson's Disease research. We identify the clinical and service barriers and facilitators to diagnosis and management of Lewy body Dementia. We explore the role of cognitive fluctuations and visual hallucinations in the process of living with Lewy Body Dementia. Drawing on the review, we propose an agenda for social science research on LBD that will contribute both to the understanding of the condition and the sociology of health and illness.

**From policy to practice? Implementation of welfare technology in daily professional practice in municipality healthcare. A case study.**

*Myren, Gunn Eva (Nord University)*

Complex interventions to improve health and social activity can only have significant impact if they are shown to be effective, capable of broad implementation and can be normalized into routine practices. There is lack of studies that explore the implementation process of welfare technology as most studies tend to focus on the effectiveness of welfare technology, and are generally based on single studies with specific interventions within specific settings.

The aim of our study is we to contribute to knowledge about implementation process of welfare technology through three case studies. In this study we focus on technology that seek to decrease social isolation by use of communication then amongst children in school (AV1) and the elderly living at home (KOMP).

By use of observations and interviews we shall collect data on the children using AV1 and their parents, teachers and classmates regarding the use of the avatar. The elderly using KOMP, their relatives, followers on KOMP and professional practitioners will be also be interviewed regarding their experiences with the use of KOMP.

An underlying assumption for this study is that the professional practitioners are crucial in realizing the success/potential of welfare technology. It is therefore important to study the processes that these professionals practitioners and users go through in their use of welfare technology.

**Diagnosis as a social influence on health: an autoethnography of diagnostic identity in anorexia**

*O’Connell, Lauren (University of Essex)*

Being diagnosed with a psychiatric condition can have a significant influence on one's identity. In anorexia, individuals sometimes come to value (and even seek) an identity based on illness, often while simultaneously experiencing such a positioning as stigmatising, life-limiting, and discrediting. My research is concerned with individuals' experiences of being diagnosed with anorexia, their relationship to the diagnosis over time, and how this informs their ongoing identity-work. In this paper, I present findings from
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the autoethnographic component of my research, in which I draw on memory, personal diaries and medical notes to analyse my experiences of being diagnosed with anorexia and undergoing inpatient treatment. I use aspects of Brinkmann's heuristic model of the lived experience of a psychiatric diagnosis to argue that, for me, the 'being' and 'doing' of anorexia played out in particular ways. I came to value 'being anorexic'; it was a positioning that felt empowering and offered me a sense of belonging. This in turn had implications for how my suffering was 'done'. In seeking to inhabit the diagnosis, I self-consciously monitored the extent to which I was performing it 'properly', in accordance with broader clinical constructions of the diagnosis. Finally, within a framework of a sociology of diagnosis, I draw on notions of diagnosis as category, process and consequence to further illuminate my experiences and to suggest that the act of diagnosis can be an iatrogenic social influence on health.

Thursday 12 September 2019 at 15:10 - 15:40
STS
PL005

The translation of multiple scripts in the tools used in quality improvement – the case of sepsis

Overton, Charlotte
(University of Nottingham)

The improvement of healthcare quality often involves the introduction of technologies to bring about behavioural change within clinical practice. Drawing on Akrich's notion of scripts this research considers how and why quality improvement tools were interpreted when used in clinical practice. The tool's script contained certain prescriptions that either did or did not materialise when in use. Consideration of the specific contexts was not built into the tools, that is, they were fixed irrespective of the site of implementation. Inevitably, this was found to have an impact of translation of the tool's scripts when used in practice. I argue that if quality improvement was to emerge, an understanding of the tool's scripts was required.

This ethnographic study involved observations, interviews and documentary analysis within and across two English NHS hospitals, exploring the implementation of tools associated with the sepsis care bundle. Data analysis found that the tools served multiple purposes and embodied diverse scripts. As a result multiple scripts were translated; evidence for a financial incentive, the delivery of evidence-based medicine, communication tool, aide-memoire and a burden. Knowledge of sepsis was on a continuum; the tool was used as an aide-memoire for junior staff or staff who had infrequent exposure to sepsis. As the healthcare worker progressed along the continuum of experience completion of the tools became perceived to be an unnecessary addition to their workload and thus a burden. For others the tools influenced interprofessional relationships by acting as an additional voice to support the escalation of patients.

Friday 13 September 2019 at 10:45 - 11:15
Health Service Delivery
PT006

Solidarity and contestation in group clinics for young people with diabetes in socioeconomically deprived settings: patient and professional experiences

Papoutsi, Chrysanthi, Greenhalgh, T., Hargreaves, D., Kanadia, J., Colligan, G., Hagell, A., Marshall, M., Vijayaraghavan, S., Finer, S.,
(University of Oxford)

As a relatively new model of care, group clinics have attracted the attention of policy makers and clinicians, with attention primarily focusing on biomedical outcomes, demand for health services and efficiency savings. Little emphasis is paid to how different forms of patienthood and professional practice are enacted.

This presentation examines patient and professional experiences as part of a NIHR-funded study on implementation, co-design and evaluation of outpatient group clinics for young people (16-25) with diabetes and other complex health and social needs in two London clinics. We carried out 32 semi-structured patient and staff interviews, and collected ethnographic fieldnotes from 27 group clinics, 20 individual consultations and other interactions. The analysis was underpinned by critical perspectives on patient expertise and experiential knowledge, articulation and invisible work, and solidarity-based practices in relational medicine.

We approach group clinics in three different ways: as practices of solidarity; as opportunities for active contestation; and as sites of hidden labour. In contrast to individual appointments, group clinics foreground relational aspects of self-care. This introduces new types of ethical relations between patients, projects new ways of enacting patienthood and requires different modes of organising professional practice. Our presentation will discuss how embodied and biomedical knowledge is negotiated among young people and health professionals. We will explore what it means for clinical care to be harnessing experiential knowledge directly through active patient participation in service provision. We will also draw out some of the tensions involved in doing this, especially when conflict and contestation arise between patients.
Organisational work in neonatal care: Decision making about place of care for babies born moderately preterm

Paton, Alexis, Armstrong, N.
(University of Leicester)

Organisation of neonatal services into geographically-based networks of units able to offer different levels of care is intended to ensure both that babies receive the care required and that transfers between different units are as smooth as possible. Identifying the appropriate level of care for babies born prematurely can sometimes be straightforward, but for babies born moderately pre-term (at 27-31 weeks’ gestation) there is little evidence to guide healthcare professionals’ decision making about optimal place of care. Even when identifying optimal place of care is relatively straightforward, achieving this in practice can be complex.

Drawing on a wider study seeking to determine optimal place of care for this group of babies, we report findings from ethnographic work exploring decision-making and the accomplishment of transfers in this complex care context. We undertook fieldwork in six neonatal units across two networks in England (two Neonatal Intensive Care Units and four Local Neonatal Units), representing 35 days of observation and interviews with 34 healthcare professionals and patients.

Drawing on sociological work illuminating the organisational labour of healthcare, we discuss how decisions about optimal place of care are made and transfers accomplished (or not) in contingent and complex care contexts often characterised by high levels of uncertainty. Place of care decisions are multifaceted, with transfers taking place for a number of different reasons and with different short and longer-term objectives. The consequences of place of care decisions and any resulting transfers can be significant for healthcare organisations, healthcare professionals, and, of course, for parents.

Thursday 12 September 2019 at 09:00 - 09:30
Screening and Diagnosis
James Hall

Understanding Non-epileptic Attack Disorder (NEAD) sociologically; can we do this?

Peacock, M.
(Edge Hill University)

Non-epileptic attack disorder (NEAD) is the most frequent functional neurological disorder (FND) seen by neurologists with an estimated 20% of patients first presenting to seizure clinics receiving a diagnosis of NEAD. Also known as psychogenic non-epileptic, dissociative or conversion seizures, NEAD is characterised by embodied events that superficially resemble epileptic attacks, but which are not associated with the abnormal electrical discharges in the brain found in epilepsy. Rather, NEAD is considered to be an involuntary, unconscious, emotional response to internal or external triggers. Characterised by episodic impairment of consciousness and loss of motor control, these experiences are frequently mistaken for epileptic seizures although there are significant differences between these disorders. NEAD can result in significant and chronic disability and, when health professionals inadvertently misdiagnose the condition as epilepsy, patients are at risk of exposure to inappropriate investigations or treatments and thus iatrogenic harm. Sitting as it does within a suite of medically unexplained symptoms (MUS), NEAD is a troubling diagnosis to both give and to receive. The sorts of psychological or emotion/stress-based explanations given by clinicians may be hard to hear, evoking fears of being labelled as mentally ill or malingering, with studies showing how the clinical space can become a battle ground as doctor and patient struggle for epistemological legitimacy. Even for those more at ease with the “psychological” nature of the diagnosis, it may be difficult to make sense of how life events might connect with their seizures. There is an extensive body of research in neurology concerning NEAD but, despite indicators of social patterning in presentation and significant limitations in what neurology can offer in the form of effective treatment, there is very epidemiological evidence to underpin and to help develop sociological understandings of NEAD. We know that around three quarters of those with a diagnosis of NEAD are women and NEAD appears to be linked with histories of neglect, trauma or conflict in childhood including childhood sexual abuse (CSA), reported by 20-30% of women and 5% of men in different patient cohorts. Increased rates of adverse life events have also been found amongst those with NEAD, with such events often serving to precipitate onset in adulthood. But around a third of patients report neither trauma nor negative life experiences. Drawing on data from a study using biographical-narrative interviews with those with NEAD, this paper asks firstly why an epidemiology might be absent using comparisons with the chronic pain and depression literatures and then endeavours to interrogate the apparent lack of curiosity in neurology concerning sociological or historical perspectives. This is particularly in the light of NEAD arguably being the contemporary heir of "hysterical conversion", Charcot’s women and psychogenic movement disorders expressed historically in dancing plagues amongst others. Finally, we offer a tentative theorising of NEAD in the present day context of burgeoning medicalisation, the demands of neoliberal governance for individual responsibility and the striving for diagnostic legitimacy.
Male circumcision and sexual functioning among males and their female partners: The role of cultural background

Peri-Rotem, Nitzan
(University of Exeter)

Male circumcision (MC) is one of the most common surgical procedures performed worldwide. Yet, this procedure has remained highly contentious and, empirical evidence about its health benefits and implications on sexual functioning is mixed. While the prevalence of MC and its drivers vary greatly across social groups, the role of cultural background in mediating the relationship between MC and sexual functioning has so far received little attention. Since sexual satisfaction can be influenced by social perceptions and attitudes about sexuality and body image, it is hypothesised that MC is more likely to be linked with improved subjective sexual functioning among those groups where MC is more prevalent. To test this hypothesis, I analysed data from the British National Survey of Sexual Attitudes and Lifestyle from 2010-2012 (Natsal-3). This survey includes over 6,000 men and 8,000 women aged 16-74. Using logistic regression models, the odds of experiencing sexual dysfunction for the male or female partner are estimated as a function of male circumcision status, religion and educational attainment, alongside both partners’ age and ethnicity. The findings show that the relationship between MC and reported sexual functioning is largely dependent on the ethnic origin of the male partner; MC is found negatively linked with reported male sexual dysfunction only among black men. In addition, MC is negatively linked with reported female sexual difficulties when the male partner is of Asian origin. These findings highlight the importance of cultural context in shaping the relationship between MC and subjective sexual functioning.

Managing hard-to-interpret talk in people with dementia in a context of person-centred care.

Pilnick, Alison, O’Brien, R., Beeke, S., Goldberg, S., Sartain, K., Parry, R. and Harwood, R.
(University of Nottingham)

Delivering care to patients with dementia in acute hospitals presents particular challenges for healthcare professionals, and they report feeling ill-equipped to deal with these challenges. One specific and commonly encountered challenge arises when the talk of patients with dementia is hard to interpret or make sense of. Observational studies identify that such talk is sometimes ignored (Goldberg et al., 2014; Featherstone et al., 2018); this ignoring is generally interpreted as a failure to provide person-centred care, but may also reflect the practical interactional difficulties healthcare professionals face in attempting to engage. This paper reports on an NIHR CLARHC East Midlands funded study to explore challenges in communication in this setting. Video recordings of 41 naturally occurring healthcare interactions between healthcare professionals (including doctors, nurses and allied health professionals) and inpatients with dementia were collected. These were analysed using conversation analysis. All occurrences of patients' hard-to-interpret talk were identified across the 41 interactions and their sequential contexts examined. We found that occurrences of patients' hard-to-interpret talk were prevalent across the dataset. Analysis revealed several different practices healthcare professionals used to manage this, linked to features of the patient's prior talk. One potential difficulty in pursuing hard-to-interpret talk is that it can expose or highlight lack of interactional competency in an individual, and professionals' responses often worked to limit this possibility. Use of video also highlighted that whilst hard-to-interpret talk might not be responded to verbally, the use of touch was a recurrent feature of these interactions.

Dying without an End of Life diagnosis: how does prioritising community End of Life care affect frail older people who have no 'life-limiting condition'? A qualitative study

Polak, Louisa, Hopkins, S., Barclay, S., Hoare, S.
(University of Cambridge)

End of Life (EoL) care in the community is gaining increasing prominence within health policies and commissioning decisions in the UK. In this paper we suggest that those who die of old age, without a specific medical diagnosis, may be disadvantaged as an unintended consequence of prioritising EoL care within a cash-limited service. Our study draws on interviews with providers of community EoL care in East Anglia. Using thematic analysis and constant comparison, we examine the way “good EoL care” is constructed by those who aim to deliver it. Participants foregrounded the challenge of responding quickly to the unexpected needs of patients and their families, and cited planning ahead as helpful for meeting this challenge. Such planning is facilitated by an “EoL” diagnosis. The uncertainty inherent in this diagnosis is reduced where death is due to a single illness whose usual trajectory is known, but greatly increased where it is due to a collection of age-related health problems. When asked about EoL care, many participants...
spoke first about patients with a diagnosis of cancer or specific organ failures; only when specifically prompted by the interviewer did they talk about caring for frail older people who turn out to be dying. Once prompted, several mentioned the better resources available for “EoL” patients: as well as “opening doors” to additional services, providers describe prioritising calls from these patients ahead of other calls. This difference cannot be ascribed to widely differing care needs. As one participant explained, “the basic care is the same”.

Thursday 12 September 2019 at 14:35 - 15:05
Experiences of Health and Illness
PL006

Understanding the ‘hard work’ patients do when seeking urgent care

Pope, Catherine.
(University of Oxford)

Urgent care is characterised by fragmentation and blurred boundaries between services. Policy research about how people use these services has focussed on utilisation and, notably the problem of ‘inappropriate attendances’ to emergency departments. Medical sociologists have attempted to reframe help-seeking as a social process, describing psycho-social determinants that explain urgent care help-seeking, but these explanations offer less insight about the work that people do to make sense of their care needs and assess care. In this paper, inspired by Wyke et al (2013), and classic work by Anselm Strauss, we shift the focus to the ‘work’ people do when they use urgent care services. We conducted semi-structured interviews with 100 people, purposively sampled to represent potential differences in care needs and socio-demographic characteristics (people aged 75+, 18-26 years and those migrant communities). We conducted second interviews with 41 of these people to extend our analysis. We delineate three related, but distinct, types of work involved in making sense of urgent care: illness, moral and navigation work and show that help-seeking requires the careful balancing of these. We argue that people do not deliberately make ‘wrong’ or ‘inappropriate’ decisions, rather, their choices are a product of ‘hard work’ by individuals and their social networks. Our paper offers a conceptual model that suggests that to change outcomes, there needs to be a change to the work people do, collectively and individually when seeking urgent care.

Friday 13 September 2019 at 12:30 - 13:00
Politics of Health
PL006

claiming benefits in the face of epistemological sabotage

Porter, Tom
(University of East Anglia)

Disability prevalence has remained relatively stable in recent decades, yet spending on benefits has increased markedly. The latter of these trends causes concern for those in power, who deem increased spending to be unsustainable, with welfare reform being a direct response.

Disability has been conceptualised in different ways: according to a medical model, the social model, and latterly, human rights and capability approaches. But for the purpose of understanding disability benefits, disability is a formal administrative category, which allows disabled claimants to move from a work-based system of redistribution to a needs-based system of redistribution.

This paper reports on data from 50 in-depth interviews with disabled claimants of Employment and Support Allowance and Personal Independence Payments, in addition to a discourse analysis of official guidance for claimants, NHS doctors, and the healthcare professionals contracted by the Department for Work and Pensions (DWP).

Findings show that disabled claimants often struggle to understand the assessment process, whilst sourcing and presenting effective evidence is particularly challenging. Analysis of DWP documents reveal a constructed ambiguity around disability and the type of evidence needed to support claims. Guidance for claimants, NHS clinicians, and private clinicians each appeal to distinct popular, medical and administrative concepts of disability. These conceptualisations each involve competing ontologies and epistemologies of disability.

We argue that the ambiguity created by official documents acts as a form of epistemological sabotage, which advances the government's goal of restricting the category of disability and therefore limiting access to the needs based system of redistribution.

Friday 13 September 2019 at 10:45 - 11:15
Politics of Health
PL006

Accessing healthcare in the UK: navigating a hostile borderscape

Potter, Jessica
(Queen Mary, University of London)
Paper Abstracts

Tuberculosis (TB) is an infectious disease of global importance. The Collaborative TB Strategy for England aims to eliminate TB with a key focus on improving access to healthcare for at-risk populations. In England the group positioned most at-risk of TB in public health reports are people not born in the UK. This study explored the experiences of recent migrants to the UK of accessing healthcare when they became unwell with tuberculosis. Data collected between 2014 and 2018 included: 100 questionnaires and 14 biographic narrative interviews with recent migrants diagnosed with TB; and 10 in-depth interviews with health system gate-keepers. Healthcare access is not simply a point in time; it is dynamic, contextual and negotiated (Dixon-Woods et al., 2006). One context apparent both within my analysis and mainstream media discourse was the 'hostile environment'. Drawing from critical border studies, I re-imagine healthcare access as a borderscape (Brambilla, 2015). Migrants’ experience of navigating this borderscape were fearful, racialising and at times violent, as their relative deservingness for care was called into question. These experiences were intersectional, (re)producing precarity along axes of race, class, gender, and immigration status. Staff were employed, persuaded or threatened into maintaining the border between those seeking care and its provision. Techniques of government in these spaces operated through mechanisms of surveillance, discipline, normalisation and bureaucracy. These practices not only shaped how hostility was experienced but maintained, sustained and (re)produced the hostile borderscape. Finally, I argue this exclusionary politics of care undermines national and global efforts to eliminate TB.

Friday 13 September 2019 at 10:10 - 10:40
Critical Public Health
PL001

Is this desire? The demand for medical interventions and moral judgments about public funding of healthcare

Pralat, Robert
(University of Cambridge)

In this paper, I discuss the notion of 'desire' as a potential driving force behind both the demand for medical interventions and the mobilisation of moral judgments about whether medical interventions should be publicly funded. Through an analysis of UK press coverage and using three case studies - sexual desire, the desire to have a child and the desire for a different body - I examine how judgments about public funding rely on the distinction between what is perceived to be 'needed' and what is seen as merely 'wanted'. This distinction, I argue, demarcates medical interventions that are understood as deserving of state support from those that are regarded as 'low priority', especially in the context of financial pressure. I explore how this logic may contribute to the framing of patient motivations as needs and a strategic de-centring of desire as an aspect of identity. I ask: what are the advantages and disadvantages of paying more attention to desire in the context of public health?

Thursday 12 September 2019 at 14:00 - 14:30
Methods
PT111

Reaching the 'hard-to-reach': creative strategies adopted while developing a complex intervention

Rai, Tanvi, Schwartz, C., Morton, K., Mc Manus, R., Hinton,L.
(University of Oxford)

UK medical guidelines continue to be informed by research carried out in largely ethnically White and middle class populations. Some medical conditions, such as stroke, disproportionately affect economically poor and BAME communities and yet these groups are underrepresented in medical research.

We have adopted different recruitment methods to facilitate a more representative sample of the national stroke population, as part of intervention development for an RCT of self-monitoring of blood pressure following a stroke. In addition to standard letters sent out by participating surgeries inviting patients to take part, we also attended (and participated in) religious services held weekly at churches and mosques, stroke group pub lunches and support group meetings in socially-deprived neighbourhoods. While not being onerous, these approaches enabled us to recruit nearly half of the intervention study participants for interviews who were working class and/or from BAME communities. The opportunity to become a research participant was met with enthusiasm and generosity; it allowed us to explore perceptions of the intervention in those with greater post-stroke morbidity and where participants’ had multidimensional relationships with families who acted as their carers and advocates.

These approaches have generated rich and relevant data to inform intervention development, making it more widely accessible. Using alternative and creative methods to recruit study participants fits within a wider shift in research discourse that recognises the importance of public engagement in scientific research. Developing new health interventions in partnership with those bearing the greatest burden of ill health is likely to improve health for all.
Social inequity in cardiovascular disease: the role of the spouse

Rasmussen, Amanda Nikolajew, Overgaard, C.
(Aalborg University)

Social inequity in health is one of the key threats to global health. Accordingly, reduction of social disparities in health is a part of WHO's Sustainable Development Goals. Cardiovascular disease is one of the diseases that shows the largest social stratification worldwide. It is well documented that social differences in lifestyle factors play an important role in social inequity in cardiovascular disease and lifestyle interventions have been the main focus of public health strategies but social inequity remains. Epidemiological research shows that social inequity is apparent even when adjusting for known risk factors. Important mechanisms underlying social inequity in cardiovascular disease are thus only partly known. This study draws on the theoretical framework proposed by Bruce Link and Jo Phelan in the "Theory of Fundamental Causes of Disease", suggesting that to understand social stratification in disease thoroughly, the significance of factors that are more distant to the disease in the casual chain, such as social conditions, must be more explored. Social conditions involve both economic and social structures, including social relationships with other people. Marriage is one of the most fundamental and significant social relationships in most cultures. Living with a spouse have been shown to have a positive effect on both physical and mental health of cardiovascular patients. This effect could be explained by use of social support theory, which highlights social relationships' ability to provide support in stressful situations. The effect of the spouse is however complex and has not been sufficiently explored. As having a spouse may potentially offer a mitigating effect on social inequity in cardiovascular disease it is crucial to gain further insight. The overall objective of this study is therefore to contribute to the understanding of underlying psychosocial factors driving social inequity in cardiovascular disease by exploring the role of the spouse in the experience of life with cardiovascular disease for patients with low socioeconomic status. The study is designed as a holistic multiple case study that includes 30 cardiovascular patients with low socioeconomic status and limited social support, with and without a spouse, who are studied through qualitative interviews with the patients and their spouses. The study setting is Denmark; a country still struggling with substantial social inequalities in health, despite a highly developed welfare system and publicly funded health care. The data collection is nationwide and carried out between October 2018 and July 2019. As the study is currently in the phase of data collection and analysis, results cannot be reported at this stage but will be ready for presentation at the conference. The insights from the study can contribute to the development of more effective interventions against social inequity in cardiovascular disease that takes the social aspects of the problem into account and are sensitive to the patients' needs and perspectives.

What is loneliness? Exploring loneliness as theoretical concept and empirical phenomenon in science

Rasmussen, Erik Børve, Johannessen, L. E. F
(Oslo Metropolitan University)

Loneliness is receiving widespread political attention – especially in Western societies, where it is considered a growing problem due to increasing individualisation and compartmentalisation. The issue also attracts much academic attention, with studies particularly addressing the extent and consequences of loneliness, asking questions such as ‘who and how many people are lonely, 'is the loneliness problem increasing' and 'what kind consequences can loneliness have’. These studies are inevitably based on assumptions about what loneliness is and implies; however, while loneliness is often conceptualised within each article, there has been little research into how the concept is defined and operationalised across current studies. In this study, we thus ask how loneliness is understood in the research context. Based on a critical and explorative document analysis of the 100 most cited articles on 'loneliness' (published in English between 1998 and 2018), we show that the literature is dominated by articulations of loneliness as a health problem for the isolated individual. As such, it is a personal problem of reduced physical and mental well-being, and primarily a matter of health care for the sick and elderly. Moreover, we show that the literature asks many questions about how to amend this problem by technological interventions, but few questions about its societal causes. We then discuss some seminal blind spots regarding the understanding and management of loneliness in existing conceptualisations, and suggest how these may be overcome in future research and debates on this highly pertinent topic.
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Thursday 12 September 2019 at 11:55 - 12:25
Health Service Delivery (Pecha Kucha)
PT007

The electronic patient record and medical ward rounds
Reay, Victoria, Brewster, L., Wood. L.
(Lancaster University)

After decades of costly national information technology programmes, electronic patient records (EPRs) are gradually starting to replace paper notes in hospitals across the NHS. Electronic patient records are presumed to improve care, transforming it in multiple ways, including increased efficiency, legibility, and accessibility. Despite these hopes, unintended consequences have been reported, and it has been shown that removal of the paper record as a central communication and collaboration device can change the way that clinicians work together (Coiera, 2016; Bardach, 2017).

Drawing on findings from my PhD research, this paper turns attention to the ways in which the EPR is transforming a central activity of daily medical work: the ward round. Using ethnographic methods (observations and staff member interviews), my project has been exploring how electronic records, newly mobilised via computers-on-wheels (‘COWs’), are reshaping the way that medical work is done.

I will present the ways in which the ward round is being reconfigured in response to, and around, the EPR and the COWs. I will show how staff are adapting to the remote accessibility of the medical record and the diversification of ward round practice that this allows. Wards rounds using mobile computers are reshaping intraprofessional collaboration practices, and whilst they increase the availability of the EPR, they introduce new barriers to communication and care.

Thursday 12 September 2019 at 15:10 - 15:40
Lifecourse
PX001

Disabling academia: how university policies construct disability and limit academics experiencing long term health conditions
Remnant, Jen
(Heriot-Watt University)

There is a lack of data regarding the experiences of disabled academic staff and staff with long-term conditions working in UK universities. This paper draws on qualitative interview data from multiple perspectives; university executives, line managers, human resources staff, trade unionists and disabled staff and a discourse analysis of university policies that relate to the management of workplace ill-health and disability. Participants were sampled primarily from two Scottish universities. A key finding from this exploratory study is how some university policies, ostensibly written to support disabled academic staff and those experiencing long-term conditions, construct disability and enable disabling practices. Data highlights how university policies (and practices) conceptualise ill-health and disability negatively, and only in relation to an individual’s capacity to work. They generated additional labour for disabled staff, and thus limited their ability to complete their paid roles. Policy analysis compared the content of staff-focused policies to organisational framings of disabled students. Disability and long-term conditions were found to be flexible concepts within universities depending on specific roles under capitalism; consumer/producer. This paper offers new insight into how health might be reconceptualised in UK workplaces and emphasises how current sociological models for illness have limited explanatory potential when exploring long-term conditions and disability in the workplace, despite pressing policy relevance.

Wednesday 11 September 2019 at 15:45 - 16:15
Health Service Delivery
PL006

How does organisational context impact on antibiotic stewardship in primary care?
Richardson, Emma, Tarrant, C.
(University of Leicester)

Reducing antibiotic use in healthcare is critical in managing the growing problem of antimicrobial resistance. We aimed to explore the impact of organisational context on how antibiotic stewardship is enacted in primary care, in order to inform the development and implementation of novel interventions. Ethnographic observations were conducted in four primary care practices in England (two high antibiotic prescribers, and two low), drawing on Bate et al’s (2008) model of six universal challenges for organising quality in healthcare. Here we focus on structural and cultural/social challenges. We identified that availability of access to appointments, prescriber confidence in patient safety netting (patients re-consulting in the case of symptom deterioration), and patient usage of alternative services, all contributed to shaping practices around antibiotic use. Our findings suggest that having better structures in place to deal with high demand and return appointments, including in-house quick access clinics and walk-in services, facilitated efforts to optimise antibiotic use. Characteristics of the patient population, including transience and vulnerability, impacted on prescribers’ confidence in using a safety netting approach. Stewardship efforts were compromised in practices in which accessibility was lower, and when patients relied more heavily on alternative out of hours or emergency services. Inconsistencies in prescribing...
activities and messages received by patients across different services could undermine practice stewardship efforts. We conclude that local systems and organisational context are strongly consequential for the implementation and effectiveness of stewardship strategies, pointing to the need for contextually-sensitive approaches to optimising antibiotic use in primary care.

Thursday 12 September 2019 at 10:10 - 10:40
Methods
PT111

'Where do I apply for a job where I can just sit around all day?': The embodied and emotional experience of doing hospice ethnography.
Richardson, Natalie
(University of Sheffield)
The research aims to look at suffering from the perspectives and experiences of palliative care workers. To appreciate how palliative care workers react to and engage with suffering, I entered into a hospice in the North of England for six months to conduct observations and interviews with staff members. This paper concentrates on the observations conducted in the research, which were conducted in different spaces of the hospice and adopted a sensory approach to focus on the day-to-day movements, experiences and interactions of hospice professionals. My experience often echoed that of Lawton (2000) and of Hockey (2007), who reflect on the confused or concerned reactions to doing fieldwork in a hospice or doing 'death research'. However, the emotions involved in doing sensitive research projects usually become a short footnote or are filtered out of the final piece altogether (Visser 2017). There is a need to write the researcher's body into a 'bodiless' qualitative health research field (Ellingson 2006: 301). Therefore, this paper seeks to discuss my research experience as an embodied one, exploring the processes of moving about spatially in the hospice and experiencing it as a physical place of emotions, senses as well as relationships with others. In doing so, I hope to appreciate the mundane, day-to-day decision making processes involved in doing ethnographic research in a hospice setting.

Thursday 12 September 2019 at 15:10 - 15:40
Theory
PL002

A realist review of advocacy interventions for abused women: taking a capability approach
Rivas, Carol, Cameron, J., Vigurs, C.
(UCL)
Worldwide, on average 30% of women experience physical or sexual intimate partner abuse ('domestic violence') in their adult lives; many more experience psychological abuse. Studies have considered the effectiveness of advocacy in supporting these women and reducing repeat abuse. Typically, advocacy aims to empower women to gain control of aspects of their lives. However, advocacy programmes vary considerably in their focus, content, setting, who they are delivered by, duration and intensity of their delivery. Moreover, advocacy is person-centred with no 'one size fits all'. These features make effectiveness and mechanisms of effect hard to evaluate, and the evidence base for advocacy remains weak. Our realist review aimed to elucidate how, why and in what contexts advocacy works and for whom. The theory we developed, foregrounding both advocates and the women they supported, was informed by Sen's capability theory. Our work, undertaken with advisory input from a panel of stakeholders including abused women, shows key 'conversion factors' include women's demographics, their relative dependency on the men who abuse them, the nature of the abuse, whether the women live in rural or more urban areas, and the advocacy setting. It was equally important to consider factors that affected the advocate, their capabilities in doing their work, and the set of functionings or activities they could choose from to support women. Advocates were worried about overstepping boundaries and often suffered burnout. Our outputs should help policymakers and practitioners designing new advocacy interventions or trying to understand existing ones, as well as other researchers.

Wednesday 11 September 2019 at 15:10 - 15:40
Lifecourse
PT007

The trouble with televising childbirth
Roberts, Julie, Spiby, H., DeBenedictis, S.
(University of Nottingham)
Medical sociologists have long investigated the mediation of health, or how media shapes experiences of health and medicine. Despite the popularity of childbirth as a topic of mainstream television, televised birth has so far received little sociological attention; yet it raises urgent questions about the place of birth in visual culture and the role and responsibilities of the media in preparing women for childbirth. Drawing on a suite of work focused on reality television, this presentation considers the 'trouble' with televising childbirth from three perspectives. First, a content analysis of reality television show One Born Every Minute, will serve as an example to highlight issues around the ways in which birth is represented. We question claims that emergencies are over-represented but explore the more subtle ways that birth is represented as medicalised and highlight a troubling absence of processes of informed
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choice and consent from the screen. Secondly, drawing on commentary and focus group data, we will explore the controversy in the birth community about the appropriateness of showing birth on mainstream television as 'entertainment', and the potential for harm, including increasing fear of birth among women and normalising the medicalisation of birth. Finally, and drawing connections with the first two sections of the paper, we will examine the 'trouble' with researching the ways in which televised birth might shape women's experiences of birth and maternity services, highlighting methodological debates and making the case for interdisciplinary collaboration.

Thursday 12 September 2019 at 10:10 - 10:40
Pharmaceuticals
PL006

Socio-cultural and Political Studies of Anti-Microbial Resistance (AMR): A Scoping Review

Rodrigues, Carla, Vedadhir, A., Lambert, H.
(University of Bristol)

Anti-Microbial Resistance (AMR) is a critical global health issue and an increasing topic of concern for academics, health professionals, policy-makers and the public across the globe. As a complex and multifaceted problem, challenges to tackle AMR can only be efficiently addressed though a transdisciplinary approach. As a result of recent efforts to champion and highlight the relevance of applied social sciences research to AMR, the value of engaging medical sociologists and anthropologists in transdisciplinary teams to address the socio-cultural, economic and cosmopolitical impacts of AMR is becoming more widely acknowledged. Notwithstanding the existing efforts to address AMR, knowledge of the theoretical, empirical and practical contributions of social science research to this issue is widely scattered. Likewise, gaps and inconsistencies in knowledge, research and evidence on the socio-cultural and political dimensions of AMR can limit our perspectives and undermine our capability to reach appropriate conclusions, make effective decisions, and develop and implement complex interventions.

This paper aims to map out and synthesize existing literature in socio-cultural and political studies on AMR, using a multi-stage scoping review methodology. Relevant studies published in English since 2000 were identified in and screened based on inclusion and exclusion criteria. Relevant grey literature sources, national policy documents, action plans, study protocols and the like were also included.

This scoping review highlights some of the ways that social science scholarship contributes to developing a solid foundation for establishing a transdisciplinary approach to address and tackle AMR and its various implications at all levels.

Friday 13 September 2019 at 11:55 - 12:25
Risk
PL002

“People expect you to work like you don’t have a child but be a mum like you don’t have a job:” a focus group study exploring parental experiences of managing acute childhood illness in the context of sepsis awareness messages

Rush, Lynne
(CSO/MRC Social and Public Health Sciences Unit)

Background Recent UK campaigns that aim to increase awareness of sepsis have been accompanied by high profile media reporting about children who have died or suffered serious complications, often as the result of misdiagnosis. Parents have been urged by the Sepsis Trust to have a low threshold for suspecting sepsis when their child is unwell and to follow ‘gut instincts’, challenging health professionals if necessary. This study aims to explore how parents enact this advice in the context of everyday life and its potential impact on uptake of healthcare resources, including antibiotic use. Method Thematic analysis of 16 focus groups comprise of parents and carers of pre-school children and 4 groups with individuals affected by sepsis. Findings Participants encountered various barriers and conflicts of interest when endeavouring to do the ‘right’ thing to manage acute childhood illness. Gaining access to healthcare appointments was often challenging, with parents weighing up the need for reassurance against fears of over using scarce health care resources. Decisions about antibiotic prescribing were frequently perceived to be based on parental preference rather than clinical indication, undermining public health messages about the importance of reducing unnecessary prescribing to reduce antimicrobial resistance. Despite recent awareness campaigns, parents often reported that the list of possible symptoms described were too non-specific and diverse to be of practical use. “Knowing your child” and being able to detect subtle deviations from normal was seen as a key factor in decision-making about the need to escalate care. However, for parents in paid employment, the need to balance the obligation to be present with their sick child in order to monitor symptoms was often in conflict with their duty to employers and co-workers. The capacity to work flexibly, while highly valued, was inconsistent and frequently based on the discretion of line managers rather than supported by official workplace policies. Conclusion Recent awareness campaigns have highlighted the need for parents to be alert to the possibility of sepsis when their child is acutely unwell. However current campaign materials do not enable parents to confidently identify when to seek help. Lack of access to primary care appointments and unsupportive employment policies may act as barriers to acting in accordance with sepsis awareness messages. Attitudes of health professionals regarding antibiotic use in managing acute childhood illness are often perceived by parents to contradict advice about reducing antimicrobial resistance.
Are clinical guidelines an effective means of achieving “disruptive innovation” in healthcare? Lessons from a recent NICE guideline controversy in the English NHS

Rushforth, Alex, Greenhalgh, T. (Oxford University)

The past three decades have seen the emergence of new logics of governance in healthcare systems that attempt to move from profession-centred models of clinical practice towards more “rational” and managerial models of care. Within this context, clinical guidelines are a central instrument of standardization. Whilst guidelines are often presented as neutral conveyers of research evidence, sociological research has found that competing political, economic and scientific arguments and interests shape their production and use. Recent research has surfaced a trend for hopeful, aspirational claims and visions linked to the inclusion of technologies within clinical guidelines. The argument is that through “evidence-based” guidelines, new technologies can be more rapidly and effectively introduced, leading to improved care and better patient outcomes. In this talk, we consider whether clinical guidelines are indeed an effective means of introducing “disruptive” technological innovations into healthcare systems, thereby reshaping clinical practice. Drawing on extensive qualitative data from an in-depth case study of a controversial attempt to introduce technology-supported testing and precision medicine into asthma management in primary care in the English NHS, we show how a “trailblazing” guideline did not initially achieve its intended radical impact on clinical practice. We contextualise our findings within a wider literature review of the promises and pitfalls of guidelines as instruments for catalysing “disruptive” innovation in healthcare and suggest ways to improve the success of such initiatives.

Using EQ5D to measure Quality of Life in Adults with Diabetes and Intellectual Disability: What are we measuring and how can we capture the experience of living with diabetes and intellectual disability?

Russell, Amy, Bryant, L. O'Dwyer, J. House, A (University of Leeds)

Background: RCTs are increasingly presented as gold standard research. Cost-effectiveness is often assessed using standardised measures, especially quality of life measures, to derive QUALYs. One of the most commonly used measures is EQ5D, which we used in a feasibility RCT with people with an ID and type 2 diabetes. This study explores the meaning and relevance of the EQ5D for people with an ID and questioned the 'absent presence' of disability in this measure.

Methods: Observational study in West Yorkshire. Qualitative interviews and post interview journals exploring experience of EQ-5D in context of an RCT.

Participants were 18+ years old, with T2DM with a mild to moderate ID. Data were collected by a researcher completing ease of use questions and producing a journal of experiences for a sample of participants. Content analyses was used on ease of use data and thematic analysis on journal data.

Results: Over a third of participants experienced difficulty completing the EQ-5D. The most common problems were terminology used, conflicts with supporter perceptions of ability and EQ-5D examples being incompatible with a person's life or failing to capture their experience.

Conclusions: This talk discusses the use of standardised measures, now routinely used to calculate cost effectiveness, to measure quality of life for people with an intellectual disability. It explores how disability is represented in the outcomes of these measures and questions whether disability can be accurately captured in these types of assessment of if their routine use is an exclusionary practice.
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enhance triage, and reduce avoidable hospital admissions. NEWS uses vital signs to identify acute deterioration in health. NEWSiCH tasked care home staff with recording resident’s NEWS onto a digital device routinely, and when a resident appeared unwell. Recordings were shared with external healthcare services. NEWSiCH was implemented across a Clinical Commissioning Group area within the North of England. This paper reports qualitative findings from an evaluation of the implementation. Interviews with stakeholders revealed an implementation that did not appreciate the complexity of the intervention or the care home setting. Despite deficiencies in the implementation, the data highlighted a propensity for care homes, and their staff, to be repositories for blame. The challenges care homes faced when engaging with NEWSiCH were viewed as excuses, caused by incompetence, rather than valid implementation issues. This study stimulated two debates. Can pressure to improve care delivery within care homes allow interventions to be implemented without an adequate design and testing cycle? And does the subordinated position of care homes, and lack of value placed on the ‘dirty work’ that occurs within them, allow for the introduction of interventions that compromise their ability to provide care that is caring?

Thursday 12 September 2019 at 10:45 - 11:15
Gender
PT007

(F)Ailing Mothers and the Quest for Redemption: A Study of Post-Natal Depression Recovery Blogs

Santino, Hannah, Monaghan, L. (University of Limerick)

Motherhood is an emotionally charged and ideologically loaded construct, identity and relationship in Western culture. Maternal distress, medicalised as postnatal depression, provides a microcosm for exploring the socially embedded complexities and emotional vicissitudes of motherhood. Furthermore, the ‘medicalisation of cyberspace’ (Miah and Rich, 2008) presents numerous opportunities for people to publicly reflect upon, discuss, confide, and seek to alleviate their problems with a virtual community of like-minded individuals. This paper draws from Burke’s (1984) theory of redemption cycles along with Schilling’s (2008) ‘ailing’ bodies, in the context of habit, crisis, and creativity, to make sense of postnatal depression recovery blogs. Using data generated from nine Anglophone blogs, this paper offers a theoretically informed reading to understand how women who have been deemed ‘failing’, by behaving outside of expected cultural norms, attempt to redeem themselves in the public arena. This paper explores the process of (1) admitting guilt, (2) seeking purification and (3) achieving redemption. These online narratives provide insight into the public representation and negotiation of medicalised maternal distress whilst also showing culturally mediated ways of potentially restoring the relational, gendered self to a respectable identity.

Thursday 12 September 2019 at 11:20 - 11:50
STS
PL005

Rehabilitation of old slow diagnosis? Observations on overdiagnosis of urinary tract infections in older adults

Saukko, Paula (Loughborough University)

Medical sociologists have chronicled how the emerging modern medicine foregrounded expert technologies, such as bacterial cultures, and detached observation as the most objective and reliable diagnostic evidence. This presentation contends that efforts to reduce unnecessary antibiotic prescribing, informed by antimicrobial resistance (AMR), challenge modern diagnostic hierarchies. Recent clinical guidance recommends that prescribing for urinary tract infections (UTIs) in older adults should primarily be based on symptoms and not bacteria in urine, which is common in older adults. Based on interviews with healthcare staff (n=27) and older adult patients (n=14) and a parallel autoethnography of my 93-year-old mother being probably misdiagnosed with a UTI twice in hospitals this presentation makes three observations. First, the notion of diagnostic technologies clearing ambiguity guided clinicians and patients to focus on bacteria in urine. Second, adopting the clinical gaze clinicians often observed non-specific signs of UTI (confusion) and could miss older adult patients’ experiences of symptoms (pain). Third, listening and waiting and traditional understandings of flushing out bacteria were conducive of delaying antibiotics. The presentation suggests that to move beyond the modern rapid seek and destroy approach to infections calls for a rehabilitation of the old slow diagnosis of waiting, listening to patient’s embodied experiences and being tolerant of ambiguity. Studying UTIs, which may or may not be dangerous, and older adults’ sometimes shifting accounts also calls for a sociology that is tolerant of and able to convey ambiguities rather than adopt the modernist perspective of omniscience.
Informal care and hospitalisation at the end of life - is there a connection? A Census-based population study

Schneider, Anna, Atherton, I. (Edinburgh Napier University & Administrative Data Research Centre Scotland (ADRC-S))

In light of increasing death rates and a high need for palliative care at the end of life, it is important to plan formal care resources and understand in what ways informal care may alleviate the pressure on healthcare services. Studies looking at the interplay of informal and formal care are, however, mostly based on survey data rather than observational data, and no studies have been published that look at the potential effect of informal care on the risk of hospital admissions for people in their last year of life.

In this study, we aim to answer the following questions: Does informal care affect the risk of hospital admission or the length of stay in the last year of life? Does it matter who the carer is?

Our study uses population data from the 2011 Scottish Census, hospital admissions records, and Scottish death records. People who died within 12 months of being enumerated in the 2011 Scottish Census are looked at in two age groups, <70 and 70+, and compared to a reference group of people aged 70+ who did not pass away to establish whether the effect of informal care on hospital use differs for people in need of end of life care and in different life stages.

46,473 deceased cases were included in the analysis and compared to 508,035 people aged 70+ who did not pass away. This study targets a knowledge gap identified by social policy makers from Scottish Government.

Medicine is not Mathematics": Constituting Epistemological and Moral Authority by GPs in the Internet Era

Shachar, Leeor (Tel Aviv University)

The last decades have seen some dramatic changes in the doctor-patient relationship. One of the most influential contributions to these processes has been the emergence of the internet, which changed people’s accessibility to information. Being a resource readily accessible to the lay public, the internet has led to the emergence of knowledgeable patients, who are able to challenge doctors’ decisions, and to assume an active part in the diagnosis, treatment and prevention of their diseases.

The control over abstract knowledge lies at the very core of the medical profession and is considered to be the basis of its claim for legitimacy and jurisdiction. While health information seeking, encouraged by many western governments, clearly reflects liberal and neo liberal trends in healthcare, the epistemologic authority of the medical profession represents the opposite.

Through the use of 30 semi-structured in-depth interviews with GPs, this study aims to explore their interpretations for their professional authority, as reflected by their experiences with internet informed patients.

The physicians find themselves facing two sets of conflicting expectations: one is to endorse liberal values like autonomy and patient rights and to reject the paternalistic model for describing patient-physician relationship; the other is to display professional authority, and to assume responsibility, when taking care of their patients. While struggling to defend their jurisdiction, they identify their source of authority not in scientific biomedical justifications but in contextual, holistic, humanistic knowledge, based on long lasting relationships and trust.

Yearning to move beyond “what the participants said”:the difficulties inherent in navigating notions of conceptuality and rejecting the descriptive in medical sociology analyses

Sheard, Laura (Bradford Teaching Hospitals)

Innovation in health research methods seems to be expected by funders and journal editors alike. Recent years have seen new ideas for how qualitative data collection can be reinvigorated such as story completion, video reflexivity and immersive simulation. Yet, this fervour for the ‘different’ has not filtered onwards to the development of new qualitative analytic approaches. Many researchers still rely on mainstream analytic approaches that have existed for decades such as grounded theory, constant comparison or thematic analysis, with the latter almost becoming a default position. I undertook a documentary analysis based on 25 peer reviews of six
Paper Abstracts

manuscripts submitted since 2015, for which I was first or a substantive author. Included documents were only those related to an atypical qualitative approach (thematic analysis, quantitative or reviews were excluded). I found a commonality in reviewers’ beliefs about the importance of using firmly established analytic techniques. A common request was to “insert a reference” to substantiate the analysis used, despite a bespoke analytic technique already being demonstrably described. Some reviewers seemed concerned with notions of replicability because the analytic technique used was not traditional. Presenting data at the level of abstraction was often met with bewilderment by reviewers who believed that because the analysis did not rest entirely on what the participants had verbalised during interviews/focus groups, it was therefore erroneous. Across several papers, reviewers pushed for the analysis to adopt a descriptive, thematic approach. This matters because rarely does theory arise from a descriptive account of “what the participants said”.

Health Service Delivery
PL006

Building a range of voices and experiences in the development of modern healthcare services
Shepherd, Andrew
(University of Manchester)

Increasingly, voices representing different forms of experience, beyond traditional professional roles, are being involved in healthcare development and service provision. This may be represented by patient and public involvement in the development of research funding proposals, policy decisions involve survivors as stakeholders, while mental health services draw on the experience of survivors as peer support workers (PSWs).

The involvement of survivors, or experts by experience, within the decision making processes of healthcare bodies brings particular challenges; for example, in relation to the manner in which competing voices may are respected alongside other forms of knowledge, such as the predominant biomedical discourse of evidence based practice. Competing narratives emerge within the discourse, as different forms of knowledge are brought together in the form of personal subjectivities and positivist representations of fact and truth.

The current paper seeks to explore the process of identity work undertaken by psychiatric survivors as they take on the role of PSWs. It addresses emergent themes from a reflective practice group for PSWs working with others in the context of mental health and personal recovery. In these sessions, survivors wrestle with a changing role and different pressures as they seek to contain the distress of those seeking their support, whilst negotiating their own identity in terms such as survivor versus professional.

Finally, this paper reflects on the tension inherent in joining different voices together in developing modern forms of healthcare, whilst also underlining and reinforcing the essential requirement for this joining in moving forward.

Wednesday 11 September 2019 at 14:00 - 14:30
Mental Health
PT006

Demystifying the debates around the depression ‘epidemic’: ‘naturalist’, ‘functionalist’, and ‘definitionalist’ accounts
Shimizu, Hiroto
(School of Social Sciences, Cardiff University)

The ‘epidemic’ of depression is a repeatedly reported issue in scholarly, policy, and popular discourses. In connection with the international rise in the number of patients (people receiving or registered to receive medical treatment), there have been numerous debates on the nature and consequences of the enlarged population. A considerable amount of literature in medical sociology has discredited the ‘epidemic’ as a myth, suggesting that change(s) in the diagnostic criteria is responsible for the increase. This account, however, can be a descriptively/normatively invalid mode of analysis that reduces the solution to demedicalising it, making certain phenomena problematic while leaving others unproblematic. A coherent and comprehensive theoretical framework informing the make-up of the ‘epidemic’ is therefore needed. The paper aims to trace and clarify debates on the cause(s) of the depression ‘epidemic’. Three ideal-typical explanatory models are identified and discussed: (1) ‘Naturalist’ explanations, which appeared in the 1970s, are a series of discourses that observe increasing prevalence of depression, often with Zeitdiagnostic reference to societal changes; (2) ‘Functionalist’ explanations, which emerged in the 1980s, in accordance with the Parsonian sick role model, deem professional/public awareness and resource utilisation in healthcare economy as the driving forces; and (3) ‘Definitionalist’ accounts attribute the rise to the conceptual expansion of conditions diagnosable as depression. The author argues that the three models are not contradictory but complementary to each other; their juxtaposition/constellation is key to making sense of the ‘epidemic’. The paper concludes with thoughts on future agendas of the medicalisation thesis.
The first perinatal hospice as a joint venture or a competitive field?

Smidova, Iva
(Masaryk University)

There is no legally established perinatal hospice in the Czech Republic. Several initiatives work to establish some and use the label of perinatal hospice in their endeavors to alter or subvert the so far narrowly defined legal framework for such an institution. Country regulation and financing of hospices from the public health insurance is an emerging pilot practice here. Hospice care generally (even palliative care to a certain extent) is becoming a legitimate segment of provision of care only in recent years. This context significantly impacts children’s hospice care and perinatal hospice care. The paper analyses several initiatives striving hard to establish and formalize perinatal hospices in the Czech Republic and concentrates on strategies that actors involved in those few initiatives engage to push their goal through. These strategies range from altruistic and self-scarifying efforts through various network and community empowerment, ideologically and politically grounded or motivated approaches to clear business plans. These initiatives across the country vary in cooperation or competitive approach to one another, yet they also strive to establish or to be recognized as “the first perinatal hospice”. The paper shows that such competitive rhetoric is adopted to attract funding of these projects, and it reflects impact of the business-like terminology on the ethos of these beneficial activities.

'Brexit meant to us that they are not happy for us to be here’ – the unsettling effects of ‘Brexit’ on the retention and recruitment of migrant NHS nurses'

Spiliopoulos, Joy, Timmons, S,
(University of Nottingham Ningbo China)

With this paper we present preliminary findings following a pilot study on retention and recruitment of migrant nurses post-Brexit. Drawing on the work of Hall (1996; 2003), Solomos (2003), Wodak (2013) and taking critical/intersectional approaches (for example, Davies, 2016; Yuval-Davis, 2006; 2011), we examine issues such as non-belonging and ‘othering’, as experienced in the everyday lives of the EU and non-EU nurses in our study. While the NHS has always relied on a migrant labour force, the more recent populist and xenophobic rhetoric, culminating in the 2016 referendum decision to leave the EU, has caused significant disruption to NHS recruitment processes, especially from EU countries. Using semi-structured interviews and thematic and narrative analyses, we present the migrant nurses’ uncomfortable feelings of non-belonging, as experienced, in their workplaces and elsewhere. This is a highly mobile and skilled workforce which is increasingly being disenfranchised and seeking alternatives to long-term commitment to working for the NHS. Additionally, we present employers’ and recruiters’ perspectives and challenges in supporting and attracting migrant nursing staff to the NHS and the private care sector. NHS England has sought to address issues of discrimination against its workforce based on gender, race, sexuality, and others. Good practices at a local level can have significant impact in providing much needed support for migrant nurses, however, more needs to be done at local and national levels to ensure retention for EU and non-EU nurses alike. Our work adds to the literature on the mobility, settlement and contributions of migrant nurses (Adhikari and Melia, 2015; Isaksen, 2012), in the context of ongoing 'Brexit' negotiations.

When public and private intersect: Sociological perspectives of ‘environments of dignity’ in community nursing

Stevens. Emma
(University of Hull)

Dignity in health care is undeniably important. This paper takes a sociological perspective to explore dignity in community nursing through considering the views and experiences of community nurses and older adult patients. Delivering nursing care in a person’s home is different to undertaking care in hospitals. Total institutions (Goffman, 1961) remain firmly under staff control, and as such, hospitals remain the domain of nurses, with patients adapting into the ward routines. In contrast, receiving care in ones’ own home is different, as the home remains the patient’s territory. Although patients may conform to the institutional regimes of hospitals, they have different behavioural expectations of themselves and others when care is delivered in the home. Nurses regard it as a “privilege” that they enter ‘private’ homes to undertake care and this paper shall consider how through displaying respect for the home nurses can assist in creating an ‘environment of dignity’. Nurse-Denise: “It’s the best job ever. It’s better than any hospital. Cos you’re going into their home…they’re letting you into their world and it’s an absolute privilege […] It’s like a little bit of fairy magic.” This study adopted an ethnographic methodology. Fieldwork was undertaken over fourteen weeks in which the
chief investigator was located within a district nursing team in a city in the north of England. Methods included observations of clinical interactions between patients and nurses (n=62) and semi-structured interviews with nurses and patients (n=22). Ethical approvals were gained from the University of Hull and South Yorkshire NHS REC 13 March 2017 (REC ref: 17/YH/0009) IRAS ID: 21677. Findings indicate that environments of dignity manifest differently in the hospital and home environment. The interaction between staff and patients varies in these environments as older adults are better placed to assert their agency and have a greater sense of empowerment in their own homes. Although community nurses gain positional power through virtue of being nurses, this power requires continual renegotiation when they become a ‘guest’ in the home. Nurses must respect the homes of their patients as this is interrelated with upholding older adults’ dignity - the home is a reflection of patients’ dignity and any disrespect for the home has the potential to violate or disrupt dignity.

Friday 13 September 2019 at 12:30 - 13:00
Lifecourse
PL005

Ageing and Mental Health: Memory Partners: the power of tai chi to make a difference
Stuart, Sue
(Bucks New University)

Hailed as a triumph of modern medicine, increased longevity can be accompanied by problems of dementia, loneliness and depression. Memory Partners (MP) attempts to address these issues by teaching tai chi to pairs of people...
The project was originally conceived as a qualitative study in support of those living at home, but has been developed for residents of care homes supported by their family members. Tai chi became a vehicle for giving partners an alternative focus and to provide strategies for coping with stress. Ethnographic methods were used over a period of 20 weeks distributed over two terms. In the final focus group family members requested that the project should be extended, thus demonstrating the value that they placed on the activity.

A substantial corpus of research already demonstrates the ability of tai chi to strengthen muscles, improve posture and balance and so help prevent falls (Robertson and Campbell, 2008). The action of consciously moving in a way which may initially seem alien to participants opens the opportunity for neuroplasticity to occur (Wayne, 2013). The gentle, steady pace and deeper breathing promote feelings of calm and stimulate the circulation (Bernard et al., 2011). However the innovative contribution that MP makes to promoting mental health resides in the quality of the relationships that the process of learning tai chi engenders between partners and amongst the other members of the group in which they learn. Benefits extend beyond the care home: they reach out to other family members.

Thursday 12 September 2019 at 15:10 - 15:40
Experiences
PL006

Crafting ‘Genomic Literacy’: Tracing multiple meanings and benefits of consent and participation
Swallow, Julia
(University of Leeds)

Informed consent processes are central to the successful delivery of genomic research, especially in large sequencing projects such as the UK’s flagship 100,000 Genomes Project. Ethical protocols aim to make consent ‘meaningful’ by ensuring participants are sufficiently informed about the science of genomics, the project design, and the uses of data to make an informed decision. This has made the consent process lengthier and more detailed, raising concerns about the burden this might place on participants, particularly patients who are unwell at the time consent is sought. In this paper, we offer a different perspective on how consent is made meaningful in practice based on observations and interviews with healthcare practitioners, cancer patients and family members involved in 100,000 Genomes Project. Looking at how meaning was made and remade through interaction in particular consent meetings and follow-up interviews, we show how meaningful consent processes were more than a matter of patients being informed. Instead we focus on how meaning was made as participants 1) received care 2) demonstrated self-care and 3) reciprocated care through the consent process. Here, the consent meeting was part of tailoring and personalising information and care for patients faced with a difficult cancer diagnosis. Practitioners, patients and accompanying family members worked to establish ‘good enough’ understandings of genomics as they sought, demonstrated and offered care as part of meaningful participation. Our findings suggest the need for more nuanced and contextual understandings and approaches to informed consent for patients in sequencing studies which focus on participants’ experiences of care and self-worth as well as the information provided as part of the consent process. Whilst developing genomic literacy is important, it is also essential to support patients and practitioners to realise the multiple meanings and benefits of participation, and to support staff to deliver the kinds of consent interactions that this requires.

Wednesday 11 September 2019 at 14:00 - 14:30
Environment
PL001
‘Medical Paternalism and Public Sphere Intervention: The Role of Health Professionals in the Poisoned Baby Milk Incident’

Tamari, Tomoko  
(Goldsmiths, University of London)

The paper examines the significant role of public health nurses, who attend to the existential everyday conditions of patients in order not only to understand and solve their problems, but also to interpret their knowledge and experience so as to make a bridge between patients, medical specialists and the public systems.

In the field of medical sociology, there has been little attention paid to the identity formation of public health nurses as medical intermediaries though clinical practice in medicine as well as their activities in the public sphere.

By examining the case of the Morinaga arsenic-poisoning baby milk incident in 1955, which caused 12,131 new-born babies to be poisoned with 130 death in Japan, the paper illustrates how nurses developed their self-awareness as public health professionals and autonomous individuals. It is also demonstrates the way in which public health nurses overcame the patient-doctor relationship in medical paternalism and uncovered the predominant forms of political power in social welfare.

Drawing on the Bourdieusian concepts of cultural intermediaries and Foucault's notion of governmentality as a theoretical framework, the paper unpacks the ways in which interactions between public health nurses, victims and medical specialists helped shape a new form of public sphere which enable them to become united political activists whose persistence efforts helped to establish an ongoing welfare system for the survivors.

Thursday 12 September 2019 at 10:10 - 10:40  
STS  
PL005

Developing a 21st century sociology of pain

Tarr, Jen  
(London School of Economics and Political Science)

Recently, the official journal of the International Association for the Study of Pain has debated the adoption of a new formal definition of pain which would foreground its social aspects (Williams and Craig, 2017). This follows from increasing awareness across the field of pain science of the fundamentally social nature of pain. Pain medicine is slowly moving beyond the dualism Bendelow and Williams (1995) identified in the biopsychosocial model. However, since the important work on pain as embodied experience in the late 1990s and early 2000s, relatively little sociological work on pain has kept pace either with neuroscience, or with contemporary STS developments such as new materialism (Graham, 2015).

I argue that there is an urgent need to develop an updated sociology of pain for the twenty first century, one which takes into account contemporary neuroscientific findings on pain as well as contemporary theories of the body and embodiment in science studies. I explore what a new materialist version of pain could look like, and how it might sit with the phenomenological approaches that have been central to taking patient experience seriously. I suggest that pain is best understood as an interstitial state, always entangled with and responsive to developments beyond the skin, rather than as an interior, private truth that is largely incommunicable. Rethinking pain in this way also offers sociologists the opportunity to potentially play a more fundamental role in understanding and treating pain.

Thursday 12 September 2019 at 11:55 - 12:25  
Health Service Delivery  
PL006

Looking through different disciplinary lenses: the super-wicked problem of antibiotic over-use in healthcare

Tarrant, Carolyn, King, C., Currie, K.  
(University of Leicester)

Antibiotic prescribing has been identified as a key driver of the global public health challenge of antimicrobial resistance. International efforts to change prescribing patterns have focused on introducing antimicrobial stewardship interventions. This paper will explore the opportunities and challenges of combining theoretical perspectives from psychology and sociology to explore the development and evaluation of such interventions. Behaviour change models from the field of psychology are increasingly being used to develop interventions, offering evidence-based approaches to changing the behaviour of practitioners and patients. While psychological models target individual behaviour, other approaches rooted in sociological traditions draw attention to how practices are shaped by organisational, social, political and technical context: reflecting the argument that “human action can be rendered meaningful only by relating it to the contexts in which it takes place” (Gouldner 1955). These discrete disciplinary perspectives are often viewed as competing: the behavioural approach offered by psychology may be perceived by policy-makers to provide concrete steps for action in health service delivery, but sociologists argue that healthcare problems are complex and cannot be reduced to simple behaviours. However, we wish to challenge this silo-based thinking and will illustrate, through exemplars from our studies into antimicrobial
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stewardship, the potential value of combining sociological and psychological lenses to collect, analyse and interpret data. Whilst acknowledging potential methodological clashes, we believe that this integrated approach enables greater learning, generating stronger understanding of the interplay between behaviour and context, thereby increasing the cohesion and effectiveness of interventions designed to improve health services delivery.

Wednesday 11 September 2019 at 14:35 - 15:05
Professions
PT111

‘Disrupting professional identities and boundaries: the integration of health and social care

Tazzyman, Abigail
(University of Manchester)

Enacting professionalism often relies on intense ‘boundary work’ by professionals to establish a stable profession and stable professional identity in negotiation with other professionals and non-professionals. Collaborative working between professional groups frequently necessitates breaking down such barriers, however, which represents a threat to professional stability and professional identity. In this paper we consider the extent to which professional identity in both health and social care in the English context is disrupted by increased collaborative working as health and care are progressively ‘integrated’.

We explore this process by examining the process of integration in health and social care, which has been advocated as a model which can harness new forms of collaboration and connectivity to better respond to the needs of contemporary societies. Recent policy initiatives, such as the NHS Five Year Forward View, has brought new emphasis to breaking down barriers between ‘family doctors and hospitals, between physical and mental health, between health and social care’ in England. This represents a significant move in the English context where health and social care services have existed in separate systems since the creation of the NHS in 1948, with different budgets, governance, statutory responsibilities, service delivery boundaries, education and socialisation. Drawing on a case study of integration in a major English city, we argue that despite an overwhelming acceptance of integration in principle, the resilience of professional boundaries and identities presents a substantial obstacle to integration initiatives in practice. The implications and inevitability of conflict between integration and professions is critically considered.

Friday 13 September 2019 at 10:10 - 10:40
Embodiment
James Hall

The impact of conflicting gendered and generational feeling rules between novice and experienced nurses on their sense of identity

Theodosius, Catherine, Koulougliotti, C., Kersten; P., Warren, Z., Clarke, A.
(University of Brighton)

Drawing on qualitative focus groups from a mixed methods study investigating the relationship between emotional labour, collegial relationships and burnout, this paper explores generational differences shaping the nature and purpose of emotional labour between novice and experienced nurses. We argue that such differences foster what Hochschild (2016) terms an ‘empathy wall’ between them, impacting on their nursing identity. Emotional labour in nursing is about ensuring patients believe the nurse cares for and about them, understands their vulnerabilities and can make them feel safe. It is a key component of the ‘soft skills’ of nursing, such as interpersonal communication skills, and is traditionally linked to gendered stereotypical feeling rules that suggest nurses are naturally caring and nurturing. For experienced nurses, such feeling rules support their identity as natural carers, who understand their patients’ needs drawing on inherent communication skills enhanced by extensive practice experience. Evidenced-based knowledge, however, questions the objectivity of such experiential knowledge of the patient. Graduate novice nurses however, consider emotional labour to involve reflexive problem solving that utilises evidence-based psychosocial and clinical knowledge that enables them to understand the patient and thereby meet their emotional needs. For novice nurses, feeling rules are shaped around knowledge and clinical skill and the demonstration of compassion. Their identity is questioned, however, as their university acquired knowledge is considered to limit their ability to really care about the patient. This paper explores how these differences create an empathy wall between novice and experienced nurses impacting on their very identity as nurses.

Thursday 12 September 2019 at 14:00 - 14:30
Experiences
PX001

‘I don’t want TV… I want resources’: unpacking (counter) configurations of disability in popular media

Thomas, Gareth
(Cardiff University)

For Ginsburg and Rapp (2015), there is a growing presence of positive disability imaginaries being enacted through a range of popular media (e.g. TV/film, newspaper articles, blogs/social networks) and across widely distributed networks of people with shared experiences of disability. This proliferation of more optimistic and complex representations may signal a crucial cultural shift in how
people feel about, and experience, reproducing a disabled child. Yet little research addresses how parents of disabled children produce, and make sense of, configurations seemingly designed to enact a more positive, visible, and rounded portrayal of disability. This is the starting point for this paper, together with locating disability as a key concern for medical sociologists (too often, a disciplinary allegiance to ‘disability studies’ or ‘medical sociology’ leads to missed opportunities for identifying obvious intersections). Drawing upon interviews with parents of children with Down’s syndrome (DS), along with a textual analysis of media materials and observations at a disability conference, I unpack the formulation of new imaginaries of difference in which people with DS are given both a ‘presence’ and a ‘future’ (Latimer 1997). Rather than assuming such configurations are fundamentally positive, however, parents complicate this popular narrative in several ways. Specifically, they point to concerns of ‘tokenism’ and an overwhelming focus on well-resourced and ‘exceptional’ (or what some parents call ‘high-functioning’) people, and particularly children, with DS may have adverse effects.

This paper, thus, captures how ‘disability worlds’ (Ginsburg and Rapp 2015) are made ‘inhabitable’ and/or an unvalued bodily state. In so doing, parents identified how the (positive) popular narrative of Down’s syndrome was complicated, even contradicted, by the wider hostility, exclusion, and indifference experienced by disabled people and their allies. Indeed, some parents felt that positive ‘news stories’, whilst applauded, equally glossed over a wider social/political context in which disability is treated as ‘uninhabitable’ (Freidner 2015) at different moments, along with how positive media coverage of disability – whilst well-intentioned – may have adverse effects.

Thursday 12 September 2019 at 09:00 - 09:30
STS
PL005

Eagerness, ambivalence and resistance within the social processes of psychiatric genetic research participation

Thomas, Julia
(Cardiff University)

In this paper, I discuss the social processes surrounding psychiatric genetic research participation by drawing on data generated using Q methodology, a research approach to elicit shared views through the sorting and discussion of various statements about a topic. Focusing on registers of eagerness, ambivalence and resistance, I explore what various accounts about participation reveal of the current hopes and fears surrounding psychiatric genetic research.

As a research area, psychiatric genetics needs a relationship with its multitude of public groups to remain viable – not least for reasons of participant recruitment. The complexity of the conditions and diagnosis mean an increasingly large number of participants are solicited such that the whole process of research recruitment has become dramatically up-scaled. According to Arribas-Ayllon, Bartlett and Lewis (2019), the various scientific and rhetorical practices within psychiatric genetics have persisted despite criticism and scientific disappointments. However, from a sociological perspective, and specifically from the standpoint of medical sociology, we know very little about what’s going on within the social processes of recruitment to this kind of research. This paper presents UK data from 36 face-to-face Q-sorts and associated in-depth discussions on what psychiatric genetic research participation means to researchers, mental health professionals, and people with experience of psychiatric conditions. Q methodology revealed four shared viewpoints that highlight the tensions existing within efforts to recruit participants to psychiatric genetic research. I demonstrate how visions of a collective or a community for research were considered necessary and motivating but were also idealised, rejected and problematic.

Thursday 12 September 2019 at 11:55 - 12:25
Lifecourse
PX001

Study of the concept of asset as a way to manage health status: assessing and visualising health status among individuals with chronic diseased conditions

Tomomatsu, Ikuko
(TOMO Lab LLC)

Aim - The aim of this study is to develop indices which assesses and visualise ‘health status’ at the individual level.

Background - One impact of the increasing extension of life-expectancy has been the corresponding extension of life for individuals living with diseased or disabled conditions. Devices to monitor health status and Internet of Things(IoT) assist social participation of individuals with any diseased or disabled condition. Looking at the change brought by those devices and IoT, the perspective to assess individuals’ health status may need to be reconsidered. I propose that the health status should be managed as an asset by each individual. The asset consists of evidence such as medical records, and social participation such as social networking/inclusion.

Method - Twenty chronic diseased individuals were recruited. They are interviewed by semi-structured face-to-face interviews, and two focus group interviews are conducted. They are audio recorded and transcribed into a simple text. Interview data are thematically analysed, looking for data that maps specifically to the term ‘social participation’.

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Tentative results - Two aspects may be important in assessing social participation. One is whether the person is communicated with by non-family members. The way of communication does not matter either face-to-face or virtual community. The number of people and opportunities of communication is more important than the length of each communication. The other important aspect is whether the person has opportunities for giving and receiving something to others. However, the balance of activities of 'giving' and 'receiving' depends on communities to which they belong.

Lifecourse
PX001

‘My life’s properly beginning’: young people with a parent who is dying talk about the future

Turner, Nicola
(University of Nottingham)

This paper explores how young people who are living with a parent who is dying talk about the future. Drawing on a qualitative, interview study of the family lives of ten young people (age 13-21) with a parent who is at the end of life, I argue that young people are able to move imaginatively beyond the death of a parent, and in doing so, to maintain biographical continuity and a sense of hope for their future selves.

In thinking about the future, young people in the study generated an alternative narrative to the 'harm story' typically associated with parental loss. Furthermore, the facility to engage with parental absence in the present enabled young people to make sense of the difficult circumstances of living with dying, and gave meaning to their imagined future lives. These findings suggest that young people's narratives of the future may act as a symbolic resource for young people to draw on, albeit one which requires an adequate level of material and social resources to construct.

The paper extends the notion of continuing bonds derived from post-bereavement accounts to suggest that relational experiences of the dead begin prior to bereavement, and may facilitate everyday living in anticipation of a significant loss. Attending to the temporal effects of life-limiting parental illness and exploring ways in which past, present and future may be imaginatively traversed may assist young people in getting by when a parent is dying.

Thursday 12 September 2019 at 14:00 - 14:30
Inequalitie
PT007

An effective behaviour change intervention in a Low-Middle Income Country (LMIC): The MaaChampion programme

Tyldesley-Marshall, Natalie, Lindenmeyer, A., Manaseki-Holland, S., Greenfield, S.
(University of Birmingham)

Background - Globally, diarrhoea is the second biggest killer of children under 5 years old; disproportionately affecting Low-Middle Income Countries (LMICs). Yet this disease can easily, and cheaply, be prevented by using soap to wash hands, utensils and surfaces before and during food preparation and consumption, and boiling water before drinking. This knowledge is prevalent, though rarely acted upon. A drama-based intervention (the MaaChampion programme) drew on the Evo-Eco model to change these behaviours, and the related social norms. Delivered through a randomised controlled trial in The Gambia, incidences of diarrhoea in the intervention villages reduced significantly. 16 focus groups undertaken 2 years post-intervention in intervention villages, showed clear evidence that the villagers still remembered the intervention, and were following its ‘rules’.

Method and results - Focus group transcripts were re-analysed using directed content analysis to provide supporting evidence of which elements of the programme – underpinning theories, behaviour change techniques, and methods of delivery - made this intervention so effective. 2 years post-intervention, focus group participants had strong recollections of the drama aspect of the intervention, the main characters, certain emotional drivers (‘motives’) from the Evo-Eco model, and the targeted hygiene behaviours.

Conclusions – This intervention provides further evidence that community-wide change in hygiene behaviours can be highly effective when drawing on the Evo-Eco theory motives (that formative research has found to be relevant) to change behaviour. In addition, by using a range of recognised behavioural change techniques and modes of delivery to change social norms, ensures that these behaviours continue.

Friday 13 September 2019 at 10:10 - 10:40
Politics of Health
PL006

Narratives and Experiences of 'Middlecut Mothers': Medicalization, Conspicuous Consumption and the Prevalence of Caesarian Section in Iran
Vedadhir, Al., Lambert, H.,
(University of Bristol & University of Tehran)

The general prevalence of Caesarian Section (CS) in Iran is over 50% and in some private health facilities 87% of all deliveries are via CS. Notwithstanding the recent adoption of pronatalist policies by the Iranian Government and recent introduction of 'the Health Transformation Plan' (HTP), a set of initiatives to increase fertility, promote natural childbirth and limit Caesarian deliveries, CS rates remain very high. The continuing high prevalence of CS is in stark contrast to WHO recommendations for using it principally when the life of mother or fetus is at risk and avoiding unnecessary and inappropriate use of CS above its reasonable proportion (5–15% of all deliveries). This paper explains this conundrum and resistance of the CS rate to the governmental top-down policies and elucidates why the 'middlecut' has become the preferred mode of childbirth in Iran. Routine records/publicly available quantitative data are used to assess national trends of CS over the past three decades and to evaluate impact of the HTP on CS since 2014. The qualitative component entailed thirty six in-depth qualitative interviews with mothers (with both CS and natural deliveries), midwives, key informants and policy-makers. The findings reveal three interlocking dimensions of Iran's market-driven healthcare system that all hinder significant decline in CS rates: the marketisation of tokophobia (fear of childbirth pain); over-medicalization of childbirth; and conspicuous consumption of medical care as a signifier of socio-economic status.

Thursday 12 September 2019 at 11:20 - 11:50
Inequalities
PL001

Body weight, eating behaviour and physical activity practices among Chilean women from different socioeconomic positions

Vega, Maria Jesus., Johnson, L., Papadaki, A.
(University of Bristol)

In Chile, 34% of people aged over 15 years have an obesity condition. Nevertheless, this prevalence is unevenly distributed among the population; women and people with lower levels of education have a higher obesity prevalence. Traditionally, obesity prevention and interventions have mostly focused on individual willingness to modify the way people eat, move and rest. However, social-structural answers have been taken less into account when developing these interventions. Considering Pierre Bourdieu’s framework on habitus and class distinction (1984), lifestyle behaviours can be considered as expressions of the social classes’ culture and habits. The habitus related to eating and physical activity practices embodies the systems of dispositions that cause actions, practices and preferences related to the body in taken-for-granted routines. This habitus will then differ between social classes, expressing differences in practices and cares around the body and the body weight. This study explores the differences in eating behaviours and physical activity practices between women from different socioeconomic positions in Santiago, Chile. The analysis focuses on the differences around eating and physical activity practices through the women biographies according to their current socioeconomic position. It also explores the differences between their past and present eating and physical activity practices according to social classes’ changes and life course events through their lives. Approximately 30 in-depth interviews were conducted with women from different socioeconomic positions. Preliminary findings from the interviews will be presented. This study was supported by the 2018 Phil Strong Memorial Prize.

Friday 13 September 2019 at 12:30 - 13:00
Embodiment
James Hall

The formations of bodily health norms among Danish primary school students – a mixed method perspective.

Vraa Justenborg, Katrine
(University College Copenhagen)

Theoretically, the project is based on a combination of Pierre Bourdieu’s (1984; 1988; 1990; 1997; 2005), Kristian Larsen’s (2013; 2017) and Maurice Merleau-Ponty (2009) sociological perspectives. Especially Larsen’s concept of health capital and its division (The surgery body, the chemical body, the nutritional body, the physical body and the mental body) will be used to understand how Danish primary school students create health norms. This project examines the formations of health norms and practices among Danish primary school students in the 5th, 7th and 9th grade and focus on answering three main questions concerning norms, mirroring, and modern technology. First, how do bodily health norms forms in the classroom, how do differences and similarities in habitual dispositions shape bodily health norms, and how do Danish primary school students navigate in and around these norms? Second, how do mutual mirroring affect the health of the students? Third, how do modern technologies effects and create new ways of negotiate health norms in the classroom? The purpose of the study is to understand how the classroom, as a social defined field, provides certain health norms and practices through the bodies of Danish primary school students, and at the same time understand why 30.3 % of all students in the Danish primary school do not thrive. The project is based on mixed methods and is distributed as a sequential design consisting of three phases: First, I will make interviews and observations in classrooms of 5th, 7th and 9th grades in two Danish public schools. I expect distinctions in the schools’ social-, cultural economic- and health capital. Second, I will make a survey with 1200 respondents divided equally among 5th, 7th and 9th grades in six Danish public schools and third, I will attain 20 individual interviews with Danish primary school students.
How mental health practitioners produce the 'patient in recovery': pastoral power in the recovery approach.

Waters, Rachel
(Cardiff University)

This study investigates the recovery approach in adult mental health services through the framework of governmentality. Modern agents of pastoral power, from mental health professionals to various kinds of recovery and support workers, monitor and facilitate 'clients' to foster responsible self-management. Strategies of autonomisation and responsibilisation align closely with those of the recovery approach, a key principle of mental health policy in the UK. Ethnographic data collected at three mental health services in Wales are analysed using a range of discourse analytic approaches to explore the ways in which service user subjectivities are constituted through the exercise of pastoral power. The study identifies a range of strategies by which an ensemble of professionals seek to elicit desired service user responses. Mental distress was reconstructed as amenable to management through practices of monitoring, planning, persuading, praising and humour. 'Recovering' service users worked with professionals to jointly construct themselves as trying hard, motivated, future-oriented and as taking responsibility for their recovery. 'Non-recovering' service users resisted the pastoral model of care, and rejected recovery discourse, constituting themselves and their distress within alternative frameworks of knowledge including biomedical and risk discourses. The implications of the findings for mental health services, practitioners and service users will be discussed.
Expertise and mothering identity: Feeding children on the ketogenic diet

Webster, Michelle  
(Royal Holloway, University of London)

The ketogenic diet is a high-fat medical treatment for drug-resistant childhood epilepsy. Children being treated with this diet are given a prescription that details the amount of fat, protein, and carbohydrate each of their meals must contain. This can cause conflicting feelings for parents, particularly mothers, who, whilst wishing to treat their child's condition, sometimes feel guilty for denying their child foods that they enjoy while encouraging them to consume foods that they find less palatable. This paper explores the impact of implementing the diet on mothering identity by drawing upon in-depth semi-structured interviews with 12 parents who were using it to treat their child's epilepsy. The way in which notions of expertise and intensive mothering helped to counteract the feelings of guilt that sometimes arose are also considered. Indeed, it will be argued that the mothers were expert carers; they were experts at implementing the diet, they were experts on their children and they were also experts at treating their child's condition. Developing and utilising this expertise required what could be described as 'intensive parenting'. However, the intensive parenting practices in these families were heavily gendered, as mothers undertook almost all of the food work related to the diet. As a result, the paper also explores the mental, emotional and physical labour that comprised intensive mothering in this context. Consequently, this paper contributes to discussions surrounding dietary treatment, intensive mothering and mothering identity.

Deteriorating times and rhythms of work and sitting: Critical experiences of self-tracking and office work

Weedon, Amie, Saukko, P  
(Loughborough University)

Office workers are often targeted for occupational and public health efforts to reduce sedentary behaviour. We invited office workers (n= 25) in a UK county council to wear a self-tracker for 2 weeks to encourage them to reduce their sitting time and conducted qualitative interviews with them before and after. The interviews featured participants' experiencing sitting within the past and present of their work, punctuated by accelerating pace brought about by redundancies and increased workload, manifesting in three themes: Firstly, participants looked back on earlier times when they could take breaks and move in and out of office during work. Secondly participants used the self-tracking device to try to reduce their sedentary behaviour as well as to document the fast pace of their work. Thirdly, participants refused to wear the self-tracker outside of work, considered time free from clock time and monitoring to do what they wanted. Drawing on the conceptual frameworks on temporalities (Adams) and rhythms (Lefebvre) we contend that office workers understood their sitting within the historical and structural temporality of accelerating work. Whilst research on office workers' sedentary behaviour has acknowledged busyness as a barrier to reducing sitting, the barriers and facilitators approach frequently proposes individualised solutions. We suggest that initiatives to improve occupational health of office workers using self-tracking should also address work conditions if the interventions are to be effective and perceived as just, so that the trackers could document not only individual but also institutional efforts to improve health and well-being.

'Like Clockwork': Exploring Temporal Rhythms of Everyday Life with Irritable Bowel Syndrome (IBS)

White, Lauren  
(The University of Sheffield)

Irritable Bowel Syndrome (IBS) is a common, long term bowel condition, characterised by symptoms of pain, constipation and/or diarrhoea, bloating, wind and urgency to use the toilet. Despite statistics demonstrating that up to 20% of the UK population live with IBS, there is little understanding of the everyday life with the condition. How individuals with IBS negotiate their symptoms in everyday life has had little attention in sociological studies. Drawing upon findings from diary and interview methods from my PhD research that has explored how individuals negotiate everyday life with IBS, I will examine how those with IBS experience and navigate their everyday routines when seeking to manage the symptoms of their condition. In this paper, I will argue that both macro and micro organisations of time are important in the lived experience of IBS. Firstly, I will return to the prominent idea of 'biographical disruption' (Bury, 1982) by telling the accounts of change, chaos and uncertainty faced whilst living with IBS. Secondly, I will consider the temporal calculations made of the body, which include the timing of eating, the expectation of bowel movements as well as the timed response or anticipation of medication and how these are met with the external world. Thirdly, I will explore the reimagining of
routine(s), told through the accounts of early mornings and everyday walks. This paper seeks to contribute to temporality, specifically from disruptions of illness to reconstructions of everyday routines in line with the movements of our bodies.

Thursday 12 September 2019 at 09:00 - 09:30
Citizenship
PT006

De-politicise to Taste: Does the Medical Curriculum have the Stomach for Health Inequalities?

Whybrow, Paul
(Hull York Medical School)

As the UK faces shortfalls in NHS staff and growing health inequalities, there has been a renewed interest in better educating future doctors about the social determinants of health (SDOH). This is partly motivated by concern that doctors lack the structural competence (Metzl & Hansen 2014) necessary to care for people that are most in need, or to work in the most deprived areas (O'Brien et al. 2011, Blane 2018).

When properly incorporated within the medical curriculum, the sociological imagination promotes an awareness of and connection between the personal and social factors that inform better medical practice (Kendall et al. 2018). However, some SDOH teaching could reinforce students' prejudices or represent inequalities as natural and apolitical (Sharma et al. 2018). Epidemiological evidence may inadvertently dehumanise issues such as immigration, homelessness and drug-use into risk factors, particularly if not framed by social accountability, social policy and political context. Sharma and colleagues have criticised medical schools for avoiding the messy issue of politics and have argued for a transformational change to how we do medical education (Ibid).

This paper critically considers the role of sociology (and sociologists) in teaching health inequalities to medical students. In part the challenges reflect the epistemological differences that both define and distinguish social and medical disciplines. In seeking a way forward, I consider movements within medicine (such as The Deep End Project) that support new doctors in gaining experience working in deprived areas.

Wednesday 11 September 2019 at 16:20 - 16:50
Citizenship
PL005

Lost in the shadows: sociological reflections on recent critiques of the 'dark side' of coproduction in Health Services Research

Williams, Oli
(King's College London)

Involving the public, patients and carers in health(care) research is an increasingly normalised practice. We are said to be experiencing a 'participatory zeitgeist', with involvement throughout the health(care) research process now an official expectation from funders (e.g., NIHR) and an externally assessed element of research ethics, design and practice. Coproduced research has been elevated as a 'gold standard' by involvement bodies, advocated on two often - but not intrinsically - competing rationales: technocratic utility and democratic rights.

However, numerous studies show Patient & Public Involvement practices are often tokenistic and inequitable - suggesting resistance, ignorance and/or inadequate infrastructure and support are commonplace. Furthermore, differences in emphasis between actors regarding the rationale for participatory approaches contributes to tensions playing out within and between involvement networks. These controversies and tensions inform critique of what was recently referred to by health service researchers as the 'dark side' of coproduction.

We argue sociological analysis has been under-utilised in - but has much to offer - these debates. While all research practice benefits from critical examination, we demonstrate the tendency in current critique to focus on the alleged inherent insufficiencies of the practice of coproduction rather than the structures and contexts of health(care) research that commonly undermine the endeavour of meaningful and useful involvement. Viewing the supposed ‘dark side’ of coproduction sociologically, our critique more adequately highlights the significance of structural restraints and power imbalances in defining what has come to be accepted (and critiqued) as ‘coproduction’, whilst also demonstrating what coproduction could/should otherwise be.

Friday 13 September 2019 at 10:45 - 11:15
Ethnicity
PT111

Mix & Match: Constituting Racialised Communities in UK Stem Cell Donor Recruitment

Williams, Ros
(University of Sheffield)
This paper presents a new Wellcome Trust-funded project starting in 2019 exploring minority ethnicity stem cell donor recruitment in the UK. Using ethnographic and digital methods to explore online and offline efforts by charities and individuals, the project investigates the role of race and notions of “mixed-race” in contemporary biomedicine. Stem cell transplants are an increasingly common cancer treatment option, but minority ethnicity and mixed-raced people in the UK—as in most of the global north—are far less likely to find matching stem cell donors than their white counterparts. A number of small charities and campaigns (generally led by people themselves racialized as minority ethnicity) seek to address this inequality by organising donor drives and using social media to encourage minority and mixed-raced people to register as stem cell donors. This paper presents pilot data, and foregrounds the theoretical notions of biosociality and biosocial communities as useful conceptual tools for critically unpicking the collectivising consequences of genetic technologies like those used to find matches between patients/donors. It also presents the project’s innovative mixed-method approach, including charity ethnography, and multi-platform social media analysis of minority ethnicity stem cell donation campaigns. The paper describes the project’s aims to (i) explore how racial difference is mobilised to encourage potentially life-saving acts of donation within minority ethnicity communities, (ii) contribute to understanding how significant ethnic health inequalities are being addressed by small charities and individuals, and (iii) understand how race and notions of heredity are being enacted in a contemporary biomedical context.

Friday 13 September 2019 at 12:30 - 13:00
Experiences
PT006

How do hospital buildings impact patients’ experiences of cancer therapy?

Wiltshire, Gareth, Pullen; E., Turner; J., Brown, F. (University of Bath)

Amidst recent calls for medical sociology to pay better attention to architecture and building design, this research investigates the patient experience of 18 cancer patients at one hospital in England. Following NHS and University ethical approval, oncology staff recruited participants to take part in one of four focus group interviews organised by diagnosis type (breast cancer, high-grade lymphoma, low-grade lymphoma and prostate cancer). Our analysis highlights how the hospital building played a part in the patient experience in a number of ways and at different stages of their journey through illness. This experience was shaped by an interplay between the physical materials of the hospital, the symbolic meaning of objects in and around the hospital, cultural understandings and expectations of cancer treatment, and embodied-sensory sensations encountered in the clinic. Drawing on existing literature related to therapeutic landscapes and the materialities of healthcare, these findings are used to explore how medical sociology can help understand the dynamics between hospital buildings and the patient experience so as to enhance the quality of care across contexts.

Thursday 12 September 2019 at 14:35 -15:05
STS
PL005

“Where will we end up from here?” Shaping of Time, Space and Place in Ambulance Work

Wood, Lisa (Lancaster University)

"In 2005, the UK government review of ambulance services Taking Healthcare to the Patient recommended that larger, centralised organisation would enable ambulance services to deliver and review operations more efficiently. The result of this policy was the creation of merged and geographically spread organisations. Such mergers created challenges and opportunities for resource allocation, organisational monitoring and streamlining. More recently, the UK government’s austerity measures have prompted organisations to further attempt new business models and modes of working based on changing socio-technical relationships. The climate of aggregation, streamlining and cost efficiencies, makes fertile ground for technological innovation and the deployment of pseudo-market disciplines to rationalise ambulance services. Inspired by recent Mobilities scholarship in crisis response and Science and Technology Studies, this paper considers how such socio-technical changes in ambulance work have shaped space, place and time and how individuals push back, manipulating spatialities. Further informed by the work of Doreen Massey, I explore how spatialities are political and also technologically constructed. Drawing on ethnographic observations of an ambulance call centre and ‘on the road’ paramedic work, I describe how methods of resource coordination create technological appearances of organisational monitoring and streamlining, and how moving vehicles from one territory to another, across fluid and flexible geographical boundaries, enables the organisation to provide emergency care in a timely manner, meeting targets. The advantages of such organisational flexibility is often used for political and economic purposes with aggregated technological overviews providing persuasive arguments for alignment, for sharing resources and increasingly, given the current era of austerity, cost savings. Yet, as stated in the Association of Ambulance Chief Executives report in 2011, the changes can be “difficult to manage.
Japanese high school students talking about sexuality: qualitative data generated by the Japanese Traffic Light Tool

Yamamoto, Beverley
(Osaka University)

Despite the huge sex industry in Japan, the country is very conservative when it comes to the subject of sexuality in school settings. There is limited sex education in schools and the approach taken is largely lecture based and bio-medical. There is little research on how young people talk about sexual and reproductive health issues.

Here we report on the results of a piloting of a Japanese version of the Traffic Light Tool (TLT). We report on the data generated from 15 focus group sessions in a high school in a provincial city in Japan. We present data on how Japanese students talk about sexuality and reproductive health.

The Japanese TLT was used in small groups facilitated either by a school nurse or a class teacher. Participants were shown cards with age-related scenarios relating to sexual and reproductive health/safety, and the participants had to come to a consensus about whether each healthy/safe (green), possibly unhealthy/risky (amber) or unhealthy/risky (red). The researcher (BY) recorded and observed each session. Participation was based on informed consent.

Students drew on a number of frameworks to decide the placement of each scenarios including legal, safety, sense of place (ba), impact on others (meiwaku), consent and age. Consensus was reached more easily with negative scenarios involving coercion, than positive ones consensusal behaviours. There was also varying views on teenage pregnancy. The emphasis placed on place and impact on other in evaluating the scenarios deserves further investigation.

Teachers praised the students’ comments as thoughtful and informed.

The assemblage of medicalised dying

Young, Jessica
(University of Otago)

Assisted dying is a globally significant issue given the continued controversies over proposed law changes, including in New Zealand. However, the voices of people with experiential knowledge of dying are missing from the discourse. My research is an open enquiry into the perspectives of New Zealanders with approximately one year’s life-expectancy who would consider an assisted death (if it was available). I recruited 14 participants through national media coverage. Eight females and six males, mostly of New Zealand European descent, aged 34–82 and a further six family members participated. In the participants’ accounts of why they might wish to hasten their death, there was ambivalence about the role of medicine in their lives. They wanted medicine to help them have a good death but at the same time anticipated the likelihood that it would not be able relieve their suffering. Participants’ accounts of wanting assisted dying were framed within a medical framework and the wish to die is itself medicalised. Therefore, they offer another insightful perspective on the relationship between the institution of medicine and patients. In this presentation, I will outline an assemblage of medicalised dying to illustrate how participants constructed dying as a medicalised process. It is comprised of dynamic relations between patients, health professionals, families, care settings, diagnosis, prognosis, treatments, technologies, pain, non-physical suffering and the End of Life Choice Bill policy. Deleuze and Guttari explicated assemblages as dynamic doing things, not just entities comprising identifiable components. Participants were not simply passive recipients of medicalisation, rather they both rejected and embraced forms of medicalisation, actively constructing it at the same time as resisting it. Participants conspired with the medicalisation of dying by framing their dying, death and suffering as activities that require medical intervention to achieve the good death that they saw ‘medicine’ as promising. The final part of this presentation explores the main benefit of medicalisation which is how participants could stake their moral claim as being deserving of an assisted death. Participants justified their claim that ‘medicine’ should help them to die because it cannot relieve their suffering. I conclude by suggesting that as a consequence of the medicalisation of dying, participants constructed assisted dying as a rational medical intervention to the problem of bad dying. Medicalisation, when viewed as an assemblage theoretic, is a construct that continuously arranges, produces and conceals its elements and relations, with identifiable affects and effects. Co-authors Associate Professor Chrystal Jaye, Dr Richard Egan, Dr Janine Winters, and Mr Tony Egan. Dunedin School of Medicine, University of Otago, New Zealand
Towards a sociology of work and wellbeing.

Yuill, Chris  
(Robert Gordon University)

This paper will make the case that work in all its relations needs to be represented and understood more in the sociology of health and illness. A sociological approach to work in wellbeing is critical for several reasons. First, over a million workers in the United Kingdom alone are affected by work-related illness and 1.2 billion people die annually because of work-related illness. Second, to counter neoliberal notions of resilience and risk in the workplace, which individualise the causes of complex social relations that lead to poor wellbeing. Third, to bring a richer theoretical understanding of the relationship between work and wellbeing. Social epidemiological approaches and research in the sociology of work provide insightful empirical data but lack the explanatory depth that sociology brings to understanding the wider sets of relations that shape society and wellbeing.

Drawing on old and new theories of materialism I will argue that work is a central relation in wellbeing. Work is where social inequalities of class, gender, ethnicity, sexuality and disability are produced and reproduced. It is where the embodied emotional social agent of the worker enters an assemblage of relations with other people, power, inequalities, technologies and the materiality of the labour process. It is these relations that influence and shape wellbeing in work.