

# Paper Abstracts

Listed in alphabetical order by first named author

**Thursday 10 September 2015 at 14:00 - 14:30**

Pharmaceuticals

PT103

## **Regulating Pharmaceuticals for Public Health: Political Challenges and Prospects**

*Abraham, J.*  
(King's College London)

Drawing on many years of fieldwork in Europe and North America, this paper begins by considering the record of key pharmaceutical regulatory agencies in those regions during the modern regulatory period, that is, from 1970 to the present. It does this along various criteria, such as patient safety protection, promotion of drug efficacy and innovation, development of international 'scientific' standards, evolution of cost-effectiveness and adequacy of pricing regulation. Key problems with the performance of pharmaceutical regulation with respect to advancing the interests of public health are identified along all these criteria. The paper then considers institutional reforms, political interventions and a re-thinking of the relationships between the politics and science of pharmaceutical development as ways of addressing those problems. For example, reform of the institutional relations between the pharmaceutical industry and the regulatory state, confrontation with the ideology of innovation, better recognition of the role of non-clinical testing, a re-construction of the regulatory science of clinical and pharmaco-vigilance testing based on the identifiable regulatory lessons of the past, and much better transparency and co-ordination between product regulation, cost-effectiveness assessment, pricing regulation, and the citizenry.

**Thursday 10 September 2015 at 08:30 - 09:00**

Embodiment and Emotion

PT103

## **Doing Emotion Work and Presentational Self-Control at Work: What Impact is this Having on Employees?**

*Addison, M.*  
(Newcastle University)

In this paper I discuss how being able to let off steam is important to employees at work, as a way of relieving the pressures of emotion work and presentational self-control. This is based on qualitative data collected from 31 semi-structured interviews with employees in a workplace setting. Tracy (2005) highlights how having space to let off steam at work, without worrying about judgements or doing emotion work, is invaluable to employees. My work supports this, and adds to it by showing that disparities of power to do with hierarchical position or social position (Bourdieu, 1984) mean that some people appear to have more freedom than others to vent their frustrations at work. This is important in that for every person who has a space to vent, there appears to be another person listening and doing emotion work themselves. My argument here then is that some people seem to have fewer outlets than others to relax and ease the tensions that are incurred through doing emotion work and presentational self-control at work. The intent of this paper is to stimulate sociological discussion around emotion work and presentational self-control, particularly related to a workplace setting.

**Wednesday 9 September 2015 at 13:55 - 14:25**

Theory

PT006

## **Insider or Outsider? Issues of Power & Habitus During Life History Interviews with Menopausal Iranian Women**

*Amini, E.*  
(Durham University)

Conducting my fieldwork among religious menopausal women in Iran raised – as a secular Iranian woman myself – the question of the position of the researcher in life history research. This issue of insider/outsider status has been explored in the context of qualitative research from the perspectives of ethnicity, gender, disability and age. This paper will discuss how power is negotiated between the interviewer and interviewee throughout the life history interview. As an Iranian woman conducting interviews with menopausal Iranian women in Iran, I found that intersections of ethnicity, culture and gender were combining during the course of the interview. I found that what Bourdieu called the 'habitus' (how I speak, sit and what I wear) was a significant factor in negotiating my insider/outsider status. During my research, this status shifted during the interviews. So rather than consider the status of the researcher static and bounded dichotomously – either insider or outsider – instead I experienced a complex, dynamic status as

## Paper Abstracts

both insider and outsider during even one interview. Utilising Connell's life history method and Bourdieu's notion of the 'habitus', this paper considers these issues.

**Thursday 10 September 2015 at 09:40 - 10:10**

Inequalities  
PT006

### **At the Intersection: Capturing the Multiple Determinants of Poor Health for Generations of Roma, Gypsy and Travellers in Europe Reported in the Literature**

*Anderson de Cuevas, R., Kovandzic, M., Such, E., Orton, L.*  
(University of Liverpool)

There is growing evidence that Roma, Gypsy and Traveller (RGT) populations in Europe have significantly poorer health and a shorter life expectancy than majority populations. This can be attributed to the adverse socio-economic, political and environmental conditions endured by RGT communities since their arrival in Europe one thousand years ago, fuelled by discrimination. The multiple social inequities affecting RGT populations which have led to differential health outcomes, their interaction and cumulative effect over time, require further exploration.

We carried out a critical review of the sociological and medical literature to investigate the complex interplay of factors which have led to health disadvantage for many RGT peoples. The review followed standard methods and reporting guidelines for systematic reviews (PRISMA).

Theories of intersectionality, which have recently been applied to the social determinants of health, were explored for their potential to frame the interacting axes of oppression driving poor RGT health. The concept of intergenerational trauma from the Canadian aboriginal context was also taken to examine how stressors have been compounded throughout history. The review highlighted commonalities and differences in the situation of RGT between and within European countries and identified protective factors. It puts forward a more nuanced understanding of the social determinants of health for RGT communities and what has caused them to persist, despite a plethora of European and national policy initiatives to redress them.

**Friday 11 September 2015 at 10:45 - 11:15**

Gender  
PX001

### **'Gender-specific Medicine' and the Biopolitics of Health**

*Annandale, E., Hammarstrom, A.*  
(University of York)

This theoretical paper develops the argument that the growth of 'gender-specific medicine' heralds a new biopolitics of health which brings the longstanding relationship between gender and medicalization more closely together and in novel ways. Drawing on the concept of 'stratified biomedicalization' (Clarke et al., 2010), we focus specifically on the problems that arise from the division and stratification of bodies through the gendered customization of pharmaceuticals and other medical goods such as off-the-counter lifestyle products. We explore how the 'gender-specific body' and a 'gender-specific ethos' in medical practice are fabricated through the accentuation of difference and the dominion of sex, and through a fragmented conception of the body. We also ask whether recent developments within the neoliberal landscape which emphasise customisation and personalisation (such as the recent push to 'precision medicine') further the 'gender specific' ethos, or whether they might have a positive, disruptive potential. For example, might the binary sex divide on which 'gender-specific medicine' ultimately rests be pushed to the margins via the intense individualisation that these developments entail? The paper reflects on the consequences of these developments for the politics of gender and health and the treatment and experience of illness.

**Thursday 10 September 2015 at 11:25 - 11:55**

Inequalities  
PT006

### **Volunteering and Wellbeing in Disadvantaged Communities: An Investigation of Cognitive and Emotive Responses to the Experiences of Volunteering in a Foodbank**

*Armour, S., Barton, G.*  
(Robert Gordon University)

Foodbanks have expanded rapidly in the UK since 2010, and could be seen as the most successful manifestation of the government's Big Society rhetoric. Voluntary work has been proposed as offering responses to a range of social issues in the UK, including social exclusion and the reduction of welfare provision.

A growing volume of studies evidence an association between structured volunteering and improved psychological well-being, potentially leading to improved physical health outcomes, including mortality rates. The experience and effects of volunteering are

likely to be influenced by setting and context, as well as individual circumstances and attributes, and yet despite persistent health inequalities, little research has focussed on volunteering within deprived communities.

This study adopts an Interpretative Phenomenological Analysis approach, using semi-structured interviews with four women of working-age, living in disadvantaged urban communities in the North-West of England, to explore their experiences of volunteering in a foodbank.

The study identified a range of beneficial social and psychological effects of this volunteering, illuminating an interplay of theoretical concepts in real lived experience, while also highlighting the importance of context.

The social justice orientation of the foodbanks added a layer of purpose and meaning to their involvement, which may provide some protection against the detrimental effects of neoliberal discourse and policies in relation to poverty.

While the findings are not generalisable, the study adds to our understanding of how voluntary activity may be beneficial to social and psychological well-being, particularly when undertaken in a community empowerment oriented organisational context.

**Thursday 10 September 2015 at 12:00 - 12:30**

Citizenship  
PL006

### **Distributed Expertise as Reflexive Narrative: Doing Personal Genomics in an Online Forum**

*Arribas-Ayllon, M.*  
(Cardiff University)

There has been considerable debate over whether direct-to-consumer genetic testing (DTCGT) is a harmful, helpful or even spurious development of genomic medicine. Most of these debates are concerned about the accuracy, validity and utility of susceptibility testing and whether the public are capable of recognising their limited predictability. As it stands, there is very little research that explores the ways in which lay people actually use these technologies to make sense of medical conditions. Drawing on a case study of an online forum, this paper explores the structure and process of participation among contributors who are using personal genomics to understand and treat a complex chronic condition. Analysis of the forum attends to the generic and discursive elements of mundane reflexivity to understand their methods of imputing and negotiating the value of genetic testing. A key finding is that online users engage in collaborative knowledge building to transform the complicated and confusing affordances of genetic data into stable, public artefacts for group interpretation. The paper argues that the distributed nature of lay expertise is capable of developing its own reflexive narrative on the limits and uses of susceptibility testing. The paper concludes that the productivity of distributed expertise resides among the heterogeneity of consumer-citizens who seem capable of questioning the expectations and developments of personal genomics.

**Friday 11 September 2015 at 10:10 - 10:40**

Mental Health  
PT006

### **Understanding Vulnerability to Self-Harm in Times of Economic Hardship: A Qualitative Study**

*Barnes, M., Donovan, J., Gunnell, D.I.*  
(University of Bristol)

Self-harm and suicide rates increase in times of recession. However, little is known about why people self-harm when in financial difficulty, or who is most at risk or when. This study used semi-structured, in-depth interviews to explore the experience of nineteen people from two large English cities who had attended hospital following self-harm with serious intent who cited job loss, economic hardship or the impact of austerity measures as a causal or contributory factor. Interviews were fully transcribed and analysed using constant comparison techniques within an inductive, grounded theory approach.

Participants often described considerable lifetime vulnerabilities, including abusive or neglectful parents, bullying and domestic violence, long-standing mental health problems, current or past relationship difficulties, frequently changing or temporary employment, or bereavements and poor self-esteem (sometimes related to sexuality). Economic hardship, related to being unable to find employment or losing their job, experience or concerns about debt and/or benefit changes or sanctions, were often cited as leading to feeling unable to cope and triggering self-harm.

Vulnerable people become more vulnerable in times of economic hardship and austerity. This should be factored into the identification of those most likely to be at risk and in the development of interventions. Those requiring practical support for financial difficulties and employment/benefit entitlements are likely also to benefit from a more holistic evaluation of their underlying or long-standing vulnerabilities.

## Paper Abstracts

Wednesday 9 September 2015 at 15:05 - 15:35

Mental Health  
PL006

### **Mental Health and Physical Activity: An Ethnographic Study of the Experiences of Current and Former Service Users' Involved in Football Sessions in Birmingham**

*Benkwitz, A.*  
(Newman University, Birmingham)

Over recent years there has been an increasing interest in forms of physical activity and sport for the benefit of individuals with mental health related issues. A volume of literature now exists that highlights the many ways that participation in various forms of physical activity can contribute to good mental health. However, within the physical activity and sport literature there remains a lacuna in terms of research and appreciation of those actually involved in these physical activities. Instead, to a large extent, there remains a 'clinical gaze'; with numerous studies that, broadly speaking, take a 'before' and 'after' of individuals involved in physical activity interventions, and then judge the effectiveness of the intervention. This approach continues to neglect the lived experiences and social interaction of those involved and lacks appreciation of what actually goes on during such an intervention. In an effort to address this, an ethnographic study has been undertaken, which aims to explore the lived experiences of, and provide a voice for, individuals involved in 'football therapy' sessions in Birmingham. The participants include current and former service users from medium-secure units, as well as non-secure service users and staff/volunteers. This work in progress paper offers a framing and a rationale for the study, a consideration of methodology, together with an insight into the on-going analysis

Friday 11 September 2015 at 10:45 - 11:15

Mental Health  
PT006

### **'We Look to the Future, But Without Knowing What it will Bring'. A Qualitative Analysis of French Youth Psychiatrists' Attitudes Towards Prognosis**

*Benoit, L., Henckes, N.*  
(École des Hautes Études en Sciences Sociales (E.H.E.S.S.) - Paris)

In most developing countries, the developing policies of early detection and intervention have turned the prediction and anticipation of mental illnesses into a core dimension of discourses and practices in the field of youth psychiatry. Yet little is known about the routine practices of psychiatrists working with young people regarding prognosis. What kinds of expectations do psychiatrists routinely have when treating young adults? To what extent do these expectations shape their work with these young patients? And to what extent and how do they communicate their expectations to patients and their families? In this study we did a series of in depth interviews with a sample of French psychiatrists specialized in the treatment of adolescents and young adults. We asked them both how they understood the concept of prognosis and how they used prognosis in their daily work with young adults. The interviews were analyzed using grounded theory methodologies. We show that while most of these psychiatrists did not spontaneously mention the fact that they made prognostications when treating young patients, they were all able to describe situations where their expectations regarding the future of their patients were problematic and called for specific action. These situations were characterized as involving both hidden symptoms and denial. In the end the uncertainties and indeterminations of prognosis in youth psychiatry reflect the many uncertainties concerning the boundaries between symptoms and existence in the realm of severe mental disorders.

Friday 11 September 2015 at 09:35 - 10:05

Patient - Professional Interaction  
PL001

### **'I Was Like, Oh My God, What Happens if it Doesn't Work?': Young People Living with HIV, Clinical Trial Participation, and the Truth Economy**

*Bernays, S., Papparini, S., Seeley, J, Rhodes, T.*  
(London School of Hygiene and Tropical Medicine)

For many HIV positive young people growing up throughout the world, clinics are amongst the very few social spaces where they can be open about their HIV status. The relationships they build with their clinical care teams are vital in the context of a long term condition they otherwise frequently experience in isolation. This paper draws on repeat in-depth interview data from a longitudinal qualitative study with 43 young people living with HIV aged 10-24 from UK, Uganda and the USA which was embedded in an international clinical trial. We found that the desire to maintain a reputation as a 'good patient' may weigh on young people's decision to participate in clinical trials. We will discuss the specificity of these relational pressures on young people, how they reason their way through them, and what they might tell us about the limits of informed consent and the acceptability of research about interventions with this cohort. What participants decided to reveal or withhold in discussions with clinicians constituted a 'truth economy' in which many aspects of their HIV experience, from treatment adherence to their feelings about trial participation, were expressed or kept hidden in an attempt to manage their reputation with their care team. Anxieties about participating in the trial were often not verbalised until the later phases of the qualitative study. This points to the contribution that longitudinal qualitative

research can bring to a more comprehensive understanding of acceptability and consent and to improving recruitment and trial procedures.

**Thursday 10 September 2015 at 17:30 - 18:00**

Experiences of Health and Illness

PX001

### **Investigating the Role of Healthcare in the Construction of Patients' Experience of Physical Disability: A Case Study of Dystonia Patients and Healthcare Practitioners in England**

*Bernstein, C., Boardman, F, Davies, G. E, Ellard, D, Griffiths, F, Lewando-Hundt, G, Sandhu, H, Tang, N, Underwood, M*  
(University of Warwick)

Sociologists exploring the role of 'experiential knowledge' in constructing lay and health experts' understandings of impairment and disability have emphasised the renegotiated nature of this process. Theorists note that patients may draw upon medical knowledge as a legitimate attempt to manage stigma or embarrassing situations, seek out support as well as make sense of their condition. Similarly, patients may 'resist' or challenge medicalising discourses and practices that appear contradictory or incongruous with their experiences of living with the biosocial effects of an impairment (Thomas 2007). Sociologists of disability suggest that exploring patients' experiential knowledge becomes pivotal for illuminating how embodied and disablist factors may interlace with lay understandings of living with an impairment.

Drawing on recent theoretical and empirical developments within the sociology of disability and impairment, this study focuses on dystonia as an example of a case study that details individuals' understandings and experiences of the condition. Dystonia is defined as a neurological movement disorder that can produce varied somatic effects. This study explores how dystonia is holistically experienced from the perspectives of lay and health experts. Data will be presented from qualitative interviews with patients, health professionals and support group attendees. Observational data of hospital consultations and support group meetings will also be discussed. Although dystonia is often understood as a disruptive and negative life experience, we suggest that attending to the complex interrelationships existing between patient and professional accounts is significant for showing how lay experiences of dystonia can become revalued and in some cases, positively transformed.

**Thursday 10 September 2015 at 14:00 - 14:30**

Lifecourse

PL002

### **Exercise, Physical Activity and the Pursuit of Virtue Amongst Older, Disadvantaged Women in South Yorkshire**

*Bissell, P., Gowans, G.*  
(University of Sheffield)

Epidemiological studies consistently demonstrate a decline in levels of exercise and physical activity (PA) with increasing age, alongside an association between this and socio-economic position, with the lowest levels of activity undertaken by women in such groups. Given that there is steep gradient in disability free life expectancy, with the most disadvantaged experiencing much higher levels of impairment, this is perhaps unsurprising. However, health policy in relation to exercise largely ignores the social gradient in ill health, expecting individuals to exercise, regardless of health or social position. Furthermore, one of the dominant discourses around ageing depicts older people as a cost or a burden to taxpayers, which not only overlooks their contribution to existing forms of solidarity, but may also negatively shape their identities.

This paper draws on findings from a qualitative study with 12 older women (65+) living in disadvantaged areas of Sheffield. The study used double narrative interviews in order to investigate the everyday contexts associated with PA and exercise and to contextualise this within the life-history of participants. In particular, we report on how the vicissitudes of chronic illness combined with isolation and limited resources framed the responses of women to the injunction to exercise. We also describe how many women also sought to protect themselves against the implicit charge of being a burden by discursively positioning themselves as virtuous in relation to other aspects of everyday life and specifically in terms of caring for others.

**Wednesday 9 September 2015 at 12:45 - 13:50**

Pecha Kucha

PT007

### **Gatekeeping and Research About the Sexuality of People, 16+, with Life-limiting Conditions (LLCs)**

*Blackburn, M.*  
(The Open University)

Background - Intimacy, relationships and addressing sexuality at the end-of-life are important matters for most people but are often regarded by care staff as difficult and complex areas for discussion (Blackburn, 2002; Hordern & Street:2007a, 2007b).

## Paper Abstracts

Researchers often identify gatekeepers as important mediators in research with marginalised groups (Eide & Allen, 2005). Gatekeepers may consciously or subconsciously hamper research contributions in their attempts to "protect" participants from sensitive questioning and discussions (Barber, 2014; Reeves, 2010, Guthrie and Barbour, 2002). Why is this? Does the word "sex" deter gatekeepers from encouraging research participation? Barriers may arise from society's attitudes and taboos about discussing sex with people with life-limiting conditions.

Methods and theoretical framework - The first author's PhD research is underpinned theoretically in the sociology of health, illness, death and dying and uses qualitative methods in face-to-face, semi-structured interviews with thirteen young adults with life-limiting conditions (LLCs), eight parents and ten care staff.

Aims - This presentation will address the following ethical considerations that arose in this research.

- Building rapport with gatekeepers
- The role of institutional gatekeeping in facilitating research
- Gatekeeping and obtaining consent.

Conclusion - People with LLCs are under researched in social sciences, largely due to access, gatekeeping and the notion that people with disabilities are vulnerable (Carter, 2009). Denying research participation in the 21st century should no longer be an option. Positive engagement with gatekeepers should encourage autonomous decision-making by individuals as to whether or not they wish to participate in research.

**Wednesday 9 September 2015 at 16:15 - 16:45**

Lifecourse  
PL002

### **The Rise and Fall of Pathways in End of Life Care**

*Borgstrom, E.*

*(London School of Hygiene and Tropical Medicine)*

In recent years, the language and practice of care pathways has come under intense scrutiny following public scandals and an independent review of the Liverpool Care Pathway for the care of the dying in England. The term pathway has been used in health service delivery, for over 10 years to describe a range of initiatives to co-ordinate and integrate health (and to some extent social) care. Within end of life care, their use has suggested that dying can be managed and this paper will address the apparent rise and fall of care pathways in end of life care. I argue that whilst re-shaping end of life care services, the concept of pathways in this context fails to match people's lived experiences of healthcare services and dying more generally. Moreover the tensions between process and event represented in the pathways, the tendency to treat the pathway as a protocol, and the negative connotation of the term 'pathway' in relation to dying, have ultimately resulted in the problems addressed within the review of the Liverpool Care Pathway. I will then turn to outline the alternatives suggested by policy – care plans – and suggest that the way they are operationalised may mean they, too, will eventually face a similar fate to care pathways.

**Thursday 10 September 2015 at 10:15 - 10:45**

Inequalities  
PT006

### **From Doctor to Butcher....Status Degradation of International Medical Graduates**

*Boroah Pyatt, R.*

*(University of Guelph, Ontario, Canada)*

Stretching Harold Garfinkel's theory of degradation ceremonies from a micro to a macro level perspective, this paper explains the systemic status degradation of International Medical Graduates (IMG) in Canada. There are 6,540 IMGs living in Ontario that are not allowed to practice medicine in a province that claims to have a shortage of doctors. To comprehend such glaring challenges and discrepancies, it is imperative to understand and dissect the nature of the existing system that not only disallows IMGs to work within the Canadian medical profession but also disables them to fully participate in civil society. Using Garfinkel's theory of degradation ceremonies to explain the status degradation of IMGs, this paper provides an in-depth analysis of how the removal of IMGs from practising medicine degrades them to a status lower than their original status, transforming their identity into a new and lowered one. The significance of the topic is further highlighted as it touches upon the impact of status degradation of IMGs on their families, on the fundamental rights as outlined in the Charter of Rights and Freedom, on the human potential and on the suffering of the medically underserved. This paper concludes by stating recommendations generated by IMGs and provides information on existing initiatives at the macro level that seek to upgrade the status of IMGs. Reiterated here is the important link that exists between recognition and identity and how recognition of appropriate status for IMGs is an integral part of the democratic dialogue and discourse of multiculturalism.

Thursday 10 September 2015 at 09:05 - 09:35

Citizenship

PL006

### **Embedding Involvement: The Challenges Faced by Health and Medical Researchers**

*Boylan, A.M., Locock, L.*  
(University of Oxford)

Patient and public involvement (PPI) in health and medical research is increasingly mandated by funders as a way of improving the relevance and quality of research, but the evidence for this is limited. This study uses Michie et al.'s theoretical domains framework to explore researchers' views on involvement and on the benefits and challenges of embedding it as common practice.

Thirty-five health (both clinical and non-clinical) researchers participated in a semi-structured interview about their experiences and views of involvement in research, including how and why they began involving people, the benefits of involvement and the challenges they had faced. Interviews were video or audio-recorded, transcribed verbatim and thematically analysed independently by two researchers. The findings have been disseminated on the health information website, [www.healthtalk.org](http://www.healthtalk.org).

Numerous personal, practical, environmental and social challenges to embedding PPI were identified. Concerns were raised by the participants about their personal skill level and knowledge, colleagues' attitudes, practicalities associated with involving people (e.g. time taken to organise meetings and payment), and academic debates about, for example, representativeness. Whilst the general attitude towards involvement was positive, some were concerned about how it may negatively impact on their career development.

Our findings suggest researchers often feel more powerless than the traditional discourse suggests. For PPI to remain an embedded part of the research process, the concerns they raise must be addressed.

Friday 11 September 2015 at 11:20 - 11:50

Critical Public Health

PT007

### **Public Health in English Local Authorities: Some Implications for the Public Health Workforce**

*Bramwell, D., Gadsby, E., Perkins, N.*  
(University of Manchester)

The English health system reforms enacted in 2012 brought about many changes for public health. Local authorities now take the lead for health improvement and coordinating local efforts to protect the public's health and wellbeing. Consequently, most public health professionals and practitioners were moved from NHS organisations to either local councils or to a new national agency – Public Health England.

Since April 2013 our Department of Health-funded research has been examining this transition, and implications for the public health workforce. Incorporating a scoping review followed by five in-depth geographical case studies, we have so far carried out 60 in-depth interviews with a wide variety of LA, public health and NHS staff and observed a range of meetings. Two national surveys of all directors of public health and council members with health portfolios have also been conducted.

Preliminary findings highlight that public health professionals need to adapt to new ways of working in LAs by using different skills and adapting their roles. They are also experiencing complex changes to autonomy, power and professional identities - all of which impact on their ability to affect significant changes in population health. In this paper we explore how these transitional experiences of professionals coming to know and be effective in their new organisational contexts can be explained through a framework of social learning systems theory (Werner, 2000) and discourses of professionalism (Fournier, 1999). We emphasise the importance of understanding this in informing and influencing the wider public health workforce.

Friday 11 September 2015 at 11:55 - 12:25

Health Service Delivery

PL005

### **The Detection and Management of Pain in Patients with Dementia in Hospital: Exploring the Impact of Social Factors**

*Briggs, M., Lichtner, V., Esterhuizen, P., Dowding, D., Allcock, N., Closs S. J.*  
(Leeds Beckett University)

Pain management is complex activity that embraces physiological, emotional, cognitive, and social dimensions. This is exacerbated when caring for people with dementia because of challenges that the progressive cognitive and functional decline present. Pain is often described as a private experience but in reality it regularly requires public expression in order to achieve relief (1). This presentation will draw on the findings of a study designed to develop decision making tools to identify and manage pain for people with dementia. The study involved 4 NHS hospitals in the UK. Data collected included observation of patients in the ward (n=31,

## Paper Abstracts

140 hours), interviews with carers (n=4) and NHS staff (n=52). This study is part of a wider project consisting of 3 interlinked phases:

1. An overview of systematic reviews of existing tools for the assessment of pain and dementia.
2. An exploratory, multiple case site study
3. Development of decision support tools and feasibility assessment.

The findings suggest that the recognition, assessment and management of pain are complex social processes, occurring within a multi-professional and hierarchical culture of the NHS. This presentation will draw on the findings of this study and explore these in light of the emerging social-physical pain overlap theory and the social communication model of pain (1, 2).

1. Craig K (2009) The social communication model of pain. *Canadian Psychology* 50, 1 22-32
2. Eisenberger NI (2012) The pain of social disconnection: examining the shared neural underpinnings of physical and social pain. *Nature Review Neuroscience* 13 421-434

**Wednesday 9 September 2015 at 15:40 - 16:10**

STS  
PL005

### **Neuroscience and the Future: Hopes, Uncertainties and Contested Temporal Imaginaries in Policy and Society**

*Broer, T., Pickersgill, M.*

*(Usher Institute for Population Health Sciences and Informatics, University of Edinburgh)*

Neuroscientific research increasingly sparks the imaginations and hopes of policy actors and families. Drawing on interviews with policy actors and families in Scotland, in this presentation we will explore the role of hopes and uncertainties in different accounts of the import of the neurosciences. The work forms part of a larger Leverhulme Trust funded project on 'Neuroscience and Family Life'. Within policy actors' discussions of their encounters with the neurosciences, hope can be both the starting point and the outcome of engagement with neurobiological findings and concepts. In turn, hope inter-relates with a range of uncertainties. In particular, about whether 'the science' will lead to substantive changes in governance. In part, these findings were mirrored in the family interviews we conducted, where the brain sciences were seen as informing a more hopeful, understanding future. However, families' ideas of this future were sometimes radically different from those of policy actors. For example, contra a common narrative of brain-based care and the import of child-centeredness, some of the citizens we interviewed argued that putting children's needs central would not prepare them for a world in which they inevitably would have to 'stick up for themselves'. We use these similarities and differences as a platform for reflection on the role of hopes and uncertainties in different kinds of futures constructed and contested through (non-)engagement with the neurosciences. We thus contribute to debates in medical sociology around the translation of biomedical knowledge and the construction of sociotechnical futures and everyday lives.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Methods  
PL001

### **Questioning the Sum and the Parts – The Challenges of Measuring Multimorbidity in the Population**

*Bromley, C., Cunningham-Burley, S., Frank, J.*

*(University of Edinburgh)*

The concurrent experience of multiple health conditions (multimorbidity) has become an important focus of health services research and policy. Concerns include negative patient outcomes, outmoded systems and guidelines developed using a single disease framework, and the increasing costs of treating multimorbidity and the ageing population. Much multimorbidity research uses data (e.g. GP or hospital records) that privilege clinical / medical perspectives and lack important socio-contextual information about the lives of multimorbid people. Population health surveys can help to overcome these limitations, but defining multimorbidity is problematic.

This paper presents detailed analyses of health conditions data collected in the 2008-2011 Scottish Health Surveys via open and closed questions. The multimorbidity measure developed was informed by theoretical perspectives offered by sociological approaches to diagnosis / classification, medicalisation and illness experiences alongside longitudinal analyses of mortality. Issues considered included hypertension (more than two-thirds of people with hypertension did not declare it unless prompted) and obesity (almost never reported), both of which revealed insights about the incongruence between clinical and lay perspectives, the nature of illness experiences, and a possible rejection of the increasing medicalisation of disease risks. Similarly, symptom and medication data suggested under-reporting of mental illness, but the consequences of potentially medicalising normal distress had to be balanced against the risk of losing important contextual insights.

Unlike traditional empirical analyses, the method adopted explicitly acknowledged the multiple, contested and constructed nature of health, illness and diagnosis; the limits of empirical enquiry; and the problems associated with approaching concepts such as multimorbidity uncritically.

Friday 11 September 2015 at 11:20 - 11:50

Professions  
PL006

**Apocalypse Now? The Global Antibiotic Crisis, Resistant 'Superbugs' and the Role of Interprofessional Power and Authority in the Hospital**

*Broom, A., Kirby, E.*  
(University of New South Wales)

The misuse of antibiotics has become a major public health problem given the global threat of multi-resistant organisms and an anticipated 'antimicrobial perfect storm' within the next few decades. Despite recent attempts by some health service providers to optimise antibiotic usage, widespread inappropriate use of antibiotics continues in hospitals internationally. While significant attention has been paid to doctors as antibiotic prescribers, antibiotic decisions within hospitals are in fact multi-stakeholder in character. In this study, drawing on qualitative interviews with Australian doctors, pharmacists and nurses, we explore the interprofessional mediation of antibiotics in the hospital, examining how professional jurisdictions, existing and emerging asymmetries, and practices of collusion and resistance, are played out in the context of antibiotic choices. We challenge the reification of medical prescribing power in the context of antibiotics, arguing that it conceals the interprofessional enactment of power and authority in the hospital, and may even work against the future of antibiotics.

Wednesday 9 September 2015 at 13:55 - 14:25

Methods  
PL001

**'I Wouldn't Have Let You in if You'd Had a Folder.' Access, Resistance and Consent in a Qualitative Interview Study.**

*Brown, S.*

Sociologists, particularly those using qualitative methods, are familiar with the need to consider how their data may have been influenced by contextual details, and how personal characteristics such as gender, age and race may have influenced the interactions between themselves as researchers and the participants in their studies. In addition, there can be an uneven power balance between researchers, who may be perceived as having an 'official' role, and participants, who may feel themselves to be powerless, which may influence the content of the interview, or even whether access is granted in the first place. In this paper I discuss examples from a recent study of how I was perceived as a researcher, and what my participants thought I was doing, and relate them to questions of access, resistance, and consent.

For a study exploring experiences of teenage parenting across generations, I visited participants in their homes to conduct in-depth interviews. A common finding was that young parents feel under surveillance all the time, both by official agencies and by their communities. This could lead to resistance (not letting people in), acceptance ('we thought you were the social worker'), and a great deal of image management, all of which potentially influenced the content of the interview. It also raises the issue of whether consent is freely given, if people feel they must accept surveillance.

Thursday 10 September 2015 at 10:50 - 11:20

Health Care Organisations  
PT111

**Engaging Young People with Long Term Conditions: The Role of Digital Clinical Communication in Improving Health Outcomes.**

*Bryce, C., Griffiths, F., Sturt, J., Dennick, K., Huxley, C., Kimani, P.*  
(University of the Warwick)

Young people living with long term conditions often disengage from health services resulting in poor health outcomes and additional costs for the NHS. Digital media has the potential to improve communication between patient and clinician to improve health outcomes in a population group familiar with the use of such technologies. This research, funded by the UK National Institute of Health Research, aims to evaluate the impacts of digital clinical communication (DCC) for young people living with long term conditions and analyse critically the provision and use of DCC by specialist care providers.

Working with 20 specialist clinics across the UK, our data collection aims to understand what works for whom, where, when and why, how much does it cost, what is the impact and what are the ethical and safety issues. Data is being collected through observation, interviews with patients, carers and staff, and examinations of clinic policy and guidelines. We will present data on how DCC is currently used and the views of its use from the perspective of both patients and clinicians, including its value, impact on care, workload and outcomes.

Through exploring the ways in which DCC works to encourage the engagement of young people within specialist services, alongside the impact it has on health staff, we expect this research will prompt a rethink in the NHS about the ways digital

## Paper Abstracts

communications are used in clinical care. This in turn will have implications for information governance including security and confidentiality.

**Thursday 10 September 2015 at 10:50 - 11:20**

Embodiment and Emotion  
PT103

### **Self-reported Health Behaviours and Knowledge Related to Cardiovascular Diseases Among a Sample of Working Age Population in Johannesburg, South Africa**

*Buldeo, P.*

*(University of the Witwatersrand)*

The prevalence of cardiovascular disease (CVD) among the working age population in South Africa is increasing despite the evidence that regular physical activity and healthy eating habits may prevent mortality and morbidity and reduce the risk of non-communicable diseases (NCDs). This paper draws on the sociological understanding of health by exploring self-reported health behaviours and knowledge related to CVD in the critical context of South Africa's quadruple burden of disease. It shows how social networks, cultural norms and gender shape workers' conceptualisation of lifestyle-related diseases and how CVD is understood. The study explored the responses of a selected sample of non-health professionals aged 19 to 75 employed at a retail pharmacy chain in Johannesburg. A mixed methods study incorporated (i) a survey (n=400) that questioned socio-demographic characteristics (age, gender, race), health behaviours (physical activity, eating habits) and CVD-related knowledge and (ii) follow-up interviews (n=50) to probe into the meanings people attach to their behaviour as related to symbolic interactionism. Data were analysed using descriptive statistical and thematic content analyses. 'Bad' health behaviours such as physical inactivity and unhealthy eating habits were found to be associated with time constraints, long working hours, financial stress and family responsibilities. 'Good' health behaviours were associated with physical attractiveness and improving or maintaining one's health. This paper therefore addresses the binary of 'good' and 'bad' health behaviours and its relationship with 'The Body', self and identity – which is important for the prevention of NCDs in the South African context.

**Thursday 10 September 2015 at 09:40 - 10:10**

Embodiment and Emotion  
PT103

### **Bodies in Mind: Architects Conceptions of the Ageing Body when Designing for Care**

*Buse, C., Nettleton, S., Martin, D.*

*(University of York)*

We explore how healthcare architects imagine the ageing body when designing care homes, as they engage in practices of 'bodywork', empathic and emotional work. In contrast to earlier research which found that architects 'rarely think about the human body' (Imrie 2003: 52), we found that in the context of designing for care, imaginings of lived bodies were prominent. The paper draws on qualitative interviews with eleven architects and designers, and forms part of a larger currently ongoing ESRC funded project 'Buildings in the making'. In our data, it emerged that architects used a range of strategies to imagine the embodied experiences of older people with dementia, drawing on personal experience, formal guidance and training, and deliberately using their bodies to imagine embodied experiences of negotiating place. The bodies they imagined were complex and 'multiple' (Mol 2003): at times lived, 'fleshy' and sensing bodies, but in other instances calculated, quantified bodies. Architects drew on multiple discourses of ageing and models of care, with conceptions of older bodies as active and consuming emerging alongside discourses of decline and risk. In negotiating the competing demands of clients, planners and other stakeholders, architects were engaged in a process of 'juggling' (Latour and Yaneva 2008) differently embodied ideas of who the end-users of their building will be, and what they will need and want from the design.

**Friday 11 September 2015 at 09:00 - 09:30**

Gender  
PX001

### **Men Cooking in Japan: Health, Gender and Ethnicity in Food Preparation**

*Castro-Vazquez, G.*

*(Nanyang Technological University)*

This paper presents data from an on-going research project on obesity and overweight in contemporary Japan. Officially, the obesity rate for Japanese men—regardless of age—has increased in the past ten years. In particular, the rate for men aged 40-60 has increased more than 30%. The rate for women aged 30-60 has slightly decreased but there is an increasing tendency to underweightness among women aged 20-40. This paper aims to explore the cultural and social implications of 'men cooking' in terms of body-weight-control. The focus is the content analysis of magazines and TV programmes to promote the preparation of food among Japanese men. Health, gender and ethnicity are proposed as three axes of analysis. While food related articles in women's magazines are chiefly concerned with the preparation of 'food as a medium for emotional management of the family' (Burridge and Barker 2009) and the promotion of nutritional knowledge, publications for men largely convey the idea that men cook to relax, enjoy and pursue the happiness of visitors and friends. Some printed materials do offer food-calorie-counts to enhance a

balanced diet, however a main concern to men cooking encompasses dishes that can be paired with alcoholic beverages and high-volume-foods to satisfy 'men's appetite'. This essentially entails the intake of red meat which seems to be against the idea that Japanese food is low-caloric and fish-based. Men cooking reinforces the idea that body-weight-control is largely a women's task but offers a different understanding of the 'ethnicization' of food in Japan.

**Friday 11 September 2015 at 09:00 - 09:30**

Screening and Diagnosis

PT111

### **Diagnosing Uncertainty: The Social Diagnosis of Neonatal Abstinence Syndrome (NAS)**

*Chandler, A., Cunningham-Burley, S., Whittaker, A., Elliot, L., Cooper, S., Midgley, P.*  
(University of Edinburgh)

Neonatal abstinence syndrome (NAS) is a contested diagnosis referring to a constellation of symptoms that may be displayed by neonates where mothers use addictive substances in pregnancy. Primarily, NAS relates to pregnancies affected by opioids. In this paper we discuss the benefits of viewing NAS as a social diagnosis (Brown et al., 2011). NAS diagnosis emerges as contingent, negotiated, and resulting from complex interactions between a range of actors, with differing resources: economic, political, educational and social.

Drawing on a narrative-informed analysis of semi-structured interviews with parents whose babies were at risk of NAS, and focus groups with health and social care practitioners, we highlight the inconsistent ways in which NAS is understood. NAS is simultaneously framed as: unpredictable and unclearly related to maternal drug-use; and as concrete evidence of maternal illicit drug misuse. However contested, NAS diagnosis can have significant implications: parents may be denied custody, be separated from babies treated in the neonatal unit, and are faced with additional guilt and stigma.

NAS symptoms may be shaped by contexts of care: symptoms can be reduced through supportive care, breastfeeding and skin-to-skin contact with parents. Conversely they may be exacerbated if parents and babies are separated, breastfeeding is not supported, or parents are stressed. We argue that understanding NAS as a social diagnosis provides clear routes through which health and social care for affected families can be improved. Crucially, this includes acknowledging the socio-cultural basis of inconsistencies in how NAS is interpretively constructed, and treated, by different social actors.

**Thursday 10 September 2015 at 15:10 - 15:40**

Professions

PT111

### **Tensions and Structural Hurdles in the Careers of Senior Women in Academic Medicine and Other Scientific Subjects: A Qualitative Study**

*Chapple, A., Ziebland, S.*  
(University of Oxford)

There are relatively few women in senior academic posts in medicine and other scientific fields in the UK. Explanations include gendered assumptions about science in education and glass ceilings due to workplace gender discrimination and individual conflicts between family and professional roles.

We are studying the experiences of highly successful women scientists in the Medical Sciences Division at the University of Oxford. We have conducted 28 narrative life history interviews. More are planned. Analysis is underway.

Most of the women we have interviewed have had children (1 to 3); few took more than the minimum maternity leave and very few had worked part-time or taken career breaks. Reasons for avoiding part time work include that science moves rapidly and one would be left behind, the practical difficulties of managing laboratory experiments on a part time basis and a view that one would not be taken 'seriously', that recognition would be hard to achieve and that one's career would not progress efficiently. Although women often described their (male) partner as 'supportive' we have interviewed no women to date whose partner took the major role in childcare.

Only a few participants saw themselves as disadvantaged compared to male colleagues, although most had had to overcome practical difficulties in relation to timing pregnancy and managing childcare. We will discuss this tension in their world view. Some recalled how important it had been to have had a good mentor. Acting as mentors themselves, nurturing the next generation was seen as a source of satisfaction.

## Paper Abstracts

**Thursday 10 September 2015 at 15:45 - 16:15**

Health Service Delivery  
PT007

### **Institutional Work and Innovation in the NHS: Creating, Maintaining and Disrupting?**

*Checkland, K., Bailey, S., Parkin, S., McBride, A., Elvey, R., Rothwell, K., Hodgson, D.*  
(University of Manchester)

The National Health Service in the UK represents a highly institutionalised field (Checkland et al., 2012); as such, it can be resistant to change (Macfarlane et al., 2011). There is widespread agreement that the NHS is in a 'crisis', and that only 'transformational change' will ensure its future as a service free at the point of delivery (Ham, 2014). The 'Five year forward view' (NHS England, 2014) represents NHS England's vision of this future, emphasising innovation, integration and the development of 'new models' of care. Such a vision implies a degree of institutional change which will need to be enacted at all levels throughout the service.

We will present the findings of a study of a suite of local innovation projects set up in response to these pressures. Provided with extra funding, local groups of GPs and managers were encouraged to modify services with a focus upon improving access to care, integration, and on innovative uses of technology. A qualitative process evaluation followed the development of the projects from their inception, carrying out 80 interviews with a wide range of actors, including GPs, consultants, managers, nurses, therapists, and support staff. In this presentation we will explore the 'institutional work' (T. B. Lawrence et al., 2006) done by those involved in the projects, highlighting the ways in which such work managed the tension between disrupting the local institutional reality to bring about change whilst simultaneously maintaining the institutional norms and values underpinning the NHS as a whole.

**Friday 11 September 2015 at 10:10 - 10:40**

Health Service Delivery  
PL005

### **Making 'Social Prescribing' Work: The Links Worker Programme in Glasgow**

*Chng, N. R., Wyke, S., O'Donnell, C., Skivington, K., Mercer, S., Mackenzie, M.*  
(Institute of Health and Wellbeing, University of Glasgow)

Primary care professionals often struggle to support patients who have problems rooted in social circumstances. One possible response is 'social prescribing', where patients are supported to access non-medical support and resources available in their communities. The Scottish Government funded 'Links Worker Programme' is one such example of social prescription. It is being implemented in some of the most socioeconomically deprived communities in Glasgow.

We are evaluating this programme. Designed as a quasi-experiment with embedded process evaluation conducted in 2 phases, we conducted interviews and focus group discussions with the programme's executive and management groups, and general practice staff in phase 1.

Using a comparative case study approach with practices as the case, we described how each practice implemented the programme. We then compared and combined these descriptions of practice activities in an overarching 'programme theory' through which the programme is expected to operate.

Preliminary analyses suggest that practice staff are gradually becoming involved in the 'Links approach'. They: a) refer individuals to Links Workers who help them access extra support, b) signpost patients to local community resources, c) increase the availability of information for patients, d) run practice-based activities such as walking groups and visits to local resources.

This suggests that practices offer their patients some solutions to long-standing social problems. Primary care team capacities seem to be improving in ways that help people make links: in their own lives, and in their communities, with the primary care team as a hub.

**Thursday 10 September 2015 at 17:30 - 18:00**

Politics of Health  
PT006

### **The Impact of Housing Arrears on Health During the Recession: A Comparison of European Nations**

*Clair, A.*  
(University of Oxford)

Background: The recent recession had its origins in the housing sector, yet the impact of housing payment problems on health has yet to be fully investigated cross nationally. We therefore present an analysis of the impact of housing arrears on overall health across Europe.

Methods: We use longitudinal data covering 27 countries from the EU Statistics on Income and Living Conditions Survey (2008-2010) to follow a baseline sample of employed persons without housing debt (45,457 persons, 136,371 person-years). This is complemented with country-level information on economic conditions, housing, social spending and social capital taken from

Eurostat and the European Social Values Study. Longitudinal multilevel models are then used to evaluate how the relationship between housing arrears and health differs across nations.

Results: Falling into housing arrears is associated with a statistically significant reduction in overall self-reported health across Europe, equivalent to that of job loss. However results for individual countries suggest a more nuanced result, with people in some countries experiencing dramatic reductions in health while for others there was no statistically significant result. The multilevel analysis with country-level measures demonstrated the importance of country characteristics such as home ownership and arrears rates in understanding the impact of housing arrears on health across nations.

Conclusions: This analysis finds that housing related financial problems have a statistically significant impact on health across Europe as well providing some insight into cross-national variation in this relationship. The results highlight the importance of considering other policy areas when looking to improve health.

**Thursday 10 September 2015 at 12:00 - 12:30**

Experiences of Health and Illness

PX001

### **Hypohidrotic Ectodermal Dysplasia (HED): Stigmatisation, Experience of Life and Self-Esteem in Decisions About Reproduction**

*Clarke, A.*

*(Cardiff University)*

Background and Objectives: Hypohidrotic ectodermal dysplasia (HED) is a rare inherited disorder that leads to sparse hair, few teeth and impaired sweating. It impacts substantially on physical appearance and often leads to stigmatisation as well as practical difficulties (e.g. overheating). When talking about HED, patients and relatives sometimes focus on the health problems and sometimes the stigmatisation. This study explores the connection between talk about the condition and decisions about reproduction. This is considered in the context of Goffman's and subsequent accounts of stigmatisation.

Methods: Interviews were conducted with members of 20 families to explore their experiences of life with HED, including stigmatisation and the transmission of HED to children. The material was organised thematically. Selected material was approached through a rhetorical discourse analysis of accounts and responsibility.

Findings: Coping with stigmatisation is as much a problem for affected males as avoiding the hazards of overheating; discussing reproduction raises challenging questions relating to self-esteem. Decisions about reproduction made by female relatives (who may carry the condition), and discussions about these decisions, may be constrained by their wish not to cause emotional hurt to affected males. Female carriers may also express a 'biological guilt' at transmitting the condition despite the absence of moral culpability.

Conclusions: There are important implications of these findings for supporting families with HED and for considering the place of experienced or anticipated stigma in making reproductive decisions. Such effects may be important components of decisions in the face of information generated through prenatal Screening and Diagnosis.

**Thursday 10 September 2015 at 09:05 - 09:35**

Inequalities

PT006

### **The Experience of Gay Male Student Nurses: Private Lives and Professional Boundaries**

*Clarke, D.*

*(Cardiff University)*

This research explores how male gay student nurses negotiate their masculinity and gay sexuality within the professional boundaries of nursing. Furthermore, it identifies how these students negotiate issues of caring and the formation of therapeutic relationships with their patients, as men and gay men. In-depth interviews were undertaken with eight participants within of a PhD study. The theoretical framing of this research drew upon Goffman's theories of presentation and performance of the self and Rubin's 'charmed circle'. Moving between these two analytical frameworks, I examined and drew together the experiences of these students and analysed their negotiation of the nursing role as gay men. I argue that the experience of these students and the negotiation of their sexuality as student nurses is fraught and precarious due to the complexities and boundaries of professional nursing roles in contemporary healthcare.

What this research has unearthed is the complexity that the gay male nursing students in this study had to negotiate to develop their identity as gay male nurses in order to construct a performance of nursing which was professionally acceptable. This presentation will briefly explore the context of men in nursing within Western society before proceeding to present my findings and analysis of how these men negotiated their masculinity and gay sexuality as student nurses. The main focus of my presentation will be how these students negotiated the clinical space of the ward and I will explore how these students sense of 'self' as gay men contributed to their conduct of care.

## Paper Abstracts

Friday 11 September 2015 at 09:35 - 10:05

Mental Health

PT006

### **'I have this Sense of Feeling in Myself that I know I'm Going to be Okay': Transforming Negative Emotions into Positive Feelings of Confidence in Clients with a Diagnosis of Personality Disorder**

*Clarke, J.*

*(University of Nottingham)*

Characterised by a cluster of symptoms including relational instability, emotional deregulation, and risky behaviour such as self-harm and suicide attempts, personality disorder (PD) is a very distressing condition to live with and treatment pathways are unclear. This study explores how negative emotions that arose during everyday interactions between client members diagnosed with PD in a therapeutic community were transformed into positive emotions such as feelings of belonging and confidence. Using interaction ritual theory (Goffman, 1967; Collins, 2004), everyday interactions, such as mealtimes and community meetings, are labelled 'rituals'. Using a combination of ritual taxonomies developed by theorists including Collins (2004), Summers-Effler (2006), Cheal (1992) and Helman (1990), interactions are categorised by their specific functions in the community to include ownership, inclusion/exclusion, reinforcement and transitional. In community rituals, high solidarity is seen between client group members and group morality defines the social norms and expectations of group members. However unlike current interaction ritual theory that stresses the role of positive emotions in sustaining successful interactions, there is a high prevalence of negative emotions during interactions between clients. This paper will explain how despite the presence of negative emotions, the rituals continued to generate feelings of solidarity and confidence through inclusion in community life. Additionally, interaction rituals illuminated internal power structures in TCs. Unequal dynamics between client members highlighted that clients were not always supportive of one another and at times, could exclude others. The impact of inclusion and exclusion upon client members is therefore considered in relation to transforming emotions.

Thursday 10 September 2015 at 15:45 - 16:15

Professions

PT111

### **What Does Learning Disability Mean in the Real World? Re-Evaluating Sociological Perspectives of Learning Disability**

*Cluley, V.*

*(University of Nottingham)*

Sociological approaches to disability, including the medical model and the social model of disability, have been critiqued for their marginalisation of learning disability. In addition to this, despite having specific criteria outlined in government policy documents and medical diagnostic manuals, learning disability can and does mean different things to different people, including those who work in learning disability practice. How learning disability is defined and understood directly affects the lives of people with learning disabilities. This paper presents the initial findings from a recent empirical study that employed a mixed methods approach to explore how different professional and lay groups understand learning disability in order to re-evaluate sociological perspectives. 12 focus groups were conducted with a range of health and social care professionals and photo-voice was carried out with 15 people with learning disabilities. The presentation specifically focuses on the interpretive repertoires that the groups drew on to co-produce their understandings and their significance to sociological theories of learning disability.

Wednesday 9 September 2015 at 14:30 - 15:00

Mental Health

PL006

### **Psychiatric Hegemony: A Marxist Theory of Mental Illness**

*Cohen, B.*

*(University of Auckland)*

With the recent publication of the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5), it is timely to consider sociology's continuing contribution to the understanding of psychiatric power. Despite ongoing problems in establishing the fundamental validity of psychiatry's stated area of expertise, categories of mental illness within western society have proliferated over the past thirty five years and arguably achieved more acceptance as categories of 'real disease'. The response from critical sociologists to the growing power of this psychiatric discourse has been largely confined to issues of 'medicalisation' which, while useful, fail to fully locate the growth of psychiatric power within the wider structural matrix of neoliberal capitalism. To fill this theoretical gap, the current presentation outlines an ideological critique influenced by neo-Marxist scholars and informed by a socio-historical understanding of the growth of psychiatric 'expertise'. Drawing on a new textual analysis of consecutive editions of the DSM (I-V, that is from 1952 to 2013), it will be demonstrated how psychiatry legitimates and promotes a neoliberal ideology through the reinforcement of values such as individualism, consumerism, cooperative labour, the nuclear family and women's reproductive responsibilities, and the maintenance of socio-economic inequalities. It will be concluded that a

more thorough and pervasive 'psychiatric hegemony' has developed within neoliberal society due to the increased ideological needs of capital over the past thirty five years.

**Thursday 10 September 2015 at 09:05 - 09:35**

Patient - Professional Interaction

PL001

### **Antenatal Diagnosis Announcement: Analysis of Medical Professional Practice**

*Colinet, S., Levitt, I. Avenel, C., Heidet, L., Bertholet-Thomas, A., Decramer, S., Salomon, R., Velasquez, P.*  
(Université de Cergy-Pontoise, France University of the West of Scotland)

Our study analyses the practice of the announcement and the presentation of the information regarding renal disease diagnosed before birth. Our aim is to improve the announcement, the care and the support for the families. The most severe forms of renal diseases constitute a risk of early severe renal impairment and in this situation the parents face a terrible choice: whether or not to perform termination of pregnancy. It is essential to define the modalities, characteristics and determinants but also the issues and the diagnostic announcement representations. Social issues such as technical and scientific details of birth are explicit but other issues have not yet been defined. Our theoretical framework is based on a pluridisciplinary approach. In regard to the parental traumatic experience of announcement, we rely on science education studies and on the fields of analysis of professional practices and sociology of birth. The focus of our research is the logical determinants of medical professional practices. In terms of methodology, this communication is a result of a qualitative research through interviews (30) with doctors (pediatric nephrologists, obstetricians gynecologists, pediatric surgeons) carried out in 11 academic hospitals in France. We have produced three analyses: thematic, discourse and interpretative. We assume that diagnostic announcement practices vary from one practitioner to another but also from one unit to another. The results of this study have demonstrated different types of stances and the modelling from 9 modalities of medical practices in the announcement situation.

**Thursday 10 September 2015 at 16:55 - 17:25**

Politics of Health

PT006

### **Variability and Vulnerability in City Health: Understanding Glasgow's 'Excess Mortality'**

*Collins, C., Levitt, I.*  
(University of the West of Scotland)

This presentation reports on work seeking to account for the phenomenon of 'excess mortality' (EM) in contemporary Scotland, and in the city of Glasgow in particular. In doing so, it seeks also to contribute to the broader development of our approach to 'the health of cities'. This work has explored the convergence in approach between two bodies of work - work on 'urban health' developed in the US, and work around EM in Scotland - focusing in particular on their shared interest in the concept of vulnerability and its role in accounting for variability between cities. It has then sought to apply a 'vulnerability' approach to the EM problematic: firstly by using existing data to highlight Scotland's and Glasgow's higher exposure (economic, social and cultural) to the health compromising impacts of neoliberal policies after 1979; secondly, and drawing on new research in government archives, by understanding how the political economy of post-war Scotland operated to foster that exposure, diminishing the relative potential for health improvement as compared to other parts of the UK, and rendering the people of Glasgow in particular vulnerable to poor health outcomes; and thirdly by exploring city-level responses to the challenges of central government's neoliberal policy agenda after 1979, leading to the view that Glasgow's orientation might well have compounded, rather than alleviating, the emerging city-level health problems. The presentation concludes with observations emerging from the Glasgow study which seem pertinent to the broader challenge of understanding 'the health of cities'.

**Thursday 10 September 2015 at 14:35 - 15:05**

Professions

PT111

### **Changing Medical Profession in Turkey: The Impact of Increasing Violence Towards Physicians**

*Corbacioglu, G.*  
(Middle East Technical University)

The neoliberal transformation of the Turkish health care system in the past decade have led to changes in financing and management of both public and private health care institutions. These changes have been structured under the principles of profit, cost-efficiency, consumerism, privatization, marketization and competition. Previous studies have demonstrated that relationships between health care professionals and patients are negatively affected when these principles dominate health care services. In line with these findings, one of the results of these developments in the daily medical practice in Turkey has been the deterioration of physician-patient relationship. In the regard, the proposed paper focuses on increasing violence towards health professions in Turkey as a major indicator of this deterioration witnessed in the recent years. Physicians have been subjected to physical attacks, verbal and psychological abuses, mostly from patients or their companions. Based on in-depth interviews conducted with 23

## Paper Abstracts

physicians working in private and public health care institutions in Ankara, this study aims to understand how physicians' daily experiences and coping mechanisms with regards to violence transform the practice of medical profession in Turkey. Research results present that increasing violence causes physicians to experience extensive insecurity, vulnerability and loss of autonomy in the workplace, and leads them to abstain from high-risk procedures and rely increasingly on medical devices in the diagnosis process.

**Wednesday 9 September 2015 at 12:45 - 13:15**

STS  
PL005

### **'Inference to the Best Diagnosis': HIV Antibody-Testing and Regulatory Expertise**

*Corbett, K.*  
(Middlesex University London)

I analyse United Kingdom (UK) regulatory guidance that since 1985 has governed diagnostic testing for HIV. I report on a STS analysis of these texts and associated sources which uses a theoretical framework of regulatory expertise based on the work of Julia Black and Harry Collins. The findings show how the interpretative flexibility in test design was addressed for optimal diagnostic inference. UK regulators nationally deployed United States (US) algorithms from the mid-1980s by virtue of their links with US contributory experts who had acquired interactional expertise for population-wide diagnostics in signal detection theory (SDT) and clinical decision analysis (CDA). Key variables like test sensitivity, specificity and exposure risk, all of which impact on interpretive flexibility, became prospective factors within the newly emerging diagnostic algorithms as UK regulators developed contributory expertise. By the 1990s this situation enabled UK regulators to innovate new diagnostic guidance which radically departed from its US counterpart in terms of deploying simpler tests inside an 'alternative' diagnostic algorithm still used in the UK. Based on these findings, I argue that this diagnostic guidance advanced a novel form of 'inference to the best diagnosis' using heterogeneous data, like risk categories and laboratory-readings which, although now adopted internationally, is still poorly understood by sceptical users. I further argue that the above theoretical approach could facilitate better understandings, especially concerning diagnostic regulation as a form of contributory expertise which may draw on interactional expertise in several specialist fields.

**Wednesday 9 September 2015 at 15:40 - 16:10**

Mental Health  
PL006

### **The Other Within the Self: Making Sense of Psychosis and Altered State Experiences**

*Cox, L.*  
(The University of Queensland)

Research on recovery from psychosis often problematises biomedical approaches to recovery, yet biopsychiatric framing of psychosis itself frequently remains unscrutinised. Psychosis is therefore often 'blackboxed' within disease framing. This forecloses possibilities for exploring the myriad ways people interpret their altered state experiences and it engenders an approach to recovery that emphasizes the closure or containment of altered states. Within this paper I draw on qualitative, in-depth interviews with 31 people who have experienced psychosis to demonstrate that while participants often draw on biopsychiatric framing to position altered states (such as voices, visions and unusual beliefs) as the product of aberrant physiology, they also resist such framing when they explore altered states in relational terms as meaningful, semi-autonomous complexes with whom they co-exist.

I demonstrate that relational sense-making is sometimes pursued by participants when they encounter altered states that actively resist psychiatric interventions (e.g., when 'voices' offer opinions on medication, therapist expertise, etc). I argue that attending to such processes allows for an understanding of sense-making as an iterative, dynamic and negotiated process. I discuss altered states as the Other within the self, and I draw on Butler and Foucault to explore the desire of participants to recognize, and be recognized by, altered states. I contend that the cultivation of relational sense-making frameworks disrupts assumed distinctions between 'illness' and 'wellness', and the common assumption that recovery entails symptom control and the cultivation of a 'self' distinct from 'illness'.

Thursday 10 September 2015 at 09:05 - 09:35

Lifecourse  
PL002

### Neutrality and the Language of Risk: The Role of Icon Arrays in Shared Decision-Making

Coxon, K.  
(King's College London)

Icon arrays are used in public health to visually illustrate the absolute and relative risk of an event occurring, often to inform treatment or medication decisions. This paper presents a project which sought to explore the potential of icon arrays to communicate outcomes for babies and women when birth is planned in different settings.

Planning where to give birth is arguably less straightforward than a medication decision. The safety of different birth settings (home, labour wards, midwife-led units) for women and babies is contested, and the right to choose where to give birth has been constructed as a feminist political issue, involving debates over autonomy and the right to control over the body. Choice of place of birth is also part of a longstanding policy debate within the NHS which involves discussions of quality, safety and sustainability, whilst foregrounding the policy motif of person-centred or individualised care. Consumerism, risk perceptions and bodily autonomy all influence this debate, and this paper reflects on how these different facets impinge upon the presumed 'neutrality' of research data communications.

This project adopted a consensus-seeking approach with women, partners, NHS clinicians and NCT practitioners to co-produce knowledge about these issues, culminating in the publication of a decision-support guide (<http://bit.ly/birthplacedecisions>). The consultation identified a range of perspectives on risk, and these will be discussed in relation to theories of knowledge translation and public understandings of risk.

Thursday 10 September 2015 at 08:30 - 09:00

Inequalities  
PT006

### Does the 'Spirit Level' Hypothesis Meet the Causal Test?

Davis, P., Lay-Yee, R.  
(University of Auckland)

The 'Spirit Level' is currently one of the most widely cited books in health and social policy. In this book Pickett and Wilkinson argue that societal income inequality is causally associated with a wide range of social and health ills; the greater income inequality in a society, the greater and more far-reaching the associated health and social pathologies. The authors have recently reviewed the evidence and argue that, despite the evidence being largely based on cross-sectional comparisons, the association is most likely a causal one.

Yet, New Zealand potentially, and surprisingly, could represent a counter example to this widely accepted hypothesis. In an analysis that substituted panel data for cross-country comparisons, Avendano determined that the association between income inequality and one key outcome – infant mortality – was by no means uniform, and, indeed, in the New Zealand case, paradoxically the relationship was in the reverse direction; that is, for data tracked over half a century New Zealand has shown a steady trend towards increasing income inequality while at the same time recording a largely unbroken reduction in infant mortality.

This finding does not necessarily mean that the 'Spirit Level' hypothesis is wrong, but it does challenge us to identify the mechanisms that may be helping to cushion the effects of income inequality, at least in the New Zealand case.

Thursday 10 September 2015 at 11:25 - 11:55

Patient - Professional Interaction  
PL001

### Quantified Food: Experiences of Mobile Calorie Counting

Didziokaite, G.  
(Loughborough University)

This paper reports findings from semi-structured interviews with MyFitnessPal calorie counting app users, which explore how it is used and how it affects users' behaviour.

While self-tracking in general, and calorie counting in particular, are not new phenomena, MyFitnessPal expands and enriches these practices by providing a food database, barcode scanning and extensive information and tracking of macro and micro nutrition.

Preliminary findings suggest that use of the app is substantially guided by nutritional and health knowledge already held by the users. Users often modify predefined calorie and macro nutrient goals, preferring to rely on their knowledge and experience rather than on, what they see as, generic rules. They rarely add their exercises into the calorie count, because MyFitnessPal is seen as

## Paper Abstracts

too imprecise for calculating burned calories. Likewise, though users' calorie counting is enclosed in single day timeframe given by MyFitnessPal, in practice it extends to single or several weeks. Thus, users are not using the technology blindly, but rather continuously negotiate between the guidelines and affordances of the app, and their knowledge and goals. This paper explores these negotiations, what knowledge they are governed by and what effect they have on user's daily choices. .

**Friday 11 September 2015 at 11:55 - 12:25**

Screening and Diagnosis

PT111

### **'Choose Well' and 'Know Who To Turn To': Are People Increasingly Required to Self-diagnose in Order to use Health Services Appropriately?**

*Doyle, E.*

*(University of Edinburgh)*

Rising demand for health care has led to attempts to modify patient behaviour and encourage the 'appropriate' use of health services. Campaigns such as 'Know Who To Turn To' (Scotland) and 'Choose Well' (England and Wales) aim to educate the public about which services to use and when, with a view to reducing inappropriate referrals.

Such campaigns are based on the premise that people can accurately assess and categorise their symptoms, according to urgency, in order to seek help appropriately. However, the interpretation of symptoms is a dynamic process, and the categories of 'minor', 'urgent' and 'emergency' are highly subjective. An individual's assessment of the urgency of their need for help may not always correspond to official versions of what constitutes appropriate demand. In addition, many people do not feel they have adequate clinical knowledge to accurately assess the urgency of symptoms.

This presentation is based on qualitative interviews with 30 callers to a telephone triage service. The research aimed to understand the decision-making process that people go through when deciding whether or not to seek advice about symptoms and how they determine the most 'appropriate' route to care. I argue that these campaigns do not take adequate account of the individual contexts, and in particular the limited levels of clinical knowledge, that shape help-seeking decisions. I therefore question how realistic it is to expect patients to 'know who to turn to' in the way that service provision increasingly seems to require.

**Thursday 10 September 2015 at 10:15 - 10:45**

Experiences of Health and Illness

PX001

### **Medical Consumerism as Emotion Management**

*Dunnett, S.*

*(University of Edinburgh)*

Frank's (2000) discussion of Baudrillard's (1998) *The Consumer Society* proposes that healthcare can be viewed through the lens of consumerism. Following this logic this study interrogates a nuanced and deliberate enactment of consumerist ideology - where patients collectively choose, resist, feedback and shape their experience of illness within a consumption landscape (Gabriel and Lang, 1995/2006). Drawing on observation and interview in patient-led myeloma support groups in the US this study reveals how a consumerist discourse is constructed, accessed and enacted in order to manage emotion (Hochschild 1979). Specifically, we outline how community, control, agency and a sense of hope are assembled and practiced.

Despite its place on the policy agenda, narrow depictions of consumerism persist in the extant literature. Ideas of "trust and faith" in medical professionals are set up in binary opposition to discourses of consumer choice (Lupton 1997). This view of the 'patient as consumer' privileges the notion that patients are dispassionate, rational and autonomous, and sidesteps the emotional, symbolic and collective quality of healthcare consumption (Frank 2000; Lupton 1997; McDonald 2007). Informants' narratives embody an ethos of consumerism which is pervasive in the wider culture and intensified within support groups. As Klawiter (2004: 846) observes '[e]xperiences of disease are shaped...by culturally, spatially and historically specific regimes of practices'. Through individual illness experience, then, this study pieces together how ideological concerns play out at a micro level. As Koski (2014: 76) highlights, the way macro-social forces - such as consumerism - 'shape illness experience' has been largely overlooked.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Theory

PT006

### **Using a Goffmanian Perspective to Aid our Understanding of Self-management and the Tensions Self-Management Presents**

*Ellis, J., Demain, S., Boger, E., Latter, S., Kennedy, A., Foster, C., Jones, F., Kellar, I.*

*(University of Southampton)*

15 million people are living with a long-term condition in the UK (DoH, 2012). In supporting these individuals the NHS spends 70% of its entire budget; by 2016 this will amount to £26 billion of the forecasted £106.1 billion budget. UK policies have endeavoured to address this growing issue, and self-management has been presented as one solution (Sprague, 2006). Self-management is a move away from an approach to health care based on the medical model, whereby the patient is a passive recipient of health care. Rather SM moves towards an approach based on the recognition that individuals are active agents capable of engaging in their own health care, and working in partnership with healthcare professionals (HCP). This paper will draw on qualitative data that investigates which outcomes of self-management matter to different stakeholders (commissioners, HCP, patients and their family). The initial findings of this research suggest that each of these stakeholder groups value different SM goals, and that there are unique challenges in the interactions between HCP and patients regarding whose agenda matters. This presentation will draw upon Goffman's ritual and dramaturgical metaphors to help explore the tensions highlighted. Furthermore, a Goffmanian approach will be used to help better our understanding of how SM is enacted, and also demonstrate how social theory can be used to contribute towards furthering the understanding of issues in health service research.

**Thursday 10 September 2015 at 16:20 - 16:50**

Politics of Health

PT006

### **Knowledge Translation and the Governance of Health Research in Canada**

*Ellis, K., Polzer, J.; Kothari, A., Rudman, D.*  
(The University of Western Ontario)

Knowledge translation has become established as a prominent requirement for funding of health research in Canada with expectations that researchers explain their strategies for ensuring research results are applicable to clinical and policy decision makers. In this presentation I draw on the final results and conclusions of a governmentality-informed critical discourse analysis of key public documents pertaining to knowledge translation at the Canadian Institutes of Health Research (CIHR). These results illustrate how knowledge translation operates as a technology of governance, with potential effects in prioritizing particular health research agendas and privileging particular kinds of researcher orientations to their research programs within the context of neoliberal rationalities of government. Health research is problematized and an imperative for knowledge translation is constructed through three rationales: a 'gap' between knowledge creation and its application in health and health care; financial and health care accountabilities for public investment in health research; and, the expectation of economic prosperity and an international competitive edge for Canada. I consider these three rationales in relation to discourses on evidence-based medicine and new public management to critically reflect on the contemporary governance of health research and researchers in Canada as well as future research in this area.

**Thursday 10 September 2015 at 12:00 - 12:30**

Healthcare Organisations

PT111

### **(In)visible Youth Work: Adolescent Medicine and the Provision of Transition in Hospitals**

*Farre, A., Wood, V.J., McDonagh, J.E., Parr, J.R., Reape, D., Rapley, T.*  
(University of Birmingham)

In recent years, adolescent health has achieved a higher profile in the UK as a result of key research and policy developments. However, in a context in which adolescent medicine is not a recognised speciality its practice still remains relatively invisible in hospital work. Transition, the coordinated movement of young people from paediatric to adult services, has been the focus of specific clinical, academic and political concern. The importance of transition has increasingly been acknowledged and is now a central issue for adolescent health.

Drawing on data from an ethnographic study across three NHS hospitals (a District General Hospital, a tertiary Paediatric Hospital and a tertiary Adult Hospital) we explore the interplay between adolescent health and the provision of transition services. We show how transition now appears as a relatively normalised object in hospital work. In this way, the transition agenda has raised the profile of adolescent medicine, in that it enables clinicians to bring facets of adolescent medicine into routine practice. However, it has also limited its potential scope, as the practice of adolescent medicine becomes seen as only focused on issues related to transition.

## Paper Abstracts

Friday 11 September 2015 at 10:45 - 11:15

Critical Public Health  
PT007

### 'Helping them get over their own Ignorance': Classed Understandings of the Role of Public Health Regulations in Addressing Obesity

*Farrell, L., Warin, M., Moore, V., Street, J.*  
(University of Adelaide)

The potential for regulatory measures to address escalating rates of obesity is widely acknowledged in public health circles. In light of the well-documented social gradient of obesity, regulations may disproportionately impact disadvantaged populations. Many advocates support regulatory measures for their potential to reduce health inequalities.

This paper examines how differing socio-economic groups understand the role of regulations in addressing obesity. Drawing upon focus group data with different social classes in a metropolitan city in southern Australia, we argue that attempts to implement obesity regulations that fail to prioritise disadvantaged communities' understandings of obesity risk further stigmatising this key target population.

Tuana's attention to the politics of ignorance and broader literature on asymmetries of knowledge-power provide a theoretical framework to demonstrate how socio-economically advantaged understandings of obesity align with dominant 'obesity epidemic' discourses. These understandings position obese people as lacking knowledge and in need of constraint, and underpin support for restrictive measures including food taxes and welfare restrictions, coupled with mandatory nutrition education programs. In contrast, disadvantaged groups emphasise the potential for a different set of regulatory measures to improve material circumstances impacting their ability to act upon existing obesity prevention messages.

Findings indicate how ignorance is produced as an explanation for obesity; replicated in political settings and mainstream public health agendas. We conclude by highlighting that this politics of ignorance and its logical reparation serves to reproduce power relations in which particular groups are constructed as lacking capacity to act on knowledge, whilst maintaining others in privileged positions of knowing.

Friday 11 September 2015 at 10:45 - 11:15

Health Service Delivery  
PL005

### Dimensions of Ambivalence: Doctors and Patient Experience Surveys in Primary and Secondary Care

*Farrington, C.*  
(University of Cambridge)

Patient surveys are playing an increasingly important role in the measurement of, and attempts to improve, the quality of health care. To date, little research has focused upon doctors' attitudes to surveys which give them personalised feedback. This paper adopts Weick's 'sensemaking' perspective to examine doctors' perceptions of individual doctor-level patient experience surveys in primary and secondary care settings. We conducted semi-structured interviews with GPs (N=21) and hospital doctors (N=20) in a range of clinical settings, subsequently undertaking thematic analysis of transcribed interviews using NVivo software. Our findings show that doctors in both settings express commitment to incorporating patient feedback in quality improvement efforts. However, they also express a wide range of negative views about patients' motivations and competence in terms of providing feedback and, more widely, the credibility of survey findings. The resulting ambivalence is likely to limit the impact of patient experience surveys on the success of quality improvement initiatives. In response, we highlight the need for 'sensegiving' initiatives on the part of policymakers, managers, and lead clinicians to address doctors' concerns about the credibility of surveys.

Thursday 10 September 2015 at 10:50 - 11:20

STS  
PL005

### Biomedicalisation of Elite Sport: Institutional Pressures and Evidence Practices

*Faulkner, A., Gabe, J., Coveney, C., McNamee, M.*  
(University of Sussex)

Elite sport is increasingly biomedicalised and scientised. A range of biological and regenerative cellular therapies such as stem cells and 'platelet-rich plasma' (PRP) are being debated, and in some cases used therapeutically to treat injury and accelerate 'return to play'. Some international producers of regenerative products address sports medicine markets, for example, 'orthobiologics'. The paper reports research drawing on sociological, science & technology studies (STS), and philosophical ethics approaches to analyse the emergence of bio-therapies in contexts of commercialisation, evidence based medicine, and elite sports culture and ethics. Football (soccer) and professional cycling are the two main case studies. The aim is to show, first: examples of the commercial, scientific, club, insurers' or other stakeholders' perspectives on appraisal and use of bio-therapies, and second: to

illustrate some of the typical decision-making emerging, and dilemmas and ethical issues raised in the context of institutional pressures and considerations of long term welfare. The paper draws on early data from a current UK-focused Economic and Social Research Council (ESRC) funded project, including observation of sports medicine conferences, and interviews with sports medicine leads at English Premier League football clubs, orthopaedic surgeons, physicians and physiotherapists in cycling, sports association medical officials, and bio-therapy companies. In spite of modest evidence for efficacy, and conservative medical policies, some biotherapies are increasingly used, sometimes as intended, sometimes to counter club/team and performer pressures. Different parties position themselves differently in relation to these tensions. Biomedicalisation is shown to be a complex, non-linear process in elite sport.

**Friday 11 September 2015 at 10:10 - 10:40**

Screening and Diagnosis

PT111

### **'Not in my Routine': Contextualizing Screening and Diagnosis-related Social (In)Action**

*Feder-Bubis, P., Hagoel, L., Rennert, G.*

*(Ben-Gurion University of the Negev)*

Colorectal-cancer (CRC) Screening and Diagnosis programs extend invitations to individuals aged 50-74 to undertake a Screening and Diagnosis test. Participation in these programs is generally free of charge, but Screening and Diagnosis uptake has been rising slowly, at varying pace in different socioeconomic groups. Participants' life-realities were elicited, as-well-as their perceptions and consequent health-related social actions. Focus group discussions with individuals invited to screen were carried out in urban primary-care clinics in Israel. They were facilitated by the researchers, audio-taped and transcribed verbatim. Analysis was conducted based on grounded theory principles. Data analysis revealed that, vis-à-vis the Screening and Diagnosis invitation, participants related to the health-care system structure on one hand, and to their agency on the other. Deciding to adhere to CRC early detection was related to the Screening and Diagnosis perceived benefits, and embedded in an enabling social context. Screening and Diagnosis avoidance stemmed from issues related to the interplay between specialist health-care services organization and participants' agency, crystallized in lifestyle routines, and to their personal higher priorities. Laypersons' explanations for adherence to CRC Screening and Diagnosis are not the opposite mirror image of their explanations for non-adherence; these explanations represent contextual elements (routine health lifestyle, health-care services accessibility) and are tied to different content domains (medical rationale for Screening and Diagnosis, insured members' unmet needs). We conclude by applying two sociological perspectives to interpret study findings: a. structure-agency, mediated by routine, and b. a relational perspective, emphasizing the adaptive interplay between doxa-field-habitus (including practices), mediated by social capitals.

**Thursday 10 September 2015 at 10:15 - 10:45**

STS

PL005

### **Between Church and Garage: The Challenge to the NHS of Personal Responsibility in the Genomic Era**

*Finlay, T.*

*(Cardiff University)*

Direct-to-consumer genetic testing (DTCGT) has been available on the Internet for a decade, and since March 2015 has been available in a UK "health and beauty" retailer's stores. Companies marketing DTCGT for common complex disease risk and genetic carrier status claim testing empowers people to take responsibility for their health. Users of DTCGT in the UK appear to endorse this personalised view of medicine, and find the NHS collective medicine incompatible with their individual needs. Genetics clinicians seek to protect the NHS from an imagined onslaught of individuals who expect care that the NHS is not resourced to provide. This is one aspect of the wider disputes about genomics that this technology has provoked.

Responsibility is the feature on which the tension between these two groups turns. Users' adoption of DTCGT could represent a more responsible approach to their health as Novas' and Rose's seminal work indicated (Novas and Rose 2000). Genetics clinicians' counselling work is centred on helping consultands to develop responsibility in terms of health behaviours and relationships with family.

This talk will draw on data from interviews with UK users' and genetics clinicians' conducted as part of my STS doctoral study on DTCGT in the UK. I shall show that while users' and clinicians' views cover common ground, disputes relating to this technology continue. The dissonance demonstrates the ambiguous position UK healthcare currently finds itself in. We are between what Klein refers to as Church (paternalistic, collectivised medicine) and Garage (consumerist, individualised medicine) (Klein 2010:282).

## Paper Abstracts

Thursday 10 September 2015 at 08:30 - 09:00

Lifecourse  
PL002

### Alcohol Policy in the UK: The Uses and Abuses of Sociology

*Foster, J.*

*(Institute of Alcohol Studies)*

In addition to focusing on the social consumption of alcohol, a sociological approach can offer valuable insights into the wider political debates that surround alcohol, focusing primarily on power, narrative and the bounding of debate.

Such a focus is important for a number of reasons, one of which includes the misuse of sociology by sections of the alcohol industry for their own profit driven ends, something which is both regrettable and in need of further investigation.

This presentation will discuss alcohol policy since 2000 from a sociological perspective, highlighting the way in which policy has moved towards an individualised focus on 'managed drunkenness' while neglecting key structural issues that underlie our social interaction with alcohol in the UK.

Key issues of concern include the construction of narrative and the 'bounding of debate' as a way of excluding politically inconvenient research from official discourse, in addition to other policy approaches which focus on individual behaviour and failings, while obscuring the wider environmental and corporate factors that significantly influence the ways in which people consume alcohol.

These include the empty promise of culture change that accompanied the 2003 Licensing Act, the demonization of binge drinking despite its encouragement as a consumerist response, and a narrow focus on the family and parental attitudes to drink.

Thursday 10 September 2015 at 10:15 - 10:45

Citizenship  
PL006

### Personal Health Technologies: From Fitbits and Dumb Patients to Democratic Data and Citizen Health

*Fox, N.*

*(University of Sheffield)*

Personal health technologies (PHTs) are proliferating, from monitors of blood pressure or blood glucose, through the FitBit and I-Watch, to implantable devices. While these technologies have been hailed by biomedical sources as enabling more personalised health care, they have been criticised sociologically for adding a further element of medicalisation of life, or for turning people into health consumers to be exploited by digital businesses such as Google or Apple.

In this paper I take a different perspective from both of these assessments. I will examine a range of PHTs from the perspective of (new) materialist theory, looking at the assemblages of person – technology – biomedicine – health professional – neo-liberalism. This analytical approach enables PHTs to be reverse engineered, in order to explore their micropolitics.

I then assess what PHTs do, from the differing perspectives of biomedicine, consumers, patients, and business, and reveal the differing politics inherent in these. On the basis of this analysis, I suggest a radical new approach to PHTs, suggesting that they may be re-engineered to challenge both biomedicine and neo-liberalism, and to contribute to the development of democratic data and citizen health..

Thursday 10 September 2015 at 10:15 - 10:45

Lifecourse  
PL002

### Do Children Endanger One's Health? The Impact of Parenthood on Subjective Health for Employees in the United States

*Fuchs, B.*

*(Universitaet Erlangen-Nuemberg)*

The compatibility of work and family is a major topic of contemporary politics. Surprisingly, it has not been regarded from the perspective of the sociology of health. This paper tries to fill this research gap by investigating the impact of parenthood on the health of working parents. It investigates (1) if there is an impact of parenthood as such and (2) if this impact differs between continuously working parents and those who interrupt their career. Previous research suggests that parenthood has different effects on specific health outcomes, such as the risk of depression or obesity. Therefore, subjective health is chosen as the outcome to get a broad view of the impact of parenthood. The focus lies on the working population of the US, with its comparatively dynamic and unregulated labour market implying serious challenges for working parents. Based on a theoretical model originating from role theory, the hypothesis that parenthood deteriorates the health of continuously working mothers is derived. Given a slight but

significant spread of egalitarian couple arrangements within the last decades, it is investigated if this relationship also holds true for men. Using data from the panel study of income dynamics, fixed-effects linear and ordered logit models show that parenthood has no impact on the subjective health of mothers, if continuously employed or not. Instead, it has a slightly negative, insignificant impact on fathers. This impact does not vary for those continuously working and the few who interrupt their careers.

**Friday 11 September 2015 at 11:20 - 11:50**

Gender  
PX001

### **Mental Health, Affect and Embodied Social Practice: Exploring Women's Recovery from Depression**

*Fullagar, S.*  
(University of Bath)

The cultural legacy of a mind-body opposition continues to haunt the epistemological landscape of mental health knowledge. In the contexts of contemporary biopolitics depression has largely been framed as an affective or cognitive disorder of the mind (obscuring the social and questions of inequality) or the brain (the neurochemical self of psychiatry and pharmacology). Recovery that is not attributed to medication ('placebo effect' in drug trials) or therapy is often termed 'natural or spontaneous'. The everyday practices that individuals engage in as they move through depression and recovery are rarely acknowledged beyond 'lifestyle' factors. In contrast this paper offers an embodied account of the everyday practices that women identify as significant in their recovery from depression within the context of the biomedical assemblage that characterises mental health policy, promotion and service provision. Drawing upon an Australian Research Council funded qualitative study with 80 women I analyse the experience of 'recovery' through social practice theory (Shove et al. 2012). The findings of this research inform a more critical conceptualisation of recovery as shaped by social practices that are relational, affective and gendered. I identify the implications of this study for non-medical approaches to support mental health and wellbeing in terms of the tensions inherent in advanced liberalism, where greater individualised responsibility for health intersects with the rise of Big Pharma markets and tightening government budgets.

**Wednesday 9 September 2015 at 13:20 - 13:50**

STS  
PL005

### **The Social Management of Biomedical Novelty: Biosocial Niches and Regenerative Medicine**

*Gardner, J., Webster, A.*  
(University of York)

This paper examines how claims to novelty are managed in new fields of biomedicine, using regenerative medicine (RM) as a case study. Drawing on both primary data (interviews with clinicians, policy makers and scientists) and secondary data from a current ESRC-funded project, the paper explores the ways in which regenerative medicine might be seen as one of a number of areas – such as cloning, nanotechnology and synthetic biology – that are generative of new forms of life and new social relations, and in which attempts are made to both enable and police novel bioscientific developments. Drawing on STS theory and using a series of examples, we look at the creation of niches – clinical, health economic, and regulatory – which have been developed and mobilised to manage and control regenerative medicine. These niches have their own forms of novelty distinct from other domains of medicine – such as pharmaceutical and devices – but at the same time are the prelude to attempted social closure and the normalisation of cell therapies in RM. We argue that these processes drive the uneven development and application of cell therapies in the RM landscape, and we suggest that they are indicative of a shift in the social reproduction of healthcare and medicine.

**Friday 11 September 2015 at 10:45 - 11:15**

Lifecourse  
PL002

### **End-of-life Care Qualitative Interviews with Post-bereaved Parents of Children with Life-limiting Conditions**

*Gibson, H., Black, R.*  
(Demelza Hospice Care for Children)

Parents' experience of end-of-life care and bereavement support following the death of a child with a life-limiting condition has rarely been explored. There is sensitivity around interviewing recently bereaved parents that has resulted in this lack of literature. However, the few studies that have interviewed post-bereaved parents have emphasised that this was not harmful to parents and could even be emotionally beneficial for them. To understand and improve bereaved parents experience of post-death care, further research is needed. Poor experience or lack of appropriate support following the death of a child could negatively impact on parent's physical and mental health in the long-term.

Demelza Hospice Care for Children provides respite, symptom management and family support for children with life-limiting conditions and their families. The hospice also provides end-of-life care and bereavement support for families post-death. Five

## Paper Abstracts

qualitative in-depth interviews with post-bereaved parents from the hospice were completed to better understand parents' experiences of this end-of-life service. A theoretical framework, with regard to the theory of emotion-focused coping (Lazarus & Folkman, 1984), will be utilised to illustrate the parent's experience. Initial examination has suggested the themes Uncertainty, Isolation, and Dependency on Hospice Support. This study aims to encourage further research involving post-bereaved families and to expand on the literature representing post-bereaved parent's views and experiences.

**Thursday 10 September 2015 at 17:30 - 18:00**

Citizenship  
PL006

### **Exercise as Medicine, or the Hinge, Technique and (In)Activity**

*Gibson, K.*

*(University of St Mark & St John)*

Exercise has long been promoted as healthy. Only recently, however, has exercise been explicitly understood 'as medicine.' Conceptualising exercise as medicine has given rise to demands for evidence and concomitantly created space for public health, professional and clinical expertise claims-making. Such interest, demands, and claims notwithstanding, the development and practice of exercise as medicine has received scant sociological attention. The dearth of sociological investigation is particularly curious given longstanding recognition exercising reflects particularised and idealised values of moral responsibility, cultural desirability, and social control as well as the intimate connection between physical activity and topics central to medical sociology such as Embodiment and Emotion, (dis)ability, and illness. Therefore, this presentation works towards building a sociological understanding of exercise as medicine by tracing knowledge of our body's responses to physical (in)activity from its generation in laboratories to its enactment in medical practice and Embodiment and Emotion in contemporary physical culture.

In doing so this presentation takes Norbert Elias' conceptualisation of the hinge as a starting point for analysis of data collected from over 1,000 hours of ethnographic investigation in an exercise physiology laboratory where such knowledge is created and 53 semi-structured interviews. Drawing on this data in further conversation with the social theorising of Jacques Ellul, Howard Becker, and Bruno Latour, this presentation demonstrates how knowledge of our body's responses to physical (in)activity is accumulated, controlled, and distributed in relation to both unlearned physiological functioning and learned conceptualisations of health, physical cultural practices, and the scientific authority and social privilege of medicine.

**Thursday 10 September 2015 at 15:10 - 15:40**

Lifecourse  
PL002

### **Old Age as an Object Class: The Rise and Fall of a Social Imaginary**

*Gilleard, C., Higgs, P.*

*(University College London)*

The health of older people has become an emerging issue in medical sociology. The connection between class and the diseases of old age is conventionally viewed through the prism of life course epidemiology. This approach reflects a much older perspective that conflates sickness, old age and poverty often expressed in the Victorian concept of the abject or impotent poor. This paper revisits this tradition of conflating material poverty with physical infirmity in the shape of those 'impotent through age' and considers its resonance in contemporary accounts of later life. This way of thinking about old age as a time of abject poverty and old people as an 'object class' shaped the moral imagination of Victorian society. This in turn led to the introduction of old age pensions, systems of public assistance and the 1948 National Assistance Act. Although the post-war attempts to disentangle the confluence of material poverty with physical infirmity were unsuccessful, the argument of this paper is that the gradual transformation of the economic standing of retired people has resulted in the abjection of Alzheimer's rather than that of poverty coming to exercise the greater hold on the social imaginary of old age.

**Thursday 10 September 2015 at 15:45 - 16:15**

Lifecourse—Ageing and Dementia  
PL001

### **Dementia and the Moral Order**

*Gjernes, T.*

*(University of Nordland)*

Dementia is a neurobiological condition with various social and behavioral consequences. Neurological progress of dementia leads under certain circumstances to social and cultural challenges. The aim of the paper is to study and discuss how institutions try to control the social and cultural manners of persons with bodily and biological restrictions because of dementia. People diagnosed with dementia are often inmates in social establishments or institutions meant to provide care for such patients. Part of this caring function is to control social situations through careful planning and governance of for instance eating situations. The study is based on observations from a day care center in Norway. We are concentrating on the meeting of such biological issues as neurological

decline and need for nourishment on the one hand, and how these biological claims are met and handled socially and culturally in institutionalized eating situations.

The study is informed by Norbert Elias ideas about civilization. The civilized is understood as the normal. The study is also informed by the sociology of the body. The body is understood as a biological entity with biological needs and limitations but also as a normatively regulated social body. Ordinary social environments presuppose a well-functioning body with no anomalies. The demented body have some anomalies and institutions like the day care center are faced with the problem of how to civilize or domesticate the 'demented body'. Our paper focuses on how such challenges are managed in eating situations.

**Thursday 10 September 2015 at 15:10 - 15:40**  
Health Service Delivery  
PT007

### **Accomplishing Person-centred Care for Patients with Dementia on Acute Hospital Wards**

*Godfrey, M., Woolley, R., Shannon, R., Skingley, A.*  
(University of Leeds)

Background - PIE (Person, Interactions and Environment) is a qualitative observational tool and change management process aimed at enhancing person-centred care for older people with dementia on acute hospital wards. It is currently being implemented and evaluated in five acute hospital wards (elderly care and acute trauma) in three Trusts in England.

The study has adopted a longitudinal mixed method, comparative case study design. This presentation will draw on data from the first phase prior to PIE implementation to describe how person centred care is understood by staff for patients with dementia and how care is accomplished for such patients in context of today's NHS.

Methodology -Data was collected via participant observation of ward routines and practices, interviews with staff and patient/caregiver case studies (comprising observation, in-the-moment conversations, qualitative interviews and case note review) particularly valuable for eliciting meaningful information from this group.

Findings - The concept of person-centred care was commonly understood by staff in universal and humanist terms: respect for individual dignity, decision-making autonomy and individualised care. Considerable variability existed in how this was translated into practice for patients with dementia, particularly those unable to verbally communicate needs and for whom individualised care required both biographical knowledge and understanding of how dementia affects emotion, interaction and action. Drawing on ethnographic fieldnotes we identify several distinct patterns in how care is accomplished in respect of toileting and response to distress; how these are informed by the culture of care and shaped by organisational routines and ward spatial environment.

**Thursday 10 September 2015 at 16:55 - 17:25**  
Health Service Delivery  
PT007

### **Exploring the Relationship Between Accountability and Blame Cultures**

*Goodwin, D.*  
(Lancaster University)

A sequence of inquiries into poor standards of healthcare repeatedly point to the pivotal role culture plays in producing and sustaining healthcare failures. The need for lasting cultural change is well recognised in the literature on patient safety. Indeed, particularly over the last decade, research and intervention into organisational culture has been a primary focus. In spite of this emphasis, the Francis report (2013) (which documents the failings at Mid-Staffordshire Trust) lamented the lack of progress on moving away from a culture of blame – a step signalled in the Bristol Royal Infirmary Inquiry (2001). And the recent Kirkup report (2015) (documenting the failings in maternity care at Furness General Hospital, part of University Hospitals of Morecambe Bay) echoes the lack of candour and culture of secrecy found at Mid-Staffordshire Trust.

Yet, 'blame', or identification of responsibility, seems to be intrinsically related to a capacity for redress when things go wrong; the call for accountability is often heard in media reporting of such events. Accountability thus acts as an anchor for 'blame cultures'. Drawing on the Francis and Kirkup reports, media reporting of these inquiries, and recent theorising on accountability and organisational culture, I present work-in-progress that explores this tension between the need to move away from a culture of blame and punitive response to healthcare failures, and the need for thorough exploration of unacceptable standards of care and accountability.

## Paper Abstracts

Wednesday 9 September 2015 at 14:30 - 15:00

Risk  
PT111

### Scientific and Everyday Concepts of Risk: The Case of Smoking in Pregnancy

*Graham, H., Flemming, K.*  
(University of York)

Background: Tensions between science-based and experience-based ('lay') knowledge represent a long-standing concern of Medical Sociology. While research has noted differences in risk perceptions, little attention has been paid to the concepts of risk themselves.

Aim: Taking smoking in pregnancy as our case study, we compare the concepts of risk used in advice literature and by pregnant smokers.

Methods: We examine the concepts of risk evident in (i) pregnancy-related websites in the UK, US, Canada, Australia and New Zealand and (ii) accounts by pregnant smokers. For (i), we identified official, commercially-sponsored and voluntary organisation websites in consultation with national experts. For (ii), we analysed accounts from qualitative studies included in two recent systematic reviews.

Results: Advice is communicated through relative risk (e.g. 'twice as likely'). The reference group ('compared to non-smokers') and the absolute risk is rarely or never mentioned. Women's accounts indicate an awareness of the scientific evidence but note its misalignment with personal experience. They repeatedly note that they know no babies affected by outcomes (e.g. low-birth weight, cot death) associated with smoking in pregnancy.

Conclusion: Advice is communicated using science-based concepts of relative risk; pregnant smokers operate with and worried about personal risk. Further, because relative framings of risk fail to accord with experience-based knowledge, it can feed into a wider distrust of professional advice and increase the weight that smokers place on their own experience-based knowledge.

Implications: Risk communication needs to be client-centred. Advice channels should give greater recognition and credence to everyday understandings of risk.

Wednesday 9 September 2015 at 14:30 - 15:00

Teaching  
PT007

### Teaching Introductory Medical Sociology - An Opportunity for Reflection

*Graham, R.*  
(Newcastle University)

In this paper, I offer commentary on the sub-discipline of medical sociology, by reflecting on my experiences of teaching introductory medical sociology. Much of this experience relates to teaching a stage two module in the context of a BA (hons) Sociology programme, but it also involves working with other student groups located in clinical and interdisciplinary settings. I argue that introductory medical sociology offers useful opportunities for reflection because of the need to frame the sub-discipline to outsiders. Drawing on information gathered informally in 2006 and in 2013, I consider a selection of key features of SHI modules in Sociology programmes: core texts, theoretical framing, and substantive topics. Whilst there is considerable variation in the selection of substantive topics available, the core texts and the theoretical framing remain remarkably consistent across different modules, and over time. This combination of consistency and variability can be seen as of positive value for the sub-discipline, as it both reflects and engenders a core of common interests for those working the field. However, it also suggests that the future development of medical sociology as a sub-discipline may lie in its relationships with other fields of study, rather than its own substantive content.

Friday 11 September 2015 at 09:00 - 09:30

Professions  
PL006

### The Everyday Negotiation of the Clinical-administrative Boundary in UK General Practice: An Ethnographic Study

*Grant, S.*  
(University of Dundee)

Receptionists have a central role in general practice work, with one of their key duties being as administrative gatekeepers to GPs (Arber & Sawyer 1985). The majority of extant research on receptionists has focused on their role at the general practice front desk and the extent to which they are understood and valued by patients (e.g. Hammond et al. 2013; Hewitt et al. 2009). However, it has become increasingly apparent that receptionists also play a significant role in ensuring the quality and safety of practice clinical work by making extensive use of tacit knowledge and situated judgements in collaboration with GPs and practice nurses (Swinglehurst et al. 2011). While previous research has examined the professional boundary between general practice clinical

professionals (i.e. GPs and practice nurses) or the professional-managerial boundary in detail, fewer studies have examined the clinical-administrative boundary as it is enacted in everyday practice. The aim of this paper is to ethnographically examine the everyday negotiation of the clinical-administrative boundary in UK general practice through the application of Strauss et al.'s (1963, 1964) 'negotiated order' perspective. Drawing on in-depth ethnographic fieldwork conducted across 8 UK general practices from 2010-14, this paper examines GP-receptionist and practice nurse-receptionist interactions during everyday routine work (e.g. repeat prescribing, test ordering, making appointments) and the ways in which inter-occupational hierarchies are continually reinforced and re-negotiated during the course of informal collaborative work.

**Thursday 10 September 2015 at 11:25 - 11:55**

Lifecourse  
PL002

### **Experiences of Recovery Following Treatment for Prostate Cancer**

*Green, R.*

*(Royal Holloway, University of London)*

Medical models of recovery from prostate cancer have historically focussed predominantly on outcomes relating to the physical recovery of the body. Yet more recent scholarship has suggested that recovery from illness involves a much broader range of concerns which are often overlooked. Sociologists are perhaps best equipped to identify and examine these; yet sociological research on recovery is scarce and on recovery from prostate cancer even scarcer.

Prostate cancer is the most commonly diagnosed cancer in men. Survival rates are high yet side-effects from treatments are frequent and often persist many years after treatment. Therefore the degree to which many men will fully recover from prostate cancer is questionable and indeed the appropriateness of the term 'recovery' is in itself worthy of investigation.

Qualitative interviews with twenty-nine men who have been treated for prostate cancer were undertaken. These men, aged 53-83 years, were recruited from prostate cancer support groups in the South East of England. Men's accounts of their illness and recovery experiences have been examined within the broader context of their changing self-perceptions of ageing, masculinity, and identity that come with the transition from working life to retirement.

These men's accounts illustrate that recoveries are not uniform. Instead, recoveries can vary significantly depending on how different forms of capitals are utilised by recovering men to achieve improved and sustained recoveries. The means by which men work to achieve better recoveries and the importance of these processes for men, particularly in later life, will be explored in this paper.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Risk  
PT111

### **The Right Place for Treatment? The Influence of Setting on Public Perceptions of CAM**

*Greenfield, S.*

*(University of Birmingham)*

Complementary and alternative (CAM) therapy can take place in a variety of different settings, for example acupuncture within an NHS hospital, osteopathy within a lay therapy clinic, a yoga class in a community centre, self-management with homeopathy within an individual's own home. All of these may be classed as places formally or informally sanctioned for health related activity (Fenner, 2011). Different locations may have different meanings for individuals, this and their perception of their own role in the particular space e.g. as patient, client, class member, self-manager of health may affect their expectations and the acceptability and outcome of the therapy. Hypnotherapy is a CAM treatment which is recommended by NICE for conditions which include irritable bowel syndrome and post-traumatic stress syndrome. However due to the way it is often portrayed in the media, hypnosis has a number of negative stereotypes surrounding it which may affect public perceptions of the therapy, the appropriate setting in which it should be delivered and the likely outcomes. This paper will use the literature on public attitudes to hypnotherapy to draw out relevant concepts from the sociology of place, in particular 'enabling places' (Duff 2011), 'compatibility' (Herzog, 2003) and 'social desire paths' (Nichols, 2014) and discuss the implications for therapists, public education and uptake of hypnotherapy and willingness to participate in hypnotherapy research.

## Paper Abstracts

Thursday 10 September 2015 at 12:00 - 12:30

Patient - Professional Interaction

PL001

### Use of Counter-power Strategies by Women with Endometriosis and the Patient-Gynaecologist Interaction

*Griffith, V.*

*(Durham University)*

Endometriosis, a chronic disease which affects approximately 1.5 million women in the UK, is defined as the ectopic placement of endometrial-related tissue, and is characterized by extremely painful menstrual periods, chronic pelvic pain, pain during sexual intercourse and infertility. The symptoms often result in severe effects on quality of life so that women may struggle to work, or even simply to walk.

This paper is based on an ethnographic study, conducted in the North-East of England, which shed light on how health professionals and patients negotiate endometriosis. Interviews and questionnaires were undertaken with 35 women suffering from endometriosis and 20 gynaecologists. In addition, participant observation was carried out in a gynaecology clinic and at endometriosis support group meetings. The data collected were coded thematically.

Results of the study show that the clinic visit remains a space where both women with endometriosis and medical professionals exhibit strong feelings of powerlessness and struggle to gain more control. Because women with endometriosis often feel dismissed by medical professionals, they employ counter-power strategies to be believed or taken at their word. Counter-power strategies include using techniques to appear ill, educating themselves on endometriosis, or seeing the same gynaecologist at each visit.

Ultimately, endometriosis patients' use of counter-power strategies exacerbate a situation in which gynaecologists already feel powerless through lack of knowledge and short visit times by increasing medical professionals' feelings of powerlessness and their negative feelings towards patients.

Thursday 10 September 2015 at 14:35 - 15:05

STS

PL005

### Muddled Bodies, Muddling Along: The Case of Everyday ICD Cyborgs

*Haddow, G.*

*(University of Edinburgh)*

It is estimated that approximately 30% of babies born today will live till their 100th year. It is likely that the demand for repair, replacement or regeneration of diseased or damaged organs will increase. The future therefore is of individuals muddled up with implant and transplants from sources such as animal, human or mechanical. I begin by asking what do we know about the experiences of individuals who currently live with mechanical implants such as Implantable Cardiac Defibrillators: a technology available for the last 40 years to prevent sudden cardiac death? I want to introduce the idea that there is a social stratification in cyborg technology with some people (men) more likely than others (women) to become everyday ICD cyborgs. We then might ask 'how does it feel' to be an everyday cyborg – using qualitative and quantitative studies with everyday ICD cyborgs I show that increasing reliance on this technology can cause specific emotional, psychological and social challenges for the individual and their families. And yet, these muddled bodies – montages of materiality – tend to acclimatise to the changes that occur – that is, they may 'muddle along'. Revisiting the writing on the cyborg such as Haraway's (1991) and Hayles (2002) I suggest that greater attention needs to be given to the existence and diversity of experiences of the 'everyday cyborg' in a manner that consolidates and moves beyond the notion of the cyborg as a trope and questions the dominance and influence of its science-fiction roots.

Wednesday 9 September 2015 at 14:30 - 15:00

STS

PL005

### Health Personnel's Translations of the Coordination Reform in Norway: Facilitator or Hindrance for Collaboration?

*Håland, E.*

*(Norwegian University of Science & Technology)*

The health care services in many countries are constantly being exposed to different reforms and change initiatives from central and local governments. These reforms often have specific aims for what the government wants to achieve, but what actually happens when these aims meet local practice, is not always so clear cut and predictable. Thus, it is important to know more of how these reforms are met by the people who do the daily work (supposedly) affected by them. How do they experience and understand these reforms? How is public policy being translated into daily practice? In this paper, we explore how the Coordination Reform in

Norway is translated by different groups of health personnel. The reform addresses the need for more integration of health care services, and aims for better collaboration and coordination between primary and secondary care.

The paper is based on empirical data from a research project, funded by the Research Council of Norway, evaluating the reform. Based on interviews with different groups of health personnel in three collaboration initiatives between primary and secondary care, we find that the reform is 1) ignored, 2) translated as a facilitator for collaboration, or 3) translated as a hindrance for collaboration. We present and discuss these findings based on insights from the STS-tradition focusing on translation, interpretive flexibility and local practice.

**Wednesday 9 September 2015 at 15:05 - 15:35**

Risk  
PT111

### **Exploring the Implementation of Surveillance Technologies in Care Homes**

*Hall, A., Brown Wilson, C., Stanmore, E. Todd, C.*  
(University of Manchester)

**Background:** An ageing society and rising prevalence in dementia are associated with rising demand for care home places. 'Surveillance' technologies are increasingly appealing to care homes because of their potential to protect residents, increase resident freedom and autonomy, and reduce staff burden. It is unclear how far use of surveillance technologies can deliver potential benefits and how these technologies are used in practice. This study explored implementation of surveillance technologies in care homes to develop understanding about their use.

**Methods:** An embedded multiple-case study design was employed with 3 care homes in North West England. Data collection included 36 semi-structured interviews with staff, relatives and residents, informed by Normalization Process Theory to focus on individual and organisational factors within implementation; 175 hours' non-participant observation; investigation of care records and technology manufacturer literature. Data were analysed inductively using Framework Analysis.

**Results:** 5 overarching themes emerged: Understanding of surveillance technologies; Business and environmental influences; Reasons for using surveillance technologies; How surveillance technologies were implemented; What happened during use. Mitigation against risk seemed to override other potential benefits as a reason for use. This strength of mitigation against risk seemed to influence understanding of surveillance technologies as being fundamentally different to other interventions, and challenged adherence to person-centred philosophies of care emphasising resident choice.

**Conclusions:** Mitigation against risk seemed to be an overriding justification for the use of surveillance technologies. Care homes may need to consider how staff and relatives understand risk and surveillance technologies in relation to person-centred care.

**Thursday 10 September 2015 at 14:35 - 15:05**

Experiences of Health and Illness  
PX001

### **Role Conflict, Interwoven Timespaces and the Social Flow of Everyday Life: Exploring the 'Non-compliance' of Adolescents With Type-1 Diabetes**

*Harries, T., Rettie, R.*  
(Kingston University)

This paper explores the way in which adolescents with type-1 diabetes deal with the conflicting demands of social life and the clinical management of their condition, and critiques the assumptions behind many chronic illness self-management programmes. Drawing on interviews and focus groups with teenagers who live with type-1 diabetes, it argues that front-of-stage performance of clinical management tasks creates role conflict and stigma, while taking these tasks off-stage disrupts the coordination of the interwoven timespaces (Schatzki 2009) that underlie social practices. Good clinical management often conflicts with presentation of self, role performance and participation in social activities, so young people sometimes sacrifice management of their condition even when they understand the consequences of this for their future health. By focussing on individual skills and understandings, the design of some self-management programmes overlooks the importance of the social contexts within which chronic illness is lived and this reduces the effectiveness of these programmes. We suggest, as avenues for exploration, some ways in which the conflicts between social life and disease management might be eased: a reduction in the density of timespaces to allow more room for self-care activities; the use of technology to allow individuals to keep self-care tasks back-stage while continuing as front-of-stage participants in social activities, and greater social acceptability of self-care tasks as part of the front-of-stage performances of people's lives.

## Paper Abstracts

Thursday 10 September 2015 at 16:55 - 17:25

Experiences of Health and Illness

PX001

### **'It's Part of Who I Am, What I Am': The Personal, Social and Political Dimensions of Narratives of Prosthetic Limb-use**

*Heavey, E.*

*(University of York)*

Recent decades have seen growing interest in the social and phenomenological aspects of illness, disability, and bodily alteration. Simultaneously, the developing field of narrative medicine emphasises storytelling as the principal way in which people construct and share experiences of health and illness. In this paper, I analyse data from interviews with ten lower limb amputees, to explore the narrative construction of prosthetic limbs, in particular their construction as social phenomena.

Using Bamberg's positioning theory, and Goffmanian concepts of stigma and self-presentation, I argue that stories about prosthesis use work to make sense of the storyteller's own embodied experience, and its relevance to other people and larger social structures, in three interlinked ways. First, prostheses are constructed as deeply embedded in or disruptive of the storyteller's sense of body-self; that is, prostheses might be presented as 'part of who I am' or as something alien and disturbing. Second, prostheses are modes of local communication and interaction between people, both prosthesis users and non-users; for instance, prostheses can be used to display the wearer's status as 'disabled' or as 'proud fellow amputee'. Third, prostheses are constructed in terms of their relevance to larger social structures, such as medical and governmental systems, and stories about prosthesis use work to make claims about the storyteller's – and other people's – place in those structures, and often to critique them. Through such stories, then, prosthetic limbs are presented as profoundly personal, necessarily social, and powerfully political.

Thursday 10 September 2015 at 12:00 - 12:30

Embodiment and Emotion

PT103

### **Using Purl Sides and Right Sides: Health Situation in Families with Disabled Children**

*Hedlund, M.*

*(Nord-Trøndelag University College)*

This study analyzes members in families having children with disability. The reason for the study was a desire to gain more insights after in another study, finding systematic differences in health situation and sickness benefit between parents with children with disabilities and other parents in Norway.

The research questions were; (1) what barriers and obstacles face family members in families with children with disability, and (2) what steps and strategies are perceived as helpful for own health situation?

Data consisted of 19 informant interviews with mothers, fathers and siblings in 11 families. Data used an inductive design and open and axial coding according to a Grounded Theory approach.

The findings show that some families were busy building an image to live as "normal life as possible" while other informants clarified that there were strong limitations in everyday life that could provide health burdens. Normality adaptation could become an additional workload on some families. The lack of spontaneity, to be constantly in readiness and haste with the support system was the most tiring additional workload in some families. Siblings claim in the study to develop care skills that they find useful and valuable. Their parents are, however, worried that care tasks to sibling become too much and causes health strain and stress on the "abled" siblings. Parents find it healthy to be at work even if they come home to the next shift. Having stable relief schemes are also important and make parents experience health promotion.

Thursday 10 September 2015 at 08:30 - 09:00

Experiences of Health and Illness

PX001

### **Living Your Life with Bronchiectasis: An Exploration of Patients' and Carers' Information Needs**

*Hester, K., Newton, J., De Soyza, A., Rapley, T.*

*(Newcastle University)*

Bronchiectasis is a chronic lung condition, causing breathlessness and chronic productive cough, with intermittent infective exacerbations. Patients often have recurrent hospital admissions, a poorer quality of life, and significant fatigue. Treatment concordance can be problematic. There is relatively little patient information currently available, yet information and education could support patients to self-manage, improve understanding and optimise engagement with treatment.

We carried out interviews with 17 people who have bronchiectasis and 9 of their carers. Ages ranged from 33 to 78 years. We sampled both newly diagnosed patients and those with an established diagnosis. The focus of the interviews was to identify, explore and understand their information needs. However, a core mediating issue emerged: what it means to learn to live your life

with bronchiectasis. Embedded in this journey, are issues around developing support and coping mechanisms, how people learn to connect with information and how they start to take back control and develop new, active partnerships with the medical team.

Understanding patient and carer experiences of living with bronchiectasis, the biographical disruptions that it imposes, and the ways in which they connect with information throughout their journey has enriched our understanding of their information needs and how these could be met. This qualitative work has been fundamental to the development, with participants, of a web-based information resource.

**Thursday 10 September 2015 at 16:55 - 17:25**

Lifecourse—Ageing and Dementia  
PL001

### **Minding the Social: Representing Dementia, Ageing and the Construction of the Normal/Abnormal**

*Hillman, A., Latimer, J.*  
(Cardiff University)

This article draws on two ethnographic studies: one of dementia in memory clinics and the other on biogerontology. Bringing these studies together provides a rare opportunity to compare interviews and observations of biomedical scientists in biogerontology, with in-clinic diagnoses of people with memory problems, and patient and family accounts of their diagnosis. We examine the contingencies and precariousness of how distinctions are made, across these multiple domains, between what counts as signs of 'normal' or 'abnormal' ageing. The 'acceptable level' of forgetfulness (that which is deemed 'normal' for an individual's age) is shown to be inherently alterable; a shifting boundary that is continually in the making. Such instability reflects continued debate amongst scientists and clinicians regarding the relationship between ageing and dementia, but also reflects everyday interactions in memory clinics, where decisions about the cause of a person's memory problems are negotiated between patients, families and clinicians.

Our paper compares accounts from the laboratory- that impute the concept of memory to animal models and cognitive function- with the interactions that occur in the memory clinic- where memory is socially mediated- and with patients and families' own accounts - where memory is inextricably bound up in relations- both social and material- that maintain identity and personhood. By understanding the relations between how 'normal' and 'abnormal' brains, and 'normal' and 'abnormal' ageing are being constituted in the laboratory, the clinic and the everyday lives of people with memory problems, we highlight the centrality of the social in contemporary understandings of dementia..

**Thursday 10 September 2015 at 09:40 - 10:10**

Citizenship  
PL006

### **Docile Bodies and Meddlesome Friends: Health Interactions as Surveillance?**

*Hiscock, J.*  
(Bangor University)

Care and support from friends at times of health problems is loaded with feel-good moral high ground. However, I suggest that we consider it not as care but as a tool of surveillance. Taking a Foucauldian perspective, this paper will suggest that people have come to govern not only themselves, but also each other.

This will be illustrated by a qualitative study about interactions about health amongst friends and informal social connections. Purposive sampling included: gender, age, condition, severity of condition, deprivation and urban/rural. Data were gathered through qualitative interviews. Case study analysis was conducted to inform the development of codes and to identify broad themes which could not be segmented into codes. Transcripts were coded, organised using NVivo and interpreted, guided by the research questions and research team discussion.

The study showed how through observing, monitoring and 'checking up', people were exerting a (lay) clinical gaze on their friends' state of health, which was imbued with judgement on what health promoting behaviour was normal and what was not. Through giving health advice people were exerting power and control and often assumed a kind of quasi-expert discourse. Through encouraging and motivating their friends to healthier lifestyles they were anticipating a docile body, willing to be 'trained.'

The paper ends with an illustration from a study participant who was particularly active in engaging in his neighbours' health problems. He described himself as living in 'a self-help cul-de-sac'. The circular image of his cul-de-sac conjured up for me an almost perfect panopticon.

## Paper Abstracts

Thursday 10 September 2015 at 14:35 - 15:05

Lifecourse  
PL002

### Managing Impressions in the Workplace During the Menopause Transition

*Hislop, J.*  
(University of Oxford)

With 63% of women aged 50-64 in the workforce (ONS 2013), the menopause is an occupational health issue which can no longer be ignored. Despite its popular portrayal as 'a natural life course transition', the menopause can be a particularly challenging time for women. Symptoms such as hot flushes, irregular periods and mood swings can be at odds with the in-control, self-assured, confident and competent image which women want to convey in the workplace.

Illustrated by video, audio and written data from a qualitative study of 46 women's experiences of the menopause, this paper explores the impact of the menopause on women in the workplace. It draws on Goffman's concept of impression management to explore the tension between the public and private self as women seek to present a professional image in the workplace while trying to manage a complex range of unpredictable physical and emotional symptoms. The paper examines the implications of being menopausal in a youth-focused workplace in which to admit to being menopausal is to admit to getting older with its associations of being less visible, less competitive, less flexible and generally less attractive than younger colleagues.

In a society in which we tend to build a wall of silence around personal matters, the menopause is rarely discussed in the workplace. The paper calls on organisations to provide better support for women during the menopause transition.

Friday 11 September 2015 at 10:10 - 10:40

Lifecourse  
PL002

### Emergency Death: Ambulance Professionals and End-of-life Patients

*Hoare, S., Barclay, S., Kelly, M. P.*  
(University of Cambridge)

For end-of-life care patients home is the ideal place to die, according to English end of life policy. However nearly half of all patients die in hospital, with many admitted in their last few days of life. Critical in these admissions are ambulance professionals, who act as both gatekeepers and enablers to hospital. Drawing on my PhD research of interviews with healthcare staff who cared for patients who died in hospital, I describe the challenges ambulance staff face and, building on the work of Johnson and Etzioni, argue that the lack of traditional professional status for ambulance staff challenges their capacity to keep dying patients at home. Ambulances for end-of-life patients are typically called out of hours when there is little support available from other healthcare providers or patient information beyond that which can be provided by critically ill patients and their families. Without evidence of the plans made by higher status healthcare professionals for an end-of-life patient, ambulance staff struggle to legitimise on their own keeping patients in the apparently risky environment of home. Disempowered to manipulate end-of-life care policy as other healthcare professionals do, constrained by their professional formal and informal codes of conduct and caught between contradictory guidelines, ambulance staff are often unable to provide the care they know to be best or to allow patients who may want to, to remain at home. Responsible for patients but without professional authority and autonomy, ambulance staff become obliged to convey dying patients to hospital.

Friday 11 September 2015 at 11:55 - 12:25

Professions  
PL006

### Profession Pedagogy Within Health Care Educations

*Højbjerg, K.*  
(Aalborg University Copenhagen)

This paper explores the intersection between health care education and professional practice. The purpose is to show how specific profession experiences sediment as part of profession habitus and form professionals' strategies. The case is clinical teachers in charge of the practical part of nurse education in Denmark.

The point of departure is that the educational initiatives cannot only be analysed as pedagogical practices but must also be seen as professionals' strategies trying to gain foothold over their own jurisdiction (Abbott 1988, 2005, Bourdieu 2009, Højbjerg 2011). In order to capture the specific quality of the professionals' experiences the notion of diasporic experiences (Hall 1996) is used.

The study behind this paper is mainly based on ethnographic field studies at two different hospital wards and at a clinical teacher education program and on 20 interviews with clinical teachers and their students. However, in order to establish contours of a group habitus, historic documents of nurses' struggle to establish own knowledgebase have been scrutinised.

The study shows that bringing abstract, academic knowledge into play and the efforts to plan and control practice is a strong marker of jurisdiction. However, organisational imperatives make it difficult to the clinical teacher to realise the educational agenda and it is shown how the efforts contrast the setbacks and add to a row of diasporic experiences (Hall 1999). These experiences of involuntary banishment from a desired position predispose the clinical teacher with a fragile and insecure profession identity forming future profession strategies.

**Friday 11 September 2015 at 11:20 - 11:50**

Screening and Diagnosis  
PT111

### **Locating Autism: Diagnosing a Social Disorder**

*Hollin, G.*

*(University of Nottingham)*

Autism spectrum conditions [ASCs] are diagnosed on the basis of socio-communicative impairments and the presence of restricted interests and repetitive behaviours. The nature of these symptoms means that they are most apparent during interpersonal interaction and, thus, diagnosticians must either obtain reports of previous socio-communicative behaviours or seek to actively elicit them during a clinical encounter. The Autism Diagnosis Observation Schedule [ADOS] opts for the latter strategy and trained clinicians and researchers interact with those undergoing diagnosis, spending approximately 45 minutes completing a number of tasks intended to prompt the behaviours of interest. The ADOS is, therefore, intrinsically relational and yet ASCs are understood as properties of a particular individual, to be considered outside of situational or institutional context. There is thus an important clinical and theoretical question concerning the manner in which ASCs come to be identified as an individual's neurodevelopmental disorder when they can be seen only during interaction. In this presentation we consider ten ADOS sessions conducted by academic researchers and with adolescents with pre-existing diagnoses of ASCs. We draw upon two data sources when considering these sessions. Firstly, we analyse the video recordings of the ADOS sessions themselves, using a conversation analytic approach. Secondly, we consider the notes and scoring charts made by the researchers during the diagnosis. Our primary interest lies in the manner in which behaviours are elicited and then made sense of within the ADOS. We conclude by arguing that this research demonstrates the importance of considering context in a diagnosis of autism.

**Friday 11 September 2015 at 09:35 - 10:05**

Health Service Delivery  
PL005

### **Three New Coordinator Roles in Norwegian Specialized Health Care: A Policy-document Analysis**

*Høyem, A., Gammon, D., Berntsen, G.*

*(University Hospital of North Norway)*

Following the Norwegian Coordination Reform, the national health authorities have introduced three different coordination arrangements in specialized health care, each of which aim to improve continuity of care for patients long-term, complex or serious conditions:

Since 2012, the hospitals have been legally obligated to offer a personal coordinator to patients with long-term needs of services from different departments and professions.

In 2015, 'cancer pathway coordinators' were introduced in the hospitals connected to the implementation of standardized pathways for diagnostics and treatment of selected cancer diagnoses.

A Green paper on new rights for patients with serious conditions – one 'responsible hospital doctor' is currently under consultation in the Parliament.

Common to these arrangements is the responsibility to provide a designated personal coordinator for the patients on behalf of the hospital. The roles have overlapping responsibilities and target groups, and are introduced more or less simultaneously. However, the rationales and strategies for forming and implementing the roles differ, and can be expected to be challenging for hospitals to design and implement in cohesive ways.

A document-analysis of Norwegian policy documents regarding these three arrangements will be carried out focusing: What are the goals, the scope and the tasks for each of the three roles, and how might these be understood in terms of role design and implementation strategies. This document-study is part of a Ph.D.-project focusing on coordination and continuity work in hospitals.

## Paper Abstracts

Thursday 10 September 2015 at 09:05 - 09:35

Experiences of Health and Illness  
PX001

### 'Breathing Space': Making Sense of Living With Breathlessness

*Hutchinson, A., Barclay-Kling, N., Galvin, K., Johnson, M.*  
(University of Hull)

Chronic breathlessness is a common symptom of cardiorespiratory conditions, which has wide-reaching effects on the lives of patients reshaping their identity and the functioning of their families and which frequently leads to presentation to healthcare professionals both in primary care and the emergency department.

Drawing on empirical data from 18 linked semi-structured interviews with breathless patients, their carer and a nominated healthcare professional and also on a systematic review and qualitative synthesis of the wider literature on the experience of breathlessness (77 papers representing 1,462 participants), it is argued that the quality of life or 'breathing space' achieved for the patient and those that care for them is dependent upon a dynamic interaction between three factors. These factors are: (i) the patient's coping strategy (engaged or disengaged), (ii) their help-seeking pattern (autonomous or dependent) and (iii) the healthcare professional's responsiveness (to the effects of breathlessness or to the underlying condition only).

The concept of 'breathing space' has arisen from this process, and offers new insight into the experience of breathless patients and those caring for them and the response of healthcare professionals. This paper will explore how each factor affects the 'breathing space' achievable so that despite living with the wide-ranging biopsychosocial limitations that breathlessness imposes, patients and their families can attain better quality of life. Implications for how healthcare professionals might help support breathless patients and their carers to achieve 'breathing space' will be discussed with the aim of informing future practice..

Thursday 10 September 2015 at 10:50 - 11:20

Experiences of Health and Illness  
PX001

### Social Representations of HIV and Identity among Latin American Gay and Bisexual Men in the UK

*Jaspal, R.*  
(De Montfort University Leicester)

This study explored the social psychological aspects of living with HIV among Latin American Gay and Bisexual Men (GBM) in the UK, with a focus on the implications for identity. 40 per cent of all new HIV diagnoses in the UK in 2013 were among people born outside the UK – many were among GBM from Latin America. Separate focus group interviews were conducted with Brazilian and Colombian GBM who had participated in a health and wellbeing intervention at a sexual health charity in London. Participants were aged between 28-54, and had been living with HIV for between 1-28 years. Data were analysed using Thematic Analysis and the analysis was informed by Identity Process Theory and Social Representations Theory. Participants experienced challenges to identity due to several social and psychological factors, including fear of rejection from others within their social and cultural contexts, self-perception as a 'minority within a minority', and the low self-esteem that accompanied living with HIV. Many felt unable to assimilate and accommodate HIV within the self-concept. Further challenges stemmed from the perceived isolation associated with low knowledge of English which inhibited access to services, and from the lack of Spanish/-Portuguese-language information about sexual health and HIV. Coping strategies included re-construal of the meanings of HIV, self-alignment alongside other HIV positive GBM and the construction of intergroup boundaries between HIV positive and negative GBM. This knowledge can help improve interventions aimed at enhancing the wellbeing of Latin American GBM.

Thursday 10 September 2015 at 16:20 - 16:50

Health Service Delivery  
PT007

### The Waiting Room: A Symbolic Re-conceptualisation

*Jeavons, S.*  
(The University of Edinburgh)

Across the UK, the integration of historically divergent specialities of genitourinary medicine (GUM) and family planning (FP) has emerged as a modern approach to sexual and reproductive health care provision. The 'one-stop shop' (OSS) exists as the most tangible example of integration policy in practice. How do those attending integrated facilities experience these sites? Conducting ethnographically informed research within a purpose-built OSS, I sought to explore this question. Spending time with 30 attendees, I learned of the complex ways in which they experienced their time at the clinic and, crucially, how their experiences were shaped by far more than the facility's integrated status.

In attending, my participants engaged in a journey comprised of moments of movement and stillness, as they passed through a variety of spaces that collectively formed their care pathway. This presentation attends to participants' time spent within the main waiting room. A particularly socio-materially complex space, the waiting room can be understood based upon its function – a

'sorting office', or the site wherein my participants became incorporated into the organizational logic of the clinic. In addition, however, the waiting room is a liminal space between the outside and inside realms of the facility, action-filled, affective, a site of transition and of shifting identities. This presentation uses my participants' stories of the waiting room, alongside anthropological and social geography theories on lived space, place and transformation, to contribute a symbolic re-conceptualisation of the seemingly every day, familiar waiting room and attendee experiences thereof.

**Thursday 10 September 2015 at 09:05 - 09:35**

Theory  
PT007

### **Rethinking Medicalisation**

*Johnsen, E., Roar Hagen, P.*  
(University Hospital of North Norway)

Near 50 years ago, Illich promoted the medicalization perspective: medicine annexes ever-larger parts of social life. In the 1990s, a demedicalisation perspective was asserted. Better informed patients, alternative treatments, and reflexive population made people less passive and dependent users of medicine. Since then, promising expectations has arisen about the patient as partner in both medical treatment and medical research. However, some maintains that increasing the role of patients in clinical decision-making has not been the solution for problems that beset today's medicine in developed countries – and one cause is persistent asymmetries in the knowledge and power bases of the two participants. Another perspective is that medicalisation has had an even more profound effect on our forms of life: that we relate to others and ourselves, individually and collectively, through an ethic and in a form of life that is inextricably associated with medicine in all its incarnations.

Are we right to expect that the patient can be empowered as a partner in medical treatment activity, especially in chronic care? We will rethink the concept of medicalisations in today's medicine by applying two different theoretical approaches. One is a Michel Foucault inspired approach and illuminates the power of medicine. The other is guided by Niklas Luhmann's work and illuminates medical treatment as one among several autonomous functional systems in modern society. Further, we will apply a concept of collective power from Talcott Parsons' work that we do not find used so far in the medicalisation discussion, within neither sociology nor medicine.

**Thursday 10 September 2015 at 09:40 - 10:10**

Healthcare Organisations  
PT111

### **At Any Cost: The Spatial Organisation of Care Work in Two Residential Homes for Older People**

*Johnson, E.*  
(Cardiff University)

The privatisation of residential care for older people has arguably resulted in a dualistic market. Whilst residential homes at the lower end of the market drive down costs in order to attract local authority purchasers of care, those at the higher end attempt to compete on quality, tailoring their services to meet the needs and demands of older people purchasing their own care. Drawing on an ethnography of two distinctly-priced residential homes, this paper examines how divergence in the costing of care has altered the manner in which residential care work is organised. The research captures a marked difference in the manner in which space is negotiated in the two homes. In the higher-cost home, clear symbolic boundaries concerning the management of personal care activities and their resulting waste products are enforced. In the lower-cost home, on the other hand, little is done to establish boundaries between different areas, tasks or matter. This paper considers how the preservation of symbolic boundaries in residential homes acts to maintain not only hygiene standards but also more immeasurable qualities - dignity, respect, privacy - which are vital to the care of older people. In short, this paper captures how the spatial organisation of care work becomes imbued (or not) with symbolic meaning(s). What is more, it establishes how pricing and funding differentials have a bearing on whether such meanings are established and/or upheld.

**Friday 11 September 2015 at 11:20 - 11:50**

Health Policy  
PT103

### **Self-care: A New Medical Cosmology?**

*Jones, L.*  
(London School of Hygiene and Tropical Medicine)

There is a tradition within medical sociology that has sought to identify dominant medical paradigms at different periods of time. So, for example, Jewson (1976) traces the shift in medical cosmology through three historical periods which he refers to as 'bedside medicine', 'hospital medicine' and 'laboratory medicine'; Armstrong (1995) describes an era of 'surveillance medicine'; and Nettleton (2004) suggests that medicine has now 'e-scaped'. This paper continues this tradition by exploring the current paradigm of 'self-care'. Like e-scaped medicine, self-care constructs the patient as informed and actively involved in seeking to prevent ill-health and

## Paper Abstracts

to self-manage in the presence of illness. This normative ideal has been challenged by Lupton (1997) who has argued that whilst the medical encounter involves information, it also involves Embodiment and Emotion and emotional features. Pain, disability and impending death are all highly emotional states whereby the suffering person becomes dependent on others. Elsewhere empirical research has found that when self-care is operationalized patients may not interpret efforts to involve them as 'empowering' but as a request to fit in with staff's needs and to 'cooperate' (Salmon and Hall 2003). These tensions form the point of departure for a discussion of initial findings from an ethnographic study of the policy of self-care, as presented in national policy documents and enacted by local health and social care managers. I approach the concept of self-care as a discursive formation and ask 'what is excluded?', 'what work is being accomplished?' and who benefits?

**Thursday 10 September 2015 at 16:20 - 16:50**

Lifecourse–Ageing and Dementia  
PL001

### **Family Involvement in the General Hospital Care of People with Dementia**

*Kelley, R., Godfrey, M., Young, J.*  
(University of Leeds)

A quarter of general hospital patients have dementia. Staff can struggle to provide high quality, person centred care to these patients and they have worse outcomes than patients without dementia. At home, people with dementia are often supported by family members who may have an in-depth knowledge and understanding of that person. Despite this knowledge, families are not always involved in the planning or delivery of hospital care and opportunities to gather and utilise their personal knowledge may be missed. This study explored current patterns of engagement with families, and how these patterns impact upon experiences and outcomes of hospital care for people with dementia.

Ethnographic data were collected from two elderly care wards, via observations, informal conversations and interviews with people with dementia, their families and staff. These methods enabled patients with a range of communication abilities to take part. A Grounded Theory approach integrated data collection and analysis.

The degree to which family knowledge of people with dementia was valued and used varied greatly between staff and settings. When family knowledge of the person's biography and relationships was sought, it typically assumed less value in decision making than staff assessments' of the person's risk and functional ability. Thus, parallel and conflicting understandings of people with dementia were commonplace, with the potential for different groups to be working towards very different care outcomes for the same person. At worst, decisions were made about the future lives of people with dementia that did not accord with their needs or wishes.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Experiences of Health and Illness  
PX001

### **Experiencing Touch: Co-Operative Inquiry in Medicine**

*Kelly, M., Nixon, L., Harvey, A., Crowshoe, L., King, N., Dornan, T.*  
(University of Calgary)

Background: Touch is part of the everyday practice of the doctor; shaking a patient's hand, examining the body, performing procedures. Despite its fundamental role, touch in medicine is a taken-for-granted experience, with little empirical research to guide practitioners or learners on the role of touch, what it means, nor how it is experienced within medicine.

Aim: to describe physician experience of touch as a form of praxis in medicine

Methods: Co-operative inquiry. A group of physician educators from family medicine, intensive care medicine and surgery (n=6) met 7 times over 15 months. The group cycled between periods of action and reflection in a Dionysian process to develop deeper understandings of our experiences of touch. In addition to descriptive narratives we role-played our experiences and used theatre games to capture embodied tacit knowledge. Dialogue was complimented by review of healthcare literature. Ideas from Merleau-Ponty, Sartre and Levinas were used to inform, challenge and frame emergent propositional knowledge. Group reflexivity was used to challenge pre-suppositions. Meetings were audio-recorded and transcribed. Template analysis is being used to analyze data.

Results: Touch is as a complex process that extends beyond skin-to-skin to embrace an important affective dimension. Touch is difficult to define because it is experienced on physical, psychological and spiritual levels. Present practice focuses on physical touch, bounded by societal norms (e.g. gender) and results in caution. Less acknowledgement is given to touch as a form of human connection, the reciprocal nature of which plays an important role in the doctor-patient relationship.

**Wednesday 9 September 2015 at 15:40 - 16:10**

Ethics  
PT103

### **Listening to Voices of Older People in Care Homes: Residents Collaborating with and Advising Researchers**

*Kenkmann, A., Killest, A., Backhouse, T., Lane, K., Penhale, B., Poland, F.*  
(University of East Anglia)

Older people living in long-term care establishments have very limited opportunities to set research agendas and shape research either carried out in or relevant to care homes settings. A systematic review on residents' involvement in PPI activities found that only eleven research projects tried to involve care home residents either as expert advisers or to collaborate with them, as in action research. A wide range of barriers to residents' involvement was evidenced in these studies.

Our team of researchers, which included care home residents and staff and older people from the community, aimed to explore the potential and actual involvement of residents in the research process in greater depth, by attending more to listening to and hearing the voices of older people and staff in care homes. This paper presents data from interviews and focus groups with residents and staff in care homes, to explore how they feel and think about research and being involved in it.

The findings of this study are not only relevant to those wanting to build research collaborations or collaborate more effectively with this hard-to-reach group, but they also raise questions about listening to and hearing the voices of marginalised groups more generally.

**Thursday 10 September 2015 at 17:30 - 18:00**

Health Policy  
PT111

### **Pharmaceutical HIV Prevention: Competing Economies of Clinical and Pharmacological Uncertainty**

*Keogh, P.*  
(Open University)

In recent years, pharmaceuticals used to treat HIV have been redeployed to prevent HIV transmission. Treatment as prevention (TasP) approaches are now prominent in global and national HIV prevention programmes. This development has generated much research into the 'acceptability' of TasP for populations of people with HIV (PWHIV) and its likely effects on sexual and other behaviours.

In this paper, I investigate the experiences of PWHIV in London, UK in managing uncertainty that emerges when they engage with TasP examining how this uncertainty is productive of a range of subject positions and responses. Of note is the contingent status afforded to clinical HIV services and doubts about the continued investment of the pharmaceutical industry in new treatments. Temporal and geographical factors (economic recession and NHS reform in the UK) mediate such engagements and uncertainty.

Bio-medicalisation theory and in particular the concepts of economisation and bio-economy are useful for capturing complexity around this engagement, allowing us to think about the forms of capital and knowledges at work in the generation of uncertainty around TasP. Specifically, we contrast two bio-economic imperatives: the promissory nature of biomedical development versus the need to conserve or husband personal bio-capital as experienced by PWHIV.

**Friday 11 September 2015 at 11:20 - 11:50**

Mental Health  
PT006

### **'You Wouldn't go into Your Office and Start Talking About Antidepressants: A Qualitative Study**

*Kirkpatrick, S., Anderson, C., Ziebland, S.*  
(University of Oxford)

This paper draws on a collection of narrative interviews (36) with a UK maximum variation sample of people taking antidepressant medication. One in four people in the UK will experience a mental health problem each year. (WHO). In 2013, more than 53 million prescriptions for antidepressants were dispensed in the UK (Social care information centre). We explore how people negotiated disclosure of mental health problems in the workplace, and in particular decisions about talking to employers or colleagues about antidepressant use.

Work can give structure and routine for people experiencing depression. However, many participants in our study faced difficulties at work when they were depressed. For some, stress at work had been a major factor in their depression, or conversely, depression had increased levels of stress about work. Symptoms such as insomnia, inability to concentrate or feeling de-motivated can be disruptive. In addition, antidepressants can leave people feeling numb, distant and detached. People may worry about how they are perceived by others, that they are performing badly, or thought of by colleagues as lazy or 'work shy'. Commonly people felt wary about disclosing antidepressant use to managers or co-workers. Some worried that disclosure of this aspect of

## Paper Abstracts

their medical history on job applications might work against them. In this paper we discuss how people negotiated their work lives whilst taking antidepressant medication. We explore the narratives in relation to Goffman's work on stigma (1968) and the 'presentation of self' (1959).

**Thursday 10 September 2015 at 14:00 - 14:30**

Citizenship  
PL006

### **'The Ship Sails On': A Multi-Site Ethnography of Citizen Participation in Health as Ritual Performance**

*Komporozos-Athanasiou, A., Fudge, N., Adams, M., McKeivitt, C.*  
(King's College London)

This paper addresses an on-going concern amongst policy makers and lay people regarding tokenistic implementation of citizen participation in health. We review the rise of 'active citizenship' discourse in UK health policy and trace its implications for existing practices of citizen participation in health research. Our focus is on the question of meaning in participation; the ways it is articulated, negotiated and legitimated – in particular: when is participation meaningful, and for whom? However, unlike studies exploring the meaning of participation by nomination of its 'antithesis', that is 'tokenism', we seek to illuminate citizen participation through foregrounding the multiplicity of meanings that it entails for those enrolled in its day-to-day performance. To do so, we analyse ethnographic data collected by the authors in three participation fora representing a range of participant meanings. Drawing on ritual theory, we conceptualise the unarticulated tension between such meanings and the aims of 'active citizenship', arguing that such tension does not lead to any damaging conflict but sustains formal top-down objectives so that 'the ship sails on'. We thus propose a view of citizen participation as a form of ritual practice undertaken for social and political reasons, and show how such view is able to enhance existing critiques of tokenism through grounding it on explicit accounts of specific attributed meanings of participation.

**Thursday 10 September 2015 at 08:30 - 09:00**

Theory  
PT007

### **Theorising Health Lifestyle Change**

*Koupaei, S.*  
(Bangor University)

With the success of medicine in controlling acute health conditions such as mechanical injuries and infectious diseases, the main problem of health care systems in today's world is treatment and management of chronic health conditions. Encouraging people to choose a healthy lifestyle to prevent the formation of chronic diseases such as diabetes and hypertension and lethal and disabling complications related to these conditions is the other important concern of health care systems. In motivating people to adopt a healthy lifestyle, communication between health professional and clients has a central place. Evidence shows that health professionals do not have sufficient capacity to help people to modify their lifestyle and adopt a healthier way of living. Change of lifestyle is possible only when people apply their agentic power to overcome the structural obstacles in the way of adopting a healthy lifestyle. In this paper I urge the necessity for theorising health lifestyle change and try to develop a model based on the theoretical framework developed by Margaret Archer. In her theories, internal conversation is considered to be the mediator between personal agency and structure. To understand the process of successful health lifestyle modification it is necessary to clarify the dynamic of the interactions between dialogue with the other (i.e. client-health professional conversation) and internal conversations (of the health professional or client). Developing stronger theories of health lifestyle change provides us with better understanding of this process and sheds light on the ways that health systems could help people to live more healthily.

**Thursday 10 September 2015 at 14:00 - 14:30**

Experiences of Health and Illness  
PX001

### **Participating in Patient Education: A Status Passage in Life?**

*Kristiansen, T. M., Antoft, R.*  
(Aalborg University)

The paper builds on previous ethnographic research in Denmark focusing on the significance of participating in a locally developed patient education programme for everyday life (Kristiansen et al. 2015). It presents a secondary analysis.

Group based patient education can be understood as a health promoting initiative set up to regularize and help people manage the status passage from being a normal person to becoming a person living with chronic illness and to support them in accepting and learning to live with this identity transition.

The theory of status passage and the concept of turning point (Glaser & Strauss, 1971; Strauss, 2008) is applied to illustrate two central status passages taking place at the locally developed patient education programme: 1) The status passage from novice to an experienced person with chronic illness, and 2) The transformation from adolescence to adulthood living with a chronic illness. Related to both status passages we analyse how the central properties of status passage are at play and how they are shaped by the social interactions among the different agents: participants, lay experts and health professionals.

We discuss how the theory of status passage might further enrich empirical studies within the field of patient education and how it can enhance our understanding of the social practices at play and the identity transitions occurring as a result of the chronic illness itself and the participation at the programme. Further we reflect on potential practical implications of our findings.

**Friday 11 September 2015 at 09:00 - 09:30**

Health Policy  
PT103

### **What's the Problem of "Health Inequality" Represented To Be? A Governmental Analysis of English Public Health Policy 1980-2011**

*Kriznik, N.,  
(Durham University)*

The analysis of policies designed to address health inequalities, or more broadly speaking "differences in health", tends to focus on evaluating policies in order to determine their effectiveness and to improve the design of future interventions. Such approaches are concerned with problem-solving as opposed to problem-questioning. Consequently there is little exploration of how the problem of "differences in health" is problematized in these policies, how these problematizations change over time, and how governable subjects are produced as a result of problematizations. Bacchi's (2009) "What's the problem represented to be?" framework, informed by Foucault's theory of governmentality and methods of problematization, archaeology and genealogy, was used to analyse 32 public health policy documents between 1980 and 2011 which discussed the problem of "differences in health" in order to address these questions. Following the analysis three problematizations of "differences in health" and their corresponding governable subjects were identified: the Informational problematization and the "responsible chooser"; the Constraints problematization and the "constrained chooser"; and the Paternalistic Libertarian problematization and the "flawed chooser". The genealogical analysis suggested that while new problematizations emerged over time as the result of contingent conditions allowing the development of new ideas, there was a consistent concern with understanding how individuals make choices about their health and how to ensure people made healthy choices in order to reduce "differences in health". Policies concentrated on creating the "right conditions" to allow individuals to make healthy choices and encouraging individuals to govern themselves when it came to making choices about their health.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Methods  
PL001

### **Designing a Qualitative Methodology to Contextualise the Everyday Interactions of People with Dementia Participating in a National Randomised Controlled Trial: Introducing Multi-sited Microethnography (MSME)**

*Lariviere, M., Poland, F., Fox, C.  
(University of East Anglia)*

The ability to examine the mechanisms behind healthcare systems or explore the experiences of patients are increasingly more important with the global push toward patient-centred care. Prestigious funding bodies such as the National Institute of Health Research and the European Commission expect large, complex projects to include elements that explore the social impact as well as the environmental or health problem in question. Due to these changing cultural shifts in research we as qualitative social scientists may find ourselves working in new and varied areas such as randomised controlled trials. However, qualitative methodologists may have difficulty designing an appropriate methodology for a clinical trial due to the trial's larger scale, fragmented participant groups, process of becoming familiar with new bureaucratic organisations and a misunderstanding about what qualitative research can add to the trial design. This paper seeks to address these disparities by drawing on my current fieldwork, an ethnographic study of people with dementia and their carers using assistive technology and telecare devices at home linked with a national clinical trial called ATTILA. To construct my ethnographic practices I adapt George Marcus' concept of "multi-sited ethnography" to ground a research field that has become "de-territorialised", and arguably de-contextualised, with in-depth microanalysis of interactions between research participants. The result, a multi-sited microethnography (MSME), can help to describe the variety of local contexts that may shape the lived realities of my informants and the participants of the ATTILA trial whilst providing nuanced accounts of how they interact with specific care technologies.

## Paper Abstracts

Thursday 10 September 2015 at 10:50 - 11:20

Lifecourse  
PL002

### Unbecoming a Carer: Conceptualising 'Former Carers'

*Larkin, M.*  
(Open University)

The profile and extent of family care is widely acknowledged. That a significant proportion of carers become 'former carers' is far less recognised.

This paper discusses a systematic literature review, conducted in 2014, which aimed to establish the nature and dimensions of knowledge about former carers. Key themes generated include: there are number of distinctive 'routes' into becoming a 'former carer', there is considerable confusion about the term 'former carer' and lack of clarity about when, in the caregiving trajectory, a carer 'unbecomes' a carer. Both the life course - often shared with cared for-person - and the care course influence former carers' experiences, health and conceptual status.

The review also identified that existing evidence is primarily generated via a narrow research paradigm focused on gathering data and evaluating services and policies for carers. There is little evidence that life course analysis, biographical approaches or broader sociological theory contributes to our understanding of former carers' lives. The subjective experience of 'unbecoming' a carer and 'being' a former carer and how it intersects with the role and identity of 'carer' is largely unexplored.

Increases in those with dependency needs and the ongoing shift towards family care means there will be growing numbers of carers and former carers. Rethinking the research paradigm taking greater account of sociological analysis has the capacity to extend understanding and generate new knowledge, contribute to former carers' improved health and well-being and help address age and care related policy challenges.

Thursday 10 September 2015 at 11:25 - 11:55

Citizenship  
PL006

### Health Capital: Investment in the Body as a New Strategy of Reproduction?

*Larsen, K.*  
(Aalborg University, Denmark)

Economic and health inequality in the Nordic welfare states has increased (Bambra 2012). Dominant groups' strategies (Bourdieu 1990), the educational system (Bourdieu 1977), or the organization of the welfare state (Eikemo et.al 2008) could all be used to explain inequality. However, inspired by Bourdieu, we ask whether health performance, as part of social groups differentiated reproductive strategies, represents a new distinctive form of Capital?

In 1950-60s shared bodily ideals included big bodies. Today, however, these same bodies are stigmatized (Brewis et. al. 2011). Investment strategies are currently focused on the outer body (strength training, fitness room) or inner body (yoga, meditation) and on diets, monitoring, body surgery, etc. This investment work is socially differentiated and the same goes for the reception of bodies (fields of labor, marriage and health care field).

Health Capital has been seen as part of human capital or used in relation to (a stock of) health, related to labor market participation, inspired by Grossman (1972). They have focused on health indicators rather than health as performance. In contrast, our concept is inspired by cultural capital. It was developed from studies of adolescents (Jensen et. Al. 2007), the socially marginalized (Larsen & Dahl 2010), and studies of the Nordic welfare state (Larsen, Cutchin & Harsløf 2013). It is based on Bourdieu's notions of distinction (1984), body and reproduction (1977). The concept shares similarities with Cultural Capital Health ( Shim 2010, Dubbin 2013).

Thursday 10 September 2015 at 10:15 - 10:45

Patient - Professional Interaction  
PL001

### Caring Relations at the Margins of Neurological Care Home Life: The Rehabilitative Work of Hotel Service Staff

*Latchem, J.*  
(Cardiff University)

Using observational and interview data from a dual-centered ethnographic study of two neurological rehabilitation care settings in the independent sector, this paper illuminates care relations at the margins. It shows how maintenance, finance and administrative, domestic and catering staff interact and perform sociality with patients with brain injuries through carrying out the mundane work of everyday life - banking, greeting visitors, sharing food, cleaning and general building and grounds maintenance.

Unlike health care workers such as nurses, therapists, doctors and care assistants conceptualised as 'frontline' staff, 'hotel service' staff are considered peripheral to the care and rehabilitative team. This paper however argues that the social accomplishments achieved through carrying out acts of the mundane, fit with the aims of more 'formalized' rehabilitation - to restore patients abilities to carry out 'activities of daily living'. In doing so it illustrates how these workers are not marginal but central to rehabilitation, and in many cases are providing important, informal rehabilitative work. Such work however goes largely unnoticed and unaccounted for. This paper therefore also considers the conditions of possibility under which these relations are concealed within such care environments.

**Friday 11 September 2015 at 09:35 - 10:05**

Professions  
PL006

### **Understanding the Experiences of Medical Students who are First in Their Family to Attend University: An Australian Perspective from one Medical School**

*Lempp, H., Brosnan, C., Southgate, E., Saxby, T., Outram, S., Harris, G., Wright, S., Bennett, A., Kelly, B.*  
(King's College London)

**Background** - Despite widening participation initiatives, medical degree programs continue to include a disproportionately low intake of students who are the first in their family (FiF) to attend university. Little qualitative research has been conducted.

**Aim** - We explored the experiences of FiF medical students to develop a deeper understanding of how socio-educational background shape their perspectives, access to resources and identities before and during their degree.

**Method** - FiF students from one regional Australian medical school participated in semi-structured interviews about their experiences of applying to and studying medicine.

**Data analysis** - Interviews were transcribed and analysed thematically in NVivo using the constant comparative method. Bourdieu's concepts of habitus and capital were drawn on in the analysis.

**Results** - 21 students across five years took part and most came from low SES backgrounds. Three key findings illustrated the influence and interaction of various forms of capital on FiF students' experiences: (i) the role social capital plays to facilitate access to clinical experience; (ii) access to economic capital had a significant impact how much time students devotes to their studies versus paid work; (iii) their status as 'medical student' provided them with new forms of cultural capital, a transition received with ambivalence by students and their social networks.

**Conclusion** - FiF students must navigate additional hurdles to apply and survive at medical school. Some barriers can be addressed immediately, e.g. altering placement allocation processes, increase student awareness of financial support. There is a need to support calls to shift perceptions of medicine as an elite profession.

**Friday 11 September 2015 at 11:20 - 11:50**

Patient–Professional Interaction  
PL001

### **Compliant Patients or Medical Consumers? A Qualitative Exploration of Recent Migrants' Perspectives on Prescription Medications**

*Lindenmeyer, A., Redwood S, Griffith L, Phillimore J*  
(University of Birmingham)

This presentation will focus on new migrants interacting with GPs around access to prescription medication using data collected as part of a qualitative study exploring migrants' health histories. The research team worked with six community researchers who recruited 24 migrants (from Iran, Poland, African countries, India, Pakistan, China) and interviewed them in their chosen language. They also translated the interviews and shared their cultural expertise.

Most respondents had previously experienced a system where they were 'medical consumers' (via direct payment or health insurance), deciding which treatment they needed and whether they could afford it. This could lead to a 'transactional' approach to the consultation where they expected prescription medications (often antibiotics) or referral to a chosen specialist. The change from operating as a medical consumer to the different role expected of a NHS patient (submitting to the authority of a gatekeeper GP while responsibly engaged in self-care) led to respondents feeling they were 'sent away with a paracetamol'; some said they were not taken seriously and their pain or long standing illness was ignored. Respondents often understood that prescription medications might be harmful but also believed they were necessary. Our analysis suggests that struggles around medications may be symbolic of a wider feeling of not being in control of their own health and healthcare. Addressing these feelings may help to improve communication with GPs and possibly encourage patients to stop obtaining prescription medications from their countries of origin or at least to tell their GPs which medications they were taking.

## Paper Abstracts

Wednesday 9 September 2015 at 13:55 - 14:25

Risk  
PT111

### **'Neutralising a Bomb': Reframing Sexual Safety Through Viral Suppression in a Time of HIV Treatment as Prevention**

Lloyd, K.,  
(University of California, San Francisco)

HIV treatment as prevention is an emerging HIV prevention approach that seeks to control HIV incidence to a point of theoretical elimination through routine HIV testing of the general population and earlier or immediate initiation of antiretroviral treatment for all persons who test HIV-positive. The aim is to utilise these pharmaceutical technologies to suppress an individual's viral load, the number of viral copies circulating in the blood, to such a low level that it cannot be detected with current technology, thus to a state of being 'undetectable', which greatly reduces or eliminates the risk of onward transmission of HIV. HIV treatment as prevention thus advocates the use of antiretroviral therapy for the protection of the broader public – a radical departure, historically, from the use of antiretrovirals merely as clinical tools. Drawing on interviews with HIV/AIDS scientists, policymakers, clinicians, and community activists, this paper explores the ways in which being virally suppressed, or having undetectable viral load, is being reframed as a marker of sexual safety and responsibility. In this sense, the HIV-positive but virally suppressed body is being conceived of as safe in contrast to the untested and unknown status body, which is being defined as risky. Part of the broader discourse around the emergent biomedical prevention strategy of HIV treatment as prevention, this reframing both potentially complicates clinical advice and relations of power between clinicians and their patients while generating new possibilities for the normalisation and de-stigmatisation of living with HIV.

Thursday 10 September 2015 at 15:45 - 16:15

STS  
PL005

### **The Multiplicity of Osteoarthritis: Disease, Condition or Ailment**

Lowey, R., Jinks, C., Richardson, J. C.  
(Keele University)

Osteoarthritis is a common, chronic health condition and a leading cause of disability. Previous research has demonstrated that negative perceptions (that are not aligned with current scientific knowledge) prevail, and are thought to adversely affect illness behaviour. The media has been identified as a source of influence and information for health related issues, and therefore may instigate and reconfirm such perceptions. Understanding media representation of osteoarthritis can allow insight into the presence and communication of predominant perspectives about the condition. This paper is based on doctoral research exploring how osteoarthritis was represented in articles from eleven national newspapers (n= 1014) and three monthly magazines (n=6), which were analysed using a combination of thematic, discourse and imagery analyses. The findings show that osteoarthritis is conceptualised in three ways- as disease, condition or ailment. These conceptualisations provide the framework of knowledge, meaning and subjective reality that influence how osteoarthritis is enacted or performed. In this paper I draw on Mol's work, which links disease enactment to ontological effects, to argue that these conceptualisations determine the disease enactments possible, and therefore the ontologies that exist. As such, osteoarthritis is not only multiple, but these multiplicities are determined by the conceptualisations that underpin the disease. I go on to demonstrate that this process is shaped by wider social issues, such as understandings of ageing and disability. Recognising the multiplicity and contingency of osteoarthritis allows insight into the variety of perceptions about the condition, and the complexity of challenging prevalent 'negative' perceptions about it.

Friday 11 September 2015 at 11:20 - 11:50

Lifecourse  
PL002

### **Natural Death**

Ludvigsen, B.H.  
(University of Copenhagen)

Everybody can say they would like to die a natural death, but what exactly does such a statement mean? What is a natural death and what does it entail? How does a natural death happen and more importantly when? A Danish anthropological study examines how 15 elderly people understand and perceive the concept of a natural death. Aged between 57-94 years – most in their mid-80's – they took part in five interviews each and numerous participant observational sessions, lasting over a period of between 6-18 months.

The main focus of the study was to shed light on elderly peoples' perceptions of their medicine, health activities and social relations. However, other topics which emerged during the project, such as on death and dying proved to be of great importance to the understanding of elderly people's life course. The purpose of this abstract is to demonstrate that elderly people's understandings and perceptions of death and the natural death especially are often contradictory. While describing the ways they

wish to die using terms such as quiet, peaceful, fast, or in dignity, they are simultaneously fearful and anxious as to the circumstances and conditions of dying. The study shows that a natural way of dying is essentially chronological - elderly people want to die before their grown-up children/ grandchildren. Although the practicalities surround one's death and funeral are discussed with relatives, elderly people's own concerns, worries, perceptions, images of death and dying largely remain unspoken in dealings with social relations.

**Thursday 10 September 2015 at 15:10 - 15:40**

STS  
PL005

### **Interventional STS: A Framework for Informing the Development of Workable Technologies**

*Lyle, K.*  
(University of Southampton)

Technological innovation is often positioned as a solution to the challenge of improving the quality of healthcare provision within a difficult financial environment. Yet, despite the hopes and expectations for technically driven improvements to services, the experience of bringing them into routine use has proven uneven and often unpredictable. The disparity between the promise of healthcare technologies and the difficulties of implementation in practice, suggests that something in the process of technological development and organizational implementation needs to change. The field of STS has resources capable of informing the development of workable technologies, but its focus on contingency and context inspires caution about intervention. This paper argues that combining Actor-Network Theory and Normalization Process Theory, under the umbrella of STS, provides a theoretical framework through which to prospectively explore the potential implementation of a technology. Drawing examples from a prospective study of the implementation of a new point of care device within three clinical settings, I illustrate that this framework enabled an understanding of the processes likely to be involved in the implementation of the device with implications for its continued development. Using the theories together allows different levels of analysis, but it is by keeping the theories in tension, using one as an irritant to the other, that this approach becomes practically applicable. If we to rely on innovation to achieve improvements in healthcare provision, we need to find a way to intervene in the implementation process, and I argue that STS offer the resources needed to achieve this.

**Wednesday 9 September 2015 at 15:05 - 15:35**

Lifecourse  
PL002

### **Locating Care at the End of Life: Burden, Vulnerability and the Practical Accomplishment of Dying**

*MacArtney, J., Broom, A., Kirby, E., Good, P., Wootton, J., Adams, J.*  
(University of Oxford)

Home is frequently idealised to be the preferred location for end-of-life care, while inpatient hospital care is viewed with suspicion and fear. Yet many people with a terminal illness spend their final days in some form of medicalised institutional setting, such as a specialist palliative care inpatient unit. Drawing on semi-structured interviews with inpatients at a specialist palliative care unit, we focus on their difficulties of finding a better place of care at the end of life. We found that participants came to conceptualise home though a sense of bodily vulnerabilities and that they frequently understood institutional care to be more about protecting their family from the social, emotional and relational burdens of dying. For a significant number of participants the experience of dying came to be understood through what could be practically accomplished in different locales. The different locales were therefore framed around providing the best care for the patient and their family.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Ethics  
PT103

### **Ethics and End of Life Care: An Ethnography of End of Life Care on Hospital Wards**

*MacCormick, F., Heaven, B., Hughes, J. C., Exley, C., Paes, P.*  
(Newcastle University)

Provision of end of life care in hospitals is an area of concern in public and political life in the UK. In 2013 concerns raised in the national press led to an independent review and subsequent withdrawal of the Liverpool Care Pathway, a tool designed to improve end of life care. In 2014 a court of appeal ruling created a legal precedent that physicians should discuss resuscitation with patients before signing do not attempt resuscitation (DNAR) forms. In 2015 a review of choice in end of life care called for better communication, greater choice, and higher quality care. Reports and reviews frequently focus on practical matters with little mention of the ethical issues encountered by patients, relatives, and staff. This paper will explore the practice of communication in end of life care on hospital wards. Data for this study were collected through ethnographic methods: observation of ward activities; interviews with clinical staff, patients and relatives, and analysed using the constant comparative method. This data revealed that communication is related to patient factors, as well as wider organisational and societal pressures, and that everyday

## Paper Abstracts

communication is not routinely understood as an 'ethical' issue. I will demonstrate that assumptions of what define an 'ethical' issue, along with external pressures on healthcare staff, shape communication in end of life care. I will discuss the potential benefits of explicit recognition of ethical presumptions and external pressures on clinical communication in the NHS.

**Friday 11 September 2015 at 09:00 - 09:30**

Health Service Delivery

PL005

### **Accomplishing 'The Patient and Family Case' For Medical Attention in Acute Illness: Negotiating Boundaries, Legitimacy and Moral Claims**

*Mackintosh, N., Sandal, JI*  
(King's College London)

Patients and families are increasingly asked to act as safety buffers and provide an additional barrier in the health system's defences. Helping to secure early intervention for acute illness, however, can be problematic for patients and families, despite their privileged status as witnesses of changing health conditions over time.

Securing help for a deteriorating condition has been constructed as a rational, linear process involving discrete components (problem definition, help seeking, and provider engagement). In this paper we consider whether 'candidacy' (Dixon-Woods et al 2006) provides a more useful way of conceptualising the problem as it acknowledges the work involved on the part of patients and families to construct a case for access to services. We report on secondary analysis of data, using candidacy as a heuristic, from patients' (30) and relatives' (11) interviews from a two year ethnographic study of escalation of care in medical and maternity settings in two UK NHS Trusts.

Our analysis shows that the candidacy concept enables re-conceptualisation of the accomplishment of the patient and family case for medical attention as a longitudinal, recursive and dialectical process. Patients and families not only access health information, but draw on social networks and previous experiences to navigate the system. Securing help involves negotiating boundaries, gate keepers and social rules while continuity of care models both facilitate and impede access. Use of candidacy draws attention to contextual inter-relationships at a structural, cultural, organisational and professional level, including resource constraints, notions of 'appropriateness' and stereotyping of 'the worried well'.

**Thursday 10 September at 2015 16:20 - 16:50**

Citizenship

PL006

### **Avoiding Waste in Health Research Through the Co-Production of Knowledge for Citizen Health and Well Being**

*Madden, M.*  
(University of Leeds)

Patient and Public Involvement (PPI) in NHS health research has become an imperative. In order to avoid waste, founder of the Cochrane Collaboration and the James Lind Initiative, Iain Chalmers, says "the public needs to be critically involved in research, from agenda setting to dissemination of results" (Chalmers, 2012). Although involving the public in health research is becoming an imperative there is no clear evidence base on its impact and outcomes (Brett et al 2010; Staley 2009). Through reflection on recent work with the James Lind Alliance Pressure Ulcer Priority Setting Partnership and Leeds Involving People, a user led charity that champions the voice of service users and their carers by involving them in the improvement and shaping of services, this paper explores what it means to be "critically involved". This is explored in the context of moves to replace publics with markets, including the creation of a de-socialised healthcare market which gives expression to the liberties of individuals and within which they are free to pursue their own self-defined ends. Such moves have been seen negatively by some as part of the deconstruction of democracy; a hollowing out of civil society which poses a challenge to traditional notions of professionalism and public service ethos. The paper examines current practices in the often separate spheres of co-production and PPI, gaps between rhetoric and reality and the possibilities and challenges of moving away from a researcher/clinician/ industry led, disease focused research model towards a more citizen focused co-production approach.

**Thursday 10 September 2015 at 15:45 - 16:15**

Citizenship

PL006

### **Patient and Public Involvement as Mutable Knowledge Spaces**

*Maguire, K., Britten, N., Gibson, A.*  
(University of Exeter Medical School)

Public concerns about science and scientists are not new. The theme was explored by Swift and Shelley. During the past quarter-century several high profile cases have highlighted and fuelled public anxieties about the environmental and human impact of

science, particularly in relation to the governance of health research. Public protests have also prompted increased interest in public engagement and involvement, from scientists and policy makers.

Using primary qualitative research on service user experiences of involvement in health research this paper explores how the concept of 'knowledge spaces', developed by Elliot and Williams, can be used to model relationships and structures that enable people with different sorts of expertise to work together. While the theoretical dimensions of the cube, described by Gibson, Britten and Lynch, do resonate in these stories, they are also problematised. Involvement spaces are mutable, adapting to fluctuating external and internal pressures, or collapsing under them. Knowledge spaces are politically, economically and culturally situated. Participants' stories are used to describe these spaces as liminal, complex and often paradoxical.

Within each space different modes of action, rules, and theoretical approaches may coexist. This means that enormous value is added when participants reflect upon and share their motivations and values when entering involvement spaces. While they arrive with strategic aims, achieving these requires goals to be set aside in favour of communicative action. This approach is what is experienced as moving beyond information sharing; to create fields in which new kinds of knowledge is co-produced.

**Thursday 10 September 2015 at 16:20 - 16:50**

Health Policy  
PT111

### **Making HPV vaccines evident: Evidence, Systematic Review and Other Technologies of Legitimation in Colombia**

*Maldonado, O. J.*  
(Lancaster University)

In this paper I discuss how evidence has been enacted in the introduction of HPV vaccines in Colombia. This process has been presented by the Colombian government as one of the first experiences of policy based on evidence (EBM) in the country. Evidence based medicine has developed sets of instructions and practices to identify pertinent and reliable evidence for decision makers. This paper analyses the role of systematic review in the production of evidence for policy, understanding systematic reviews as a devices of calculation. Following Moreira's analysis (2007, 2012) of the systematic review I have called this calculative space the textual laboratory. Nevertheless, evidence enactments are not limited to technical documents. Evidence is multiple, it travels through –in the case of policymaking- institutional pathways where it is reproduced, re-enacted and transformed. This paper discusses some ways in which the evidence about HPV vaccines is enacted in different institutional pathways of the Colombian State. Each one involves the disentanglement of the entities that were produced within the textual laboratory and their re-entanglement with other objects, practices and narratives. This paper traces different versions of evidence that are enacted in the movement of data from systematic reviews to the discussions in the technical committee of the Expanded Programme of Immunisations (NCIP).

**Friday 11 September 2015 at 10:45 - 11:15**

Professions  
PL006

### **The Changing Work Experience of Hospital Consultants in the NHS: Evidence on the Deprofessionalization Debate**

*Martin, G., Siebert, S., Howieson, B., Bushfield, S*  
(University of Dundee)

Drawing on the literature on institutional logics and the deprofessionalization of clinical professional work, this mixed-methods study sought to understand changes in hospital consultants' work experience and the impact of these changes on consultants' voice, trust in their organizations, and engagement with their work and employers. We undertook 68 semi-structured interviews with consultants employed in NHS Scotland during 2014, followed by an extensive questionnaire to 3874 Scottish-based consultants, which achieved a 30% response rate. We found significant evidence of deprofessionalization, re-stratification and proletarianization, which were associated with a widespread lack of trust in managers and deeply held feelings concerning a lack of voice and participation in decision-making. However, consultants' perceptions and accounts of de-professionalization were not matched by their disengagement from work, from their clinical teams, or from the values of the NHS in Scotland, all of which remained positive despite their negative outlook on the future of the healthcare system as a whole. The underlying factors that seemed to explain feelings of deprofessionalization were the increasing incursion of business-related and political logics rather than medical professionalism. However, we also found that consultants with experience of medical management were much more accepting of the hybrid nature of the NHS, as were early career consultants and certain specialties. These findings have allowed us to extend the theory of deprofessionalization by including voice as a key element and we contributed to gaps in the institutional logics literature on medical professionals by identifying and analysing different segments of the consultant workforce.

## Paper Abstracts

Wednesday 9 September 2015 at 16:15 - 16:45

Health Care Organisations

PT111

### **Of Leaders and Networks, Pastors and Flocks: Developing Governmentality Theory to Understand the Spread of Patient Safety Discourses in Professional Communities**

*Martin, G., Waring, J.*

*(University of Leicester)*

Michel Foucault's theory of governmentality has been fruitfully deployed as a framework for understanding the translation of discourses around appropriate conduct into the values, behaviours and self-conceptions of individual subjects. Advocates of the theory highlight its advantage in offering a de-centred understanding of the operation of power in late-modern societies and contemporary organisations; for critics, however, this results in an under-theorisation of the role of agency, and a failure to account for the means by which powerful discourses are propagated and taken up. In this paper we seek to address these deficiencies by developing a related concept coined, but little elaborated, by Foucault: 'pastoral power'. Building on the work of others who have taken up this notion, we use pastoral power to conceptualise the work of clinical leaders in introducing and implementing patient safety initiatives in professional communities.

Through a secondary analysis of our own empirical work on quality and safety in healthcare, we derive four sets of activities undertaken by such leaders in their work to promote change in professional work, covering the translation and promulgation of new practices, and the normalisation and ongoing monitoring of change. We suggest that this active work is an essential, and perhaps distinctive, component of the operation of governmentality in healthcare, where new governmental discourses may conflict with the long-established norms and rules of professional collegia, requiring active intervention from 'pastors'. We offer a preliminary model of pastoral power that might be further tested, elaborated and expanded in healthcare and other professionalised fields.

Thursday 10 September 2015 at 11:25 - 11:55

STS

PL005

### **The NHS and the Making of a New (Bio)Economy: Creating Value from Patient Data in Health and Genomic Research**

*Martin, P., Hollin, G.*

*(University of Sheffield)*

This paper explores the changing relationship between the public and private sector in two major UK biomedical research initiatives (UK Biobank and Genomics England) that use personal medical information. It draws on the findings of an evidence report commissioned by the Nuffield Council on Bioethics as part of an inquiry into the use of biological and health data. In particular, it will describe how new forms of collaboration are being created between the health service and industry to enable the commercial exploitation of public resources as a means of creating economic value. In particular, it will chart the shift from a more traditional knowledge transfer model with a clear separation between the public and private realm (Biobank UK) to one which uses business principles to fundamentally restructure state activities (Genomics England). This shift has been accompanied by a reimagining of the NHS as a key source of economic growth in the knowledge economy. The paper will conclude by sketching a theoretical framework for understanding this shift and will explore the implications of this move to create a new bioeconomy for patients, professionals and public policy.

Thursday 10 September 2015 at 11:25 - 11:55

Embodiment and Emotion

PT103

### **Visual Representations of Health, Risk and the Body in Everyday Life**

*Martin, W., Pilcher, K.*

*(Brunel University London)*

Health practices are performed and understood within the context of the daily lives of people as they grow older. There is however limited research into the ways health, risk and the body are lived and experienced when situated within everyday life. This paper draws on data from the study 'Photographing Everyday Life: Ageing, Lived Experiences, Time and Space' funded by the ESRC. The focus of the project was to explore the significance of the ordinary and day-to-day and focus on the everyday meanings, lived experiences, practical activities, and social contexts in which people in mid to later life live their daily lives. The research involved a diverse sample of 62 women and men aged 50 years and over who took photographs of their different daily routines to create a weekly visual diary. This diary was then explored through in-depth photo-elicitation interviews to make visible the rhythms, patterns and meanings that underlie habitual and routinised everyday worlds. The data was analysed using the software Atlas Ti. The analysis highlighted: (1) the role of food practices to the organisation of daily life and how participants draw on wider discourses of health promotion and risk; (2) the embodied performance and visual representation of being 'active'; and (3) the incorporation of health practices into daily life, such as, taking medication, supplements, and visits to health practitioners. The paper will conclude

by exploring the significance of these discourses around health, risk and the body in relation to debates on the medicalisation of everyday life.

**Wednesday 9 September 2015 at 13:55 - 14:25**

Mental Health

PL006

### **Murderers, Paedophiles and Hope: Designing New Models of Care in English Forensic Psychiatry**

*McDonald, R., Vollm, B., Edworthy, R.*

*(University of Manchester, University of Nottingham)*

In the UK, most forensic psychiatrists are employed by the NHS, in specialist secure units caring for mentally ill offenders. Whilst treatments are underpinned where possible by evidence, decisions about how quickly patients should move through treatment pathways often reflect 'taken for granted' assumptions about ways of processing patients, rather than evidence of what is best for their needs. Anecdotal evidence and some research suggest that length of stay is excessive for some patient groups. At the same time, a proportion of patients will require long-term, potentially life-long, secure forensic-psychiatric care. Our study drawing on interviews with forensic psychiatrists finds that many psychiatrists are uncomfortable with explicitly accepting this notion. Instead they emphasise the need for 'hope' and reject labels such as 'long stay'. At the same time, some psychiatrists describe participating in the development of facilities for such patients. Labels such as 'slow stream rehabilitation' or 'enhanced recovery' are used as acceptable ways of framing 'long stay' services. Our study suggests that the entrenched beliefs and patterns of clinical practice can be understood in terms of a forensic psychiatry habitus. Bourdieu focuses much more on continuity than change and the concept of habitus explains how forensic psychiatry practices are reproduced. However, we contribute to theory by showing how change occurs as a result of structural pressures (the need for long stay facilities) and the ways in which these are incorporated as part of a changing habitus.

**Friday 11 September 2015 at 09:35 - 10:05**

Screening and Diagnosis

PT111

### **What's in a Name? Meningitis as a Category and a Process: An Interview Study of the Experiences of Patients and Doctors**

*McGill, F., Griffiths, M., Geretti, A. M., Solomon, T., Byrne, P.*

*(University of Liverpool)*

**Background:** 40% of adults with meningitis in the UK never have a cause found, often because appropriate diagnostic tests are not performed. Most previous work within the theoretical framework of the sociology of diagnosis focuses on outpatient or chronic conditions. This work is novel in that it examines the process of diagnosis in an acute medical situation.

**Methods:** Following a sociology of diagnosis theoretical approach, I interviewed medical staff and patients to explore and understand their practices and experiences of the diagnostic process. 27 semi-structured interviews were carried out, 19 with doctors and 8 with patients. Sampling was purposive and theoretical. Constructivist grounded theory was used to conduct and analyse the interviews.

**Findings:** Themes found were: 1) diagnosis as a process; 2) diagnosis as a category; 3) uncertainty; 4) distributive diagnosis; 5) the art of diagnosis and 6) the science of diagnosis. Of particular interest and novelty was the concept of the perseverance of diagnosis. The process of diagnosis follows a different trajectory in acute settings – exemplified here by meningitis - compared with chronic disease. The diagnostic labelling occurs earlier, and is often followed by a period of steadfast perseverance with little opportunity for refinement, clarification or correction.

**Conclusion:** This works adds to the theory on the sociology of diagnosis by analysing the process in an acute medical condition. In order to 'improve' the diagnosis in cases of meningitis we need to focus and refine the period of the diagnostic process that occurs after the label has been applied.

**Thursday 10 September 2015 at 10:50 - 11:20**

Citizenship

PL006

### **Embodied Independent Citizenship in the Context of Disability**

*McLaughlin, J., Coleman-Fountain, E.*

*(Newcastle University)*

The 'normal' trajectory of childhood is that it is about developing towards independent citizenship as young adults. Disabled children and young people problematize that trajectory; one implication is that medical interventions such as surgery and physiotherapy can be used to try to produce a body more in line with the goals of independent citizenship. This presentation will explore some of the

## Paper Abstracts

implications of such interventions for how we think about the relationship between normality, independence and citizenship. We argue that an imperative towards fixing the body is produced through associating citizenship with independence and productivity, which medicine becomes a part of. In contemporary contexts of economic austerity and a reducing welfare state, the presence of that imperative may be increasing and heightening the hierarchies between those who appear to have a body that is fixable and work to do so and those unable or unwilling to participate in such activities. The presentation will draw from material produced with disabled young people in a completed Economic and Social Research Council project examining disability and Embodiment and Emotion through the use of narrative interviews, photography and creative practice. All of which will be drawn from in the presentation.

**Thursday 10 September 2015 at 14:35 - 15:05**

Health Service Delivery

PT007

### **Community Care Nurses Changing Role in the Management of Complex Caring Trajectories**

*Melby, L.*

*(SINTEF)*

Nurses' role is susceptible to changes due to political, financial, technological, and professional developments. In Norway, we are witnessing a change in the community care nursing role. One major reason is a health reform which transferred responsibilities from hospitals to communities, in turn leading to more patients with complex and severe health problems living at home in need of community care services. In this paper I explore how the community care nursing role is (re)shaped in the intersection of the patient, the (material) surroundings and the nurse. An objective is to expand on the understanding of complex caring trajectories and how they are shaped.

Theoretically the paper draws on the concept of 'illness trajectory' (Strauss et al. 1985) and 'caring trajectory' (Allen, 2004; Hannigan, 2013) which reflects the combined health and social care contributions made in hospitals and in community care. Also insights from actor-network theory (ANT) are applied. The paper draws on material from two different research projects (2010-2014). Observations of community care nurses' work and interviews with community care nurses, GPs, and hospitals nurses make up the material.

The results highlight three features of the changing community care nursing role, which must be seen as a response to current health policies. (1) Nurses are increasingly performing advanced assessments and clinical work in the patient's home. (2) Negotiations with other healthcare providers to determine the amount and level of services for the patients have become more important. (3) Nurses have a more visible role in coordinating patients' trajectories.

**Wednesday 9 September 2015 at 16:15 - 16:45**

STS

PL005

### **Is Addiction Neuroscience Information Useful? Findings From an Australian Anticipatory Stakeholder Analysis**

*Meurk, C.*

*(The University of Queensland)*

Neuroscience research on the effects of chronic drug use on brain function has been used to argue that addiction is a 'brain disease'. The public health, policy and social implications of this model of addiction have been the matter of some debate among neuroscientists, philosophers and STS scholars. Central to these debates, as with other debates over the 'neuro', has been the degree to which neuroscience information can be said to have 'impacts', good or bad, sociocultural or personal. In this paper I consider the 'impact', 'acceptance' and 'usefulness' triad, with regards a recently completed Australian study of the views of approximately 1450 drug dependent persons, their families and the general public about the benefits and drawbacks of addiction neuroscience information and technologies that formed part of a broader anticipatory analysis of addiction neuroscience. Remarkably, across all groups we engaged, a similar story emerged: brain-based explanations of addiction were deemed acceptable, and useful in some ways, but their 'impact' was limited insofar as new ideas were incorporated into pre-existing conceptions of addiction in complex ways. The usefulness of the 'disease' label was somewhat more contested. Views on neurotechnologies were mixed. In short, our findings deflated the extreme predictions of academic debate while we nonetheless concluded that the dissemination of neuroscientific information should be encouraged, subject to some qualifications. By reframing our analytical focus from 'impact' to 'acceptance' and 'usefulness', we uncovered what is socially valuable about ambivalence and its somewhat paradoxical implications for science communication.

Wednesday 9 September 2015 at 15:40 - 16:10

Theory  
PT006

**Biography, Authority and Health Message Legitimacy: Researching NHS Health Checks and Wellbeing and Theorising the Inherent Tensions Between Received Advice and Self-efficacy**

*Miles, P.*  
(University of Bedfordshire)

This paper draws on data generated by NIHR-funded, qualitative research undertaken at GP Surgeries and Health Centres in Cambridgeshire involving observations of the NHS Health Check program sessions and consequent, one-to-one patient interviews exploring perceived effectiveness and value of the program. When exploring the impact of setting and agency in health checks an interesting narrative emerged based on patient receipt of information aimed at encouraging positive health-related activity and lifestyle choices. Self-evaluation of 'legitimacy' of messages was consciously undertaken by patients both in-session and post-session, drawing conclusions categorising established biographical 'conditioning' (including norms, values and educational influences); experiential judgements based on a highly individualised, self-efficacy; and the dialogue with public discourses of media, internet and peer group communications. I was, therefore, able to develop taxonomy of authority and its effects on maintenance of wellbeing, concentrating on the impact of pre-existing values and the patients' requirement to 'suspend or surrender' control of such values for the duration of the health check. The impact of such research is to instigate greater understanding of health educational messages and their impact on a wider societal sense of health and wellbeing, creating deeper enlightenment on the impact and usefulness of direct advisory and educative programmes.

Friday 11 September 2015 at 09:35 - 10:05

Lifecourse  
PL002

**Failed Surrogate Conceptions: Not a Pregnancy Loss?**

*Mitra, S., Schick Tanz, S.*  
(University Medical Center Göttingen, Germany)

This paper attempts to reconstruct the experiences of loss and grief of the surrogate mothers and the intended parents resulting out of their collective failure to conceive a surrogate pregnancy. This failure results out of their failed attempt to conceive after an embryo transfer. During a gestational surrogacy arrangement, the event of embryo transfer can be seen as the formal starting point of the arrangement. However, it is extremely common for the surrogate to receive a negative pregnancy confirmation test. This raises an important question as to whether such failed attempts can be understood as 'loss'? Based on a sociological study conducted in Delhi and Kolkata during 2014-15, we reconstruct the perceptions and affects of surrogates and intended parents regarding the failure of assisted reproductive technologies. We argue that while the surrogate grieves the non-arrival of 'good news' or a 'new entity', the intended parents experience yet another sense of failure in their journey towards becoming parents. The body of the surrogate becomes a site of 'a lost opportunity'. She 'embodies a loss' in her quest to achieve social mobility while the intended parents experience a 'disembodied pregnancy loss'. In the discourse of the fertility industry, such failed attempts get normalized as non-events. Their narrative of assisting a successful pregnancy neglects the impact of these failures upon the actors concerned. In this paper, we address how disclosure or non-disclosure of such 'risks of failure' can oversee the experiences of hope, loss and bereavement of the actors concerned.

Thursday 10 September 2015 at 10:15 - 10:45

Embodiment and Emotion  
PT103

**Embodying Health Identities: Understandings from a Qualitative Study of Young People with Asthma**

*Monaghan, L., Gabe, J.*  
(University of Limerick)

During the past decade there has been a growing interest in the sociology of health and the embodiment of health identities in everyday life. Relevant questions, issues and themes in this largely adult-centric literature include: how are definitions of health sustained in the contexts of risk and chronic illness, how does the body figure in people's understandings of their health status and how do social divisions influence or mediate these embodied interpretations? In addressing such questions, this paper draws from a qualitative study of mild to moderate asthma among young people in Ireland. Data are drawn from 31 in-depth interviews with respondents aged between 5 and 17, including boys (n=15) and girls (n=16) from the Irish Traveller community (n=14) and the larger 'settled community' (n=17). In focusing on dimensions of health as socially constructed, experienced and understood, themes include: the importance of play, physical activity and sports; diet/nutrition; grooming or personal hygiene; and, the importance of bodily appearance (e.g. weight or not being fat). Asthma sometimes presented challenges in relation to specific domains, notably strenuous physical activity, though in many other respects its potential impact was discursively minimised as young people normalised their condition. Formally, this paper furthers an embodied perspective which challenges dichotomies within the

## Paper Abstracts

sociology of health and illness, illustrating that definitions of health may be sustained and actively reproduced even among young people diagnosed with a potentially disruptive chronic condition.

**Wednesday 9 September 2015 at 14:30 - 15:00**

Theory  
PT006

### **The Sociology of Diagnosis: Recent Developments and Future Directions in the Social Life of Diagnosis**

*Morrison, M., Salter, C., Nettleton, S., Kelly, S., Cohn, S., Stockl, A.*  
(University of Oxford)

In this paper the authors reflect on the recent ESRC-funded seminar series on the Sociology of Diagnosis which ran from 2013-4. The series consisted of five events; each dedicated to a different thematic aspect of diagnosis and held in different locations throughout the UK. The major organising themes of the series were: technology, innovation and diagnosis; theorising diagnosis; politics and collective health movements; practitioners and patient experience, with the final seminar discussing future directions for policy and practice. A number of cross-cutting themes emerged, in particular a sense that diagnostic categories not only move between individual and population level but increasingly travel across multiple sites, from scientific research to medical education, patient activism and political strategies, adopting different configurations and different meanings in different contexts. As part of our post-seminar series work-in-progress, we propose that while diagnosis remains at the heart of medical practice, the clinical encounter between patient and physician is only one of many sites of diagnostic knowledge production. We suggest diagnosis is decentred, multiple and always politicised, before considering what this means for the understanding and study of diagnosis within medical sociology and for the subfield of the sociology of diagnosis.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Lifecourse  
PL002

### **A Longitudinal Ethnographic Study of Couples' Experiences of Starting Infertility Treatments: Early Findings**

*Mounce, G., Allan H., Carey, N.*  
(University of Surrey)

This study investigates the experiences of couples seeking medical assistance in their desire for biological children. Infertility is a complex social experience for couples, which evolves over time and with differing circumstances. Unlike previous research around this topic, this study utilises a longitudinal ethnographic design with a prolonged data collection period of 18 months (March 2013 to September 2014).

Fourteen (14) couples took part in the study. Data were collected at the first medical encounter and then after any subsequent consultations. Data collection involved repeated rounds of observation (22) and interviews (22) with the same participants, facilitating an iterative process to inform and refine analytic ideas as they emerged. The researcher, as participant observer, attributes cultural meaning to the couples' experiences and uses field notes to reflect on other senses, to fully embody inquiry in the field. The philosophy of interpretative phenomenology informs the analysis of interview data; with the aim of eliciting the subjective lived experience for couples at each point.

Initial thematic analysis of the interview transcripts was undertaken. Expressions of infertility 'as a journey' were common, and the initial medical consultation can be considered like a 'junction box' on this journey. The junction box offers several alternative possibilities but is not always helpfully configured and may sometimes be the cause of unexpected delays. Significantly the junction is situated in a wide social and political landscape, which is a prism through which couples' perceive the relevance of this junction – and medicalisation - in their own journey.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Mental Health  
PL006

### **The Complexities of 'Health' and 'Care' in Disordered Eating**

*Musulino, C., Warin, M., Wade, T., Gilchrist, P.*  
(The University of Adelaide)

This paper examines how contemporary understandings of health and care are engaged with by women with disordered eating. Based on findings from an Australian study investigating why people with disordered eating are reluctant to engage with treatment services, we demonstrate how women use elements of a 'health habitus' and 'care' to rationalise and justify their practices. Moving beyond Foucauldian theories of self-discipline and individual responsibility we argue that Bourdieu's (1977) concept of habitus and Mol, Moser and Pols (2010) concept of care provide a deeper understanding of the ways in which people with disordered eating

embody health practices not only as a means of maintaining their disordered eating, but also as an active pursuit of care, symbolic capital and distinction. We demonstrate how eating and bodily practices that entail 'natural', medical and ethical concerns (in particular, the new food regime known as orthorexia) are successfully incorporated into participants' eating disorder repertoires and embodied as a logic of care. This points to a difference between the ways in which people with disordered eating may understand their practices (as 'not sick' and often productive), and the clinical view of a psychiatric disorder and the need for intervention and treatment. Understanding how categories of 'health' and 'care' are tinkered with (Mol et al., 2010) and practiced by people with disordered eating has important implications for health professionals, family members and peers engaging with and identifying people at all stages of help-seeking.

**Thursday 10 September 2015 at 12:00 - 12:30**

STS  
PL005

### **'Passive Labour' or Gift Exchanges? Exploring the Role of the Body and Financial Rewards in First In-human Clinical Trials Among Healthy Volunteers in the UK**

*Mwale, S.*  
(University of Brighton)

This paper examines the role of the body and financial rewards in first in- human clinical trials (FIHCTs) involving healthy volunteers. Drawing on data from an on-going PhD project on human involvement in clinical trials, focused on ethical and regulatory issues of human involvement in FIHCTs in the UK. Current policy discourse and debates heavily influenced by the Titmussian ideal of gift giving (Titmus 1974) tends to situate healthy volunteer involvement in clinical trials as mostly altruistic, commercially and ethically unproblematic. The paper build's on existing work on human engagement with medical technological innovations and practice (Waldby and Cooper 2014; Rajan 2006). Within this context, debates have focused on how the body has been used in different contexts both as a resource and site for research in clinical trials, surrogacy and even donation of body parts, raising questions about the body and the financial value it generates and is assigned.

This paper adds to this debate by extending the focus of analysis solely on how bodies are delineated and utilised by both those who embody them and the corporate research companies and researchers that use them in FIHCTs. Drawing on healthy volunteer accounts and experiences of taking part in FIHCTs, the paper aims to show how some healthy volunteers' contest claims to altruism and show an acute awareness that their involvement in clinical trials is an economic exchange; and subsequently come to see their bodies as a resource for making a living in a process I call 'passive labour'.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Ethics  
PT103

### **Narcissism or Necessity? The Web, Aesthetic Surgery and Representations of 'Deficient' Female Bodies**

*Nash, R., Pope, C., Halford, S.*  
(University of Southampton)

Aesthetic standards for how bodies 'should look' have become incorporated into contemporary culture. Technologies and media inform and support discourses about bodies, and aesthetic surgery is increasingly used to modify physical bodies. The Web provides a virtual space to advertise, discuss and pursue procedures. It enables a pervasive cosmetic gaze (Wegenstein and Ruck 2011).

This paper addresses earlier feminist scholarly debates that variably regard aesthetic surgery as oppressive, empowering or potentially subversive. I explore Web spaces to examine potentially shifting discourses, focusing on how the Web may be altering engagement with aesthetic surgery. My empirical study employed multimodal critical discourse analysis to explore how aesthetic surgery is represented online. The data presented here includes online news resources, forum and Webpages and videos from YouTube. My analysis suggests that the Web shapes and represents female bodies in different ways. In commercial surgical spaces, surgery is a solution to imperfections. In other virtual media the Web debates vanity and narcissism; bodies that have – or are perceived to have - undergone - aesthetic surgery are applauded, criticised, or derided. Individuals are faced with a plethora of Web spaces providing multiple and apparently conflicting representations that together perpetuate a discourse that female bodies are aesthetically deficient. Building upon earlier strands of feminist theory, the analysis here suggests that hypertextual feminism may arise from access to diverse aesthetic surgery materials online. Browsing aesthetic surgery online exposes individuals to myriad arguments debating necessity, narcissism and the complex ethics of aesthetic procedures.

## Paper Abstracts

Wednesday 9 September 2015 at 15:05 - 15:35

Ethics  
PT103

### **Nudging: What are the Theoretical, Empirical and Ethical Questions to be Addressed to Answer to What Extent Nudging is the Modern Way in Public Health?**

*Nielsen, M., Reinbacher, G. S.*  
(University College Metropol)

In the International and Danish debate about Health improvement and Health policy during the last thirty years, the individualistic approach to citizens has been the overall attempt, but it has been not very effective so government, institutions as well as researchers are looking for another approach. Structuralistic approaches on society level, such as change in taxes, change in local communities, collaboration with industry for better food supply could be seen as new and more effective ways to go. But it is complex and might only work in the very long run.

Nudging as population and individualistic change in behaviour for smaller or bigger groups in society is a modern attempt to improve Health for the population. By "nudging" people, step by step to increase smaller change in Health behaviour, we could expect in the long run change on the societal level, but will it happen?

This paper will look at some Nudging projects, trying to find out on an evaluation basis, wheather and which improvement we can expect to find to answer the question in this paper. We will address the cases on an empirical level and look at documentation and expected outcomes.

The paper will address Nudging on a more theoretical level, to look at the power and possibility for such a new concept in between individualistic and structuralistic approaches based on sociological theory. Is it a way to move forward or is it a blind alley? Politicians might be very interested in Nudging because of its expected effectiveness.

Wednesday 9 September 2015 at 12:45 - 13:15

Lifecourse  
PL002

### **Alcohol use Across Retirement: Emergent Themes from a Qualitative Exploration of Alcohol Consumption in Later Life**

*Nicholson, D.*  
(University of the West of Scotland)

Rising alcohol consumption among middle aged and older people has attracted concern for the future if current patterns are continued into old age (Health Scotland, 2006). Published reviews are available that examine alcohol (use and misuse) in relation to older people (e.g. Johnson, 2000; Ferreira and Weems, 2008; Coulton, 2009; Simmill-Binning et al, 2009) and retirement specifically (e.g. Kuerbis and Sacco, 2012; Zantinge, 2014; Bamberger, 2014). However, much of the existing literature on older adults' alcohol use appears to be from a clinical perspective, with less emphasis on the sociocultural aspects of older adults' alcohol use. This is in contrast to research into younger adults' drinking which explores their experiences from a broader range of perspectives. Furthermore, changing experiences of retirement and life-course, increased service demand and the reshaping care agenda (Scottish Government, 2011) reaffirm the need to better understand 'where, when, what and how older people drink' (Clough et al, 2004).

In this qualitative study, alcohol's role in the lives of retired people is investigated. Data collection is underway and, to date, semi structured interviews have been carried out with 30 participants from an overall target of 48. Recruitment is via the Scottish Primary Care Research Network, social clubs and organisations such as Seniors Together. Quota sampling is being employed in terms of gender, age and socioeconomic status (using the Scottish Index of Multiple Deprivation) to ensure a broad spread of respondents. This work-in-progress paper will present key preliminary findings and emerging themes around alcohol, ageing and retirement.

Friday 11 September 2015 at 11:20 - 11:50

Health Service Delivery  
PL005

### **We Are Each Other: New Hybrid Forms of Public-Private Models and Interventions in the Health Care Sector**

*Nordin, P., Koskela, I., Husman, P., Johanson, J. E.*  
(University of Tampere)

With the ever increasing interaction between public and private actors in health care sector, the boundaries between these two have started to lose their meaning and new institutional fields have emerged. Instead of being public, private or public-private, these fields are complex, hybrid constellations, where the emerging forms of interplay are still taking form. There is a gap in understanding the theoretical conceptualization of these hybrids in institutional fields that this paper aims to fill by presenting a new

framework that can be implemented to the inherent institutional logics of hybrid forms of governance and applied to research on new forms of health care services and innovations.

The ultimate goal with all health care innovations is to improve the well-being of the people and this requires adoption of new ways to think how to organize the health care services. This paper is a synthesis of a research project that combines six different cases of innovation capture and diffusion in public-private health services. Each of the cases deals with new innovations that have been borne out of these public-private hybrids as a response to increasing burden put on the health care services amid financial constraints and changes in the legislation. Through innovation capture paradigm issues such as organizational change, complexity, network governance and knowledge management in the Finnish health care service landscape will be discussed.

**Thursday 10 September 2015 at 14:35 - 15:05**

Citizenship  
PL006

### **An Exploration of Participation and Engagement in a Birth Cohort Study**

*Ochieng, C., Minion, J., Turner, A., Murtagh, M.*  
(University of Bristol)

Birth cohort studies aim to follow a study population born at a pre-defined period. They take a longitudinal approach to data collection. Although data is collected from participants periodically, it is surprising to discover that participants rarely get an opportunity to express their own thoughts about the research. As such there is little evidence to describe participant experiences of engagement in birth cohort studies, particularly those that also collect biomedical specimens.

We conducted a qualitative study among members of a birth cohort study in Bristol, ALSPAC. Semi-structured interviews were conducted with 42 (male and female) differentially engaged members of the cohort. The interviews explored participant experiences and thoughts on engagement in ALSPAC.

Engagement meant different things to different participants including: awareness of the cohort's discoveries; attending research sessions; having an autonomous choice to stay involved. Participants also had differing expectations, although the prime expectation was confidentiality and data security of their data and samples. Participants had an implicit relationship with ALSPAC that was embodied in strong feelings of trust. This trust enabled participants to exercise altruism. In the event of any unlikely exposure to risk participants believed that ALSPAC would act in a reciprocal way to protect participants.

ALSPAC has invested in nearly 25 years of creating a relationship of trust and an atmosphere of loyalty among its participants. Engagement is, in this case, reliant on concepts of trust, loyalty, altruism and reciprocity. These are key ideas that could aid in understanding engagement as experienced in other similar studies.

**Friday 11 September 2015 at 10:45 - 11:15**

Screening and Diagnosis  
PT111

### **Diagnosis-as-emergence: Explicating Diagnostic (Trans)Formations of Intimate Partner Violence in Emergency Department Consultations**

*Olive, P.*  
(University of Cumbria)

In this paper I present findings of research that aimed for greater approximations of knowledge of the diagnosis of intimate partner violence in emergency department consultations and through which diagnosis-as-emergence was conceptualised.

Research has evidenced that intimate partner violence is often 'missed' in emergency department consultations. Taking missed cases as its focus, this research investigated the borders and properties of (mis)classifications of intimate partner violence in consultations. Positioned at the boundary of critical realist and postmodern complexity theory this research employed a multi-method design of interviews with practitioners and service users, and a review of emergency department attendance records. Analysis and interpretation was shaped through sociology of diagnosis (Brown 1995, Jutel and Nettleton 2011) and sociology of science (Mol 2002, Latour 1983, Woolgar and Lezuan 2013). The research found an overall transformation and erasure of intimate partner violence across the course of consultations, however this was not straightforward and different versions of intimate partner violence co-existed at different locations. This classificatory multiplicity signalled practices and systems relations through which different versions, each mobilising different diagnostic category, process and consequence properties, were brought into being. Bringing complexity theory and sociology of diagnosis together, these different versions of intimate partner violence are conceptualised as diagnosis-as-emergence: differently valorised diagnoses produced through heterogeneous sets of relations between systems. Diagnosis-as-emergence is forwarded as a conceptual framework for this and wider health research to address difficult 'what happens' questions by explicating interconnections of multiple systems and their mobilising properties that effect health outcomes.

## Paper Abstracts

Thursday 10 September 2015 at 16:20 - 16:50

Pharmaceuticals

PT103

### **The Politics of Breakthrough Drug Pricing and Reimbursement in England: A Qualitative Case Study of Sofosbuvir for Hepatitis C**

*Ozieranski, P., Hoey, A., King, L., Roy V.*

*(University of Bath)*

New antiviral medicines are a turning point for Hepatitis C patients, with cure rates of over 90% and few side-effects. These treatments offer the possibility of eradicating Hepatitis C in the UK, but their widespread introduction to the NHS has been delayed. High prices are cited as a central reason.

We present results of a study on the political and social dynamics at play with high price medicines. We ask: 'How was sofosbuvir priced and reimbursed in England?' and 'Who had the most power in this process?'. Our data include semi-structured interviews with purposively sampled stakeholders, ethnographic observations at relevant policy events and documentary sources. We analyse the data based on grounded theory.

Preliminary findings from seven interviews with key stakeholders and observations at four events reveal tensions and policy challenges. The National Institute for Health Care Excellence (NICE) recommends sofosbuvir for most patients, based on long-term cost-effectiveness, compared with treating worsening liver disease. But NHS England struggles to afford access for all Hepatitis C patients. Instead, it seeks to balance competing stakeholder interests and define priority groups.

Clinicians, patients and the industry exert considerable pressure throughout the pricing and reimbursement (P&R) process. We will interpret our findings drawing on the neoliberal corporate bias, agency capture and the disease-based politics theories from the political sociology of pharmaceuticals, combined with broader perspectives in medical sociology discussing the power of medical professions, patients, health consumers and healthcare managers.

This research addresses the gap in P&R research within the political sociology of pharmaceuticals.

Wednesday 9 September 2015 at 13:20 - 13:50

Risk

PT111

### **Queering Risk Governance: Attending to the Temporal Dimensions of Breast Cancer Survivorship Discourse**

*Pack, R.*

*(The University of Western Ontario)*

Breast cancer survivorship has emerged as a focus of sociological inquiry in the last twenty years. Sociological studies of breast cancer informed by governmentality and feminist theory have critically explored how women's bodies are governed, and highlighted how risk discourse produces new possibilities for intervention and novel forms of (biomedicalized) citizen-subjects. Such insights regarding risk governance rest uneasily with breast cancer survivorship because they cannot account for the ways in which survivors of breast cancer are always already 'at risk' of recurrence, and thus occupy a particular ambiguous subject position that can be seen as a temporal suspension in what Jain has conceptualized as 'living in prognosis'.

This paper proposes that theories of queer time can further illuminate the temporal dimensions of survivorship, and contends that these are important to consider in the critical examination of how breast cancer survivorship functions as a governing discourse. Queer theory suggests that temporality provides another lens through which we can critically examine how bodies are regulated and compelled towards particular trajectories of normality. I argue that theories of queer time provide the tools to attend to 'survivorship' as a temporal relation, as well as a constructed identity, and to the ambiguity and instability that are significant to the sociological study of survivorship because they illuminate the particularly precarious state of the 'survivor'.

Thursday 10 September 2015 at 15:10 - 15:40

Experiences of Health and Illness

PX001

### **The Critical Illness Trajectory: A Parallel Experience for Survivors and Their Relatives**

*Page, P.*

*(Anglia Ruskin University)*

The Critical Illness Trajectory- a parallel experience for survivors and their relatives

Introduction: The missing voice of the critically ill has been highlighted by Rier (2000). Whilst physiological survival of the critically ill is a driving imperative there is an increasing awareness of the psychological, cognitive and physiological sequelae that may follow survival. Liminality may provide a theoretical lens to view the parallel realities of survivors and family members.

Method: Utilizing Constructivist Grounded Theory cycles, constant comparative data have been collected from survivors of critical illness and their relatives. Substantive or formal theory may develop that accounts for data and context variations. IRAS and NHS Trust R&D approval granted.

Findings: Analysis of 16 patient and 17 relative interviews is ongoing but emergent focused codes include: (1) Ambiguous Loss (2) Disruption of relationships (3) Dreams and hallucinations (4) Critical junctures (5) Facing mortality. A core category of parallel realities may be linked with the concept of liminality.

Practical relevance: This study provides a 'medical gaze' on critical illness rather than chronic illness and may bring new sociological insights to the illness experience. The concept of 'survivorship' -moving from surviving to thriving is a new imperative in acute health care (Hart 2014).

Hart, N. 2014 Therapeutic and Rehabilitation Strategies in ICU in *The Legacy of Critical Care –Textbook of Post-ICU medicine*, Oxford University Press

Rier, D.A., 2000 The missing voice of the critically ill: a medical sociologist's first person account. *Sociology of Health & Illness* Vol. 22, No 1, p68-93

**Thursday 10 September 2015 at 11:25 - 11:55**

Experiences of Health and Illness

PX001

### **Childhood Epilepsy: Experiences and Involvement**

*Parry, R.*

*(University of Edinburgh)*

A diagnosis of childhood epilepsy holds a variety of implications for the child and their family beyond epileptic seizures, including intricate and multidimensional care arrangements. Despite growing recognition of the importance of listening to and consulting with children regarding their healthcare, children's accounts regarding their epilepsy and their involvement in the associated care is woefully under-examined.

In this paper preliminary findings from my PhD research will be discussed, drawing on data gathered from fourteen families. The study explores the everyday experiences of children with epilepsy and examines their involvement in their own healthcare management in formal and informal contexts. Children with a diagnosis of active epilepsy and their parent(s) were interviewed separately on two occasions. Observations of a clinical consultation guided the second interview to generate more in-depth discussions. Participatory tools were used within the child interviews to facilitate conversation.

Key themes from the preliminary findings have emerged in relation to children's participation in care, including their felt and perceived autonomy, and responsibility. Additionally the negotiation of care, in particular medication regimes, has been seen to dominate parents' narratives and influence their perceptions of their child's autonomy and competence in terms of epilepsy care. Such findings will be explored in terms of child agency and its implications for informal and formal care practices associated with epilepsy care. Attention will also be paid to normalisation and biography literatures, in discussing how families normalise and assume epilepsy into part of their individual and family biographies, reflecting a further theme to emerge.

**Thursday 10 September 2015 at 10:15 - 10:45**

Healthcare Organisations

PT111

### **A Comparison of Organizational Cultures Around Promoting Equity in Public and Hybrid Healthcare Organizations**

*Patnaik, A.*

*(University of Huddersfield)*

Background: The public health sector in England has been increasingly subjected to private market principles such as competition. To promote competitive markets, governments have encouraged a plurality of providers and organizational forms, for example, by supporting parts of the English National Health Service to break away to form independent, competing providers called 'social enterprises'.

Critics have expressed concerns that competitive markets may lead to the erosion of equity in the provision of services. This paper tests this contention by comparing organizational cultures in the NHS and social enterprises around promoting equity.

Research Aims: This research project aimed to find out whether an organization's form as 'public (NHS)' or 'hybrid (social enterprise)' affects its organizational culture around promoting equity in service provision.

Methods: This study employed a mixed methods approach. The quantitative strand used an online survey to compare cultures in the NHS and social enterprises in terms of their support for equity. Hierarchical regression modelling was used to analyse the survey data and identify variations at both the individual and the organizational level. The qualitative strand used semi-structured interviews (thematic analysis) to examine cultural changes in social enterprises and their impact on equity in service provision.

## Paper Abstracts

Findings: Social enterprises offer the potential for improving equity in service provision. By reducing bureaucracy, speeding up decision-making, giving staff more operational autonomy, encouraging initiative and risk-taking, and making better use of technology, social enterprises are showing themselves capable of promoting equity to an equal or greater degree than public organizations like the NHS.

**Friday 11 September at 2015 09:00 - 09:30**

Patient - Professional Interaction

PL001

### **Shared Breath: Re-evaluating the Therapeutic Relationship**

*Patterson, J.*

*(The University of Greenwich)*

This paper will discuss the context and some of the initial demographics from the Listening to Patients Project. Located at the University of Greenwich, the project aims to create an experience-based evaluation and seed innovative approaches to healthcare, through listening to patients' voices in support of constructing a wider understanding of the influence of experience on health and wellbeing, grounded in narrative.

Critically, the paper presents findings and advances in healthcare from fields such as Narrative Medicine, Counselling and Psychoneurobiology to suggest how overall patient experience and individual concepts of health and illness affect health and wellbeing. It discusses how experiences of medical and healthcare interventions can be used to rethink the therapeutic relationship. It argues that outcomes-based evaluations used in biomedicine and measures such as MYMOP (Paterson, 2000) used extensively in Complementary Medicine, serve useful and appropriate ways of managing care. However, as evaluation instruments, they nonetheless serve to reinforce the problematic locus of power in the therapeutic relationship and are essentially driven by institutional aspects of healthcare management.

Employing mixed methods approaches (Denzin, 1970; Tashakkori and Teddlie, 2010), and drawing on French Feminist critical theory, the paper reports on interim analysis of survey data and explores the wider and complex contexts in which the data needs to be located. It concludes by presenting the necessity for complexity in auto ethnographic research (Denzin, 2014) with the potential need for a post-deconstruction shift in paradigm.

Denzin, N. K. (1970) *The Research Act in Sociology: A Theoretical Introduction to Sociological Methods*, Butterworths.

Denzin, N. K. (2014) *Interpretive autoethnography*. Norman K. Denzin. 17, Second edition., Los Angeles, SAGE.

Paterson, Charlotte. "Complementary practitioners as part of the primary health care team: consulting patterns, patient characteristics and patient outcomes." *Family Practice* 14.5 (1997): 347-354.

Paterson, C, Britten, N. (2000) In pursuit of patient-centred outcomes: a qualitative evaluation of the "Measure Yourself Outcome Profile." *J Health Serv Res Policy* 5:27-36.

Tashakkori, A. and Teddlie, C. (2010) *SAGE Handbook of Mixed Methods in Social & Behavioral Research*, SAGE.

**Wednesday 9 September 2015 at 15:40 - 16:10**

Lifecourse

PL002

### **'End of Lifers'; Anticipated Dying in Prisons and the Health Impacts of Neoliberalism**

*Peacock, M., Turner, M.*

*(Lancaster University)*

In the last decade the UK prison population has doubled with older prisoners being the most rapidly growing group. Despite popular misconceptions, most prisoners will not be released in the event of them developing a terminal illness and thus numbers of anticipated deaths (those from natural causes which are foreseeable and likely to require palliative care), in prisons are rising as are the numbers of chronically ill and disabled prisoners. These changes have been argued to be a consequence of neoliberal policies and practices characterised by both higher rates of incarceration and longer sentences.

Drawing on data from a study of palliative care in prison, we explore the impacts of these changes for staff and prisoners and, in particular, the discursive resources drawn upon to protect from both the 'pains of imprisonment' and from the daily contact with pain and suffering. The majority of those dying in prison are not serving life sentences, resulting in the construction of 'end of lifers' and there has been little debate concerning the ethics of such changes.

Neoliberal austerity measures have resulted in the loss of large numbers of experienced staff who, we propose, draw on 'jail craft' as a protective narrative; a narrative also valued by older prisoners. As the individualised discourses of neoliberalism increasingly dominate, the practical strains on staff are magnified by the erosion of the collective and pride-driven discourses such as that of jail craft, weakening a source of protection from the challenges of an ageing and ill prison population.

**Thursday 10 September 2015 at 17:30 - 18:00**

Pharmaceuticals

PT103

### **Negotiating Recruitment: Collaboration Between Patient Recruitment Companies and Sponsors**

*Poplavska, E.*

*(Riga Stradins University)*

Patient recruitment companies are small, private businesses that specialize in finding and selecting patients for clinical trials on behalf of pharmaceutical and medical device industries. The emergence of these companies around the 1990's is part of a broader tendency within the pharmaceutical industry to focus on outsourcing clinical trial research. The shift of clinical research to the private sector has raised new questions and ethical concerns about relationships that emerge between the industry, regulating bodies, researchers and human participants. In this paper I will examine the relationship between the recruitment companies and sponsors. In their daily work the recruitment companies are attempting to manage various interests as the success of a recruitment program depends on close collaboration with the key stakeholders – sponsoring company, clinicians and potential research participants. Often interest and needs of these groups collide and create ethical tensions for the recruiters. I will discuss how recruitment programs are negotiated between the recruiters and sponsors along with the factors that influence prioritization of the needs of involved groups. This paper is based on findings from a year long ethnographic study in the US that consisted of participant observations in a patient recruitment company, document reviews and 35 semi structured in-depth interviews with the representatives of the recruitment companies and of the research clinics. The aim of this study was to investigate professional patient recruitment activities and relationship between different stakeholder, including patients, in the clinical trials industry.

**Friday 11 September 2015 at 11:55 - 12:25**

Patient–Professional Interaction

PL001

### **Good and Bad Diagnoses, Their Talents and Forecasts: A Qualitative Study of Norwegian GPs' Reflexive Diagnosis Work**

*Rasmussen, E.*

*(Oslo and Akershus University College of Applied Sciences)*

Medical diagnoses are not neutral or value-free, but loaded with value and social meaning. Some diagnoses are highly prestigious, others are stigmatizing; some are self-evident, others are deeply contested; and some are connected to certain rights and benefits that others are not. As such, any diagnosis is always more than an answer to the question "what is wrong with the patient"? The value and meaning of different medical diagnoses enter into and affect their application in clinical work. The paper explores how GPs think about and make use of medical diagnoses when patients present with medically unexplained symptoms (MUS). Based on three focus group interviews with Norwegian GPs (N=23), I show various ways GPs approaches to diagnosis are affected by their knowledge and beliefs about different diagnoses. The main finding is that diagnosing patients is often a deeply reflexive undertaking, requiring GPs to include the value and social meaning of the diagnoses they employ in their work. In other words, GPs attempt to include the expected or possible psychological, social, economic and moral consequences of using specific diagnoses in the diagnostic process. Not enough is known about how medical doctors approach diagnoses and diagnosis. I hope to contribute to the understanding of diagnoses and diagnosis in the sociology of health and illness in general and the sociology of diagnoses in particular. Knowledge about medical doctors' approaches to diagnostics is crucial, both to our understanding of the medical profession, and of the care received by their patients.

**Thursday 10 September 2015 at 16:55 - 17:25**

Pharmaceuticals

PT103

### **Medicines Adherence as a Lived, Socially-Constructed Phenomenon of Survival: A Phenomenological Investigation in Men with Diabetes**

*Rathbone, A., Jamie, K., Husband, A. K., Todd, A.*

*(Durham University)*

Non-adherence to medicines results in poor health outcomes and financial waste. There is little evidence supporting interventions and on-going debate about the definition of adherence and its measurement. In addition medicines use has been shown to be socially and culturally located. This research explores patients' lived experiences of medicines adherence in diabetes to deliver insights into the phenomenon.

We collected and will present data from 9 semi-structured interviews with men prescribed medicines for diabetes aged 38-77 years and recruited from community pharmacies and general practices. Interviews were conducted in patients' homes, the university or public places using a topic guide and were audio-recorded. Analysis was conducted using a phenomenological thematic framework, including epoche (the bracketing and awareness of prior knowledge). Findings suggest that patients' medicine use is constructed as a means of 'survival'. In adopting medicines as a part of everyday life patients i) personify medicines, using

## Paper Abstracts

names, habitats and storage and ii) personalise their prescriptions. This process is mediated through interactions with healthcare professionals, family, friends, the mass media and the medicines themselves as symbolic social entities.

The findings speak to the lay pharmacology outlined by Webster and colleagues in relation to how medicines 'work'. This work builds on the Health Belief Model and Self-Regulatory Model where the 'need' for the medicine is considered as a way to 'cope' with physical symptoms.

**Thursday 10 September 2015 at 16:55 - 17:25**

Citizenship  
PL006

### **How Recently Arrived Migrants to the UK Make Decisions about their Healthcare**

*Redwood, S., Griffith, L., Lindenmeyer, A., Phillimore, J.*  
(University of Birmingham)

Changes in migration patterns over the last two decades have led to an unprecedented cultural and ethnic diversification in the UK to which health services are struggling to respond. We report on a study conducted with recently arrived migrants into the West Midlands, exploring their previous experience of health and healthcare in their countries of origin and recent experiences in the UK. Working with community researchers drawn from the same areas of origin as the new migrants, we interviewed 24 respondents from Africa, China, Middle East, South Asia and Eastern Europe. These narratives generated data across the course of their lives and incorporated experiences of health, illness and help-seeking in many different health systems. The focus of this paper is to explore how new migrants actively negotiate different medical epistemologies, systems of care provision and therapeutic and self-care practices in order to achieve health for themselves and their families. We show how decisions about health and healthcare are shaped by material, social and cultural resources both in the UK and in the country of origin through transnational and local links, and how migrants re-evaluate their health beliefs and practices in light of their experiences in the UK. We conclude with thoughts about how the insights from this study can inform our understanding of medical pluralism as a practice in which people access health resources from different countries pragmatically and often simultaneously to solve health problems, and the implication of this on interactions between migrants and UK health care service providers.

**Wednesday 9 September 2015 at 13:55 - 14:25**

STS  
PL005

### **Crimes of the Sandman or the Bottle: A Controversy Study of the Alcohol Challenge Debate in Sleep Medicine**

*Rees, G.*  
(Newcastle University)

In 2014 the American Academy of Sleep Medicine categorically stated in its International Classification of Sleep Disorders (ICSD, the chief diagnostic manual for the discipline) that '[d]isorders of arousal should not be diagnosed in the presence of alcohol intoxication'. Such a statement was an attempt at closing, once and for all, a controversy that had been ongoing in sleep medicine since the mid-2000s regarding the Alcohol-Challenge Test. The controversy involved the question of whether a person who could not remember their actions (often violent) was more likely to have conducted them due to an underlying problem with their sleep architecture (the 'disorders of arousal' mentioned in the ICSD) or due to an alcoholic blackout. In response, the Alcohol Challenge Test was developed in Britain in order to test whether a patient, normally following a criminal-justice referral, did indeed have an underlying sleep condition that caused them to act violently in their sleep following intoxication. The medical test was vehemently challenged by sleep experts in the United States, and in this paper, drawing upon the controversy study method, I will chart the ways in which 'core-sets' and 'law sets' were developed in order to generate the consensus statement that is presently in the ICSD. In doing so, I will also explore the problems that are encountered, and the necessary boundary-work that ensues, when routine clinical work enters the legal context.

**Thursday 10 September 2015 at 10:50 - 11:20**

Inequalities  
PT006

### **Disintegration, Suicidality and Egalitarian Gender Norms**

*Reeves, A., McKee, M., Stuckler, D.*  
(University of Oxford)

Durkheim conceived of suicide as a product of social integration and regulation. Although the sociology of suicide has focused on the role of disintegration, to our knowledge the interaction between integration and regulation has yet to be empirically evaluated. In this paper we test whether more egalitarian gender norms, an important form of macro-regulation, protects men and women against suicidality during periods of economic disintegration. Using cross-national data covering 20 EU countries from the years 1991-2011,

including the recent economic crises in Europe, we first assessed the relation between economic disintegration through unemployment, a form of disintegration, with suicide. Then we evaluated potential effect modification using three measures of gender equality, the gender ratio in labour force participation, the gender pay gap, and women's representation in parliament. Consistent with our theory, we found no evidence of a significant, direct link between greater gender equality and suicide rates in either men or women. However, a greater degree of gender equality helped protect against suicidality during spells of economic disintegration. At relatively high levels of gender equality in Europe, such as those seen in Sweden and Austria, the relationship between disintegration and suicide disappeared altogether. Our findings suggest that more egalitarian forms of gender regulation may help buffer the suicidal consequences of disintegration, especially in men.

**Thursday 10 September 2015 at 15:45 - 16:15**

Experiences of Health and Illness

PX001

### **Managing Cancer: The Employment Consequences of a Cancer Diagnosis for Older Workers**

*Remnant, J., Moffatt, S., Bambra, C., Exley, C.*

*(Newcastle University)*

This narrative based study explores the employment consequences of living with cancer, from the perspective of cancer survivors aged over fifty and employers in County Durham. Cancer incidence increases with age and the proportion of people living longer after cancer is increasing. There will therefore be a growing number of older workers with a cancer diagnosis. We are also seeing a concomitant rise in the age at which people receive their state pension. There is a lack of qualitative research on the employment experiences of older working cancer survivors, and their employers. This ongoing research examines the accounts of cancer survivors and employers. This paper will focus on a sub-sample of the data from interviews with cancer survivors (n=8), line managers of an employee with a cancer diagnosis (n=6), and occupational health professionals about managing employees with cancer (n=3). Participants to this study were recruited via the Macmillan 'Working with Cancer' programme in collaboration with Durham County Council, and then from snowball sampling. The study uses a constant comparison analytical framework, with data managed in NVivo qualitative research software. This study supports and adds to the critique of neoliberal discourse as the findings highlight the personal accountability felt by cancer survivors to access information and help, and recover. So far, the employment experiences of cancer survivors post diagnosis appear to be heavily shaped by the value they perceive is attributed to them by the government through policy and benefit entitlement, society with regard to 'deservingness', their employers, and themselves.

**Wednesday 9 September 2015 at 14:30 - 15:00**

Methods

PL001

### **'Missing out'? Reflections on the Contributions, Limitations and Dynamics of Ethnographic Research Within an Evaluation of a Complex, Area-Based Initiative**

*Reynolds, J.,*

*(London School of Hygiene & Tropical Medicine)*

This paper presents reflections on the methodological potential of the idea and practice of 'missing out', drawing on experiences of conducting ethnographic research to explore conceptualisations of 'community' alongside a programme of work to evaluate the health impacts of an area-based initiative in the UK. I will reflect on the methodological and epistemological negotiations that occurred as I situated my ethnographic fieldwork alongside this evaluation research, and I will explore the constraints and opportunities presented by this approach. Specifically, I will consider the extent to which being positioned within an evaluative framing and agenda circumscribed the intent of the traditional ethnographic perspective to embed oneself in the 'field', and I will consider what might be 'missed out' (on) as a result of this. Additionally, I will examine the potential for an ethnographic lens to draw attention to what is 'missed out' from other methodological approaches adopted within the evaluation of a complex programme. Finally, I will trace possible links between 'missing out' as a methodological concern, and the findings of my research: how constructions of 'community' were negotiated via narratives of inclusion and exclusion, and how 'missing out' was experienced in relation to people, places and identities. Thus, I will consider the role that reflections on 'missing out' can play in understanding how, and for whom, a complex, area-based initiative might bring about changes to health.

## Paper Abstracts

**Friday 11 September 2015 at 10:10 - 10:40**

Patient - Professional Interaction

PL001

### **Parents, Clinicians and the Genesis of a Contested Diagnosis: The Case of Pediatric Bipolar Disorder in the United States**

*Roberts, J.*

*(London School of Economics and Political Science)*

The diagnosis of paediatric bipolar disorder (PBD) has emerged as an object of controversy in the US over the last two decades as it continues to expand despite a lack of professional consensus surrounding diagnostic criteria. At the same time there is a push among parents for greater acknowledgement and awareness of their position, as well as clinical alignment with what they see as indicative of the disorder. Interaction between these two groups, and their local systems of professional versus experiential knowledge, sheds light how a diagnosis is constructed by providing insight into how a contested disorder is conceptualized by competing knowledge systems, why certain disorders are perpetuated, and why others continue to be resisted. This paper will present findings from dialogical analyses of interviews with 10 American child psychiatrists and 18 parents of children with PBD. Using a socio-psychological framework emphasizing theories of social representations and positioning, the circular influence at play among and between these two key actors in the genesis and development of PBD as a diagnostic category will be explored. Sociological literature has made significant contributions to the medicalisation of childhood, and the construction of related diagnoses such as ADHD and Autism, however much of the literature on PBD remains in the clinical realm. As a disorder still attempting to establish itself, an exploration into the processes behind how PBD emerges and takes hold is warranted.

**Wednesday 9 September 2015 at 13:55 - 14:25**

Lifecourse

PL002

### **Men, Masculinity and Early Labour**

*Roberts, J.*

*(University of Nottingham)*

Women in the UK are advised to stay at home during 'early labour' – defined clinically as before cervical dilation of 4cm - and to only come to hospital when in 'active labour'. For women in heterosexual relationships, at a time when men's active engagement with pregnancy and birth is a matter of NHS policy and subject to cultural imperative, this may mean that their male partner is their main source of support during this time. However, 'early' labour is problematic for maternity services, women and birth partners. Although staying at home has benefits for women and services, this has been difficult to negotiate with women and their partners and the policy often puts midwives and families in conflict. Despite an established sociology of childbirth, and growing sociological interest in men's experiences during labour and birth (e.g. Dolan 2011, Miller 2011), early labour has so far been neglected by the discipline. Preliminary findings will be presented from a qualitative study drawing on both textual analyses of parenting guides depicting the role of fathers in labour, and interviews with men who were with their partner during labour and birth. The presentation will interrogate the notion of the rhetoric and the experience of the 'involved father' in the context of labour, with particular attention paid to the specificities of 'early' labour.

**Thursday 10 September 2015 at 10:50 - 11:20**

Patient - Professional Interaction

PL001

### **If the Shoe Fits: Enabling Patient-centred Podiatry Through Social Science Methodology**

*Robinson, V., Nicholls, E.*

*(University of Sheffield)*

Research from a previous ESRC funded project on footwear (2010-2013): 'If the Shoe Fits, Footwear, Identification and Transition', provided rich data on embodied attitudes to the wearing of footwear which were gathered through research methods utilising focus groups, shoe log diaries, accompanied shopping trips, and interviews, as well as engagement with shoe manufacturers. An unexpected, but very welcome level of interest in the findings were shown by public and private sector podiatrists. More specifically, the project's findings proved to have relevance for podiatrists and the difficulty they have persuading the population in general to wear healthy footwear and, in the case of foot problems, to ensure that they wear shoes that will protect vulnerable feet (see Vernon et al., 2007).

This new research is concerned with podiatrists' understanding of patients' diverse motivations for choosing to act, or not, on their expert advice as to appropriate footwear for different medical conditions, and the well-being and economic implications for this advice not being followed in practice, over a sustained period of time. The paper will discuss how the qualitative research with participants has enabled a more interactive and informed relationship, between podiatrists and their patients, with the aim of furthering the health and well being of patients and potentially saving NHS resources. The paper will also critically address how the

data from the project has produced an online toolkit, suitable for podiatrists' training, informed by a social science concept of identity and social science methodologies.

**Thursday 10 September 2015 at 09:40 - 10:10**

Lifecourse  
PL002

### **Now all it's Doing is Putting on Fat: Foetal Viability and Pregnant Embodiment in the Context of Uncertainty**

*Ross, E.*  
(University of Edinburgh)

Accounts of the foetus within the social sciences have considered cross-cultural understandings of foetal and infant personhood, and the potential for the foetus to be portrayed as a work-object in medical research. Such work has pointed to the contingent nature of the 'foetal subject' observed in US and European culture, constructed through visualising technologies, consumerism, and the private actions of women and their families. This understanding of the foetus has shaped expectations placed on women with regards their behaviours during pregnancy.

My presentation describes conceptualisations of foetal personhood articulated by women themselves. It is based on data from a qualitative longitudinal interview study, exploring fifteen women's experiences of pregnancy and the foetus throughout gestation. In a context where for many, the status of the foetus was initially viewed as uncertain, the notion of foetal 'viability' was a key milestone at which women understood themselves to be carrying a baby. Viability is a term used in neonatal medicine to denote a level of foetal growth, measured in gestational age, compatible with survival outside the womb.

I describe participants' understandings of foetal viability, a concept rarely discussed in existing literature. This provides a case through which to explore women's engagement with biomedical framings of pregnancy, and the resources drawn on in their interpretation of these discourses. Here, these included embodied experience, which played an additional role in shifting women's understandings of their pregnancy as uncertain. I therefore counter discussions of embodied experience as having become devalued through the biomedical management of pregnancy.

**Wednesday 9 September 2015 at 13:20 - 13:50**

Mental Health  
PL006

### **Mental Health Family Caregiving and Coercion in the Community**

*Rugkåsa, J.*  
(University of Oxford/Akershus University Hospital)

Family members have always been key actors in providing care for the mentally ill and with the deinstitutionalisation of mental health services this role has been accentuated. Yet there is limited sociological theorising about caregivers' position, particularly as regards adults who care for other adults. As severe mental illness often has implications for/impacts upon autonomy and self-determination, there may be prolonged periods when (legal) responsibilities for those who are unwell are shared by families and professionals. While this can lead to improved care, conflicting views between family and professionals does occur. Similarly, conflict between carers and service users is also common, often stemming from disagreement about the boundaries for legitimate influencing behaviour from family members. Drawing on two separate qualitative studies of personal experience of caregiving in the UK and an extensive review of the international literature, this presentation discusses the role of family in coercive practices in the community with focus on their personal experiences of this role. Much of this constitutes 'informal' treatment pressure, but as the role of family is usually specified in mental health legislation, experiences of their involvement in legal processes will also be considered. The analysis draws on Carol Smart's concept of Personal Life to explore how the role of family carer is simultaneously cultural, social and deeply personal. A new model will be presented incorporating three dimensions to the role of family carers: (i) their interactions with patients (ii) their interactions with service providers and (iii) their interaction with the 'State'.

**Thursday 10 September 2015 at 17:30 - 18:00**

Lifecourse—Ageing and Dementia  
PL001

### **Understanding Patients' Experience of Hip Fracture in Acute Care**

*Saletti-Cuesta, L., Tutton, L.*  
(Kadoorie Centre. Oxford University Hospitals NHS Trust)

We already know that recovering from a hip fracture is a complex and traumatic experience in which patients describe dramatic changes in relation to their body, mobility, pain management and dependency on others. Current evidence suggests that people's experiences and feelings change over time after the fall. Despite this, there is limited research examining the early phase of recovery whilst in acute care. In addition, the knowledge regarding hip fracture experience for those with memory loss is overwhelmingly told from the carer's perspective. The interaction of multiple and diverse factors into hip fracture lived experience has not been studied and an in-depth qualitative approach is necessary to gain a better understanding. This paper draws on

## Paper Abstracts

recently collected data to understand the complexity of the hip fracture experience from the patients' point of view. We undertook semi-structured interviews and participant observations whilst participants were in acute care, normally between the third day after surgery and discharge. Data was collected and analysed using a hermeneutical phenomenological perspective which was underpinned by an intersectional approach to participants' lives. This paper presents work in progress and will explore the social factors that underlie 'what having a fractured hip is like' from a patient's point of view. We will also discuss some of the methodology challenges of working with older people, some of whom have memory loss, within the context of a public space such as the acute trauma ward.

**Thursday 10 September 2015 at 14:00 - 14:30**

Health Service Delivery  
PT007

### **Decentralization of Health Care Provision: A Norwegian Example**

*Sandaunet, A. G.*  
(University of Tromsø)

This presentation reports on an intervention where supervision of seriously obese children and their families was decentralized from the specialized to primary level of health care in a Norwegian health care region. Health professionals from the pediatric department of the regional hospital and seven municipalities in the region participated. Educational activities and supervision were part of the intervention and were provided by the hospital team to public health nurses and other health professionals that were involved at the municipal level. The research presented here is based on interviews with health professionals in the hospital team and public health nurses at the municipal level, in addition to observations of summary meetings between the hospital team and the municipal level. A main finding in the material is that the public health nurses described an experience of being better able to take responsibility for this particular patient group after being part of the intervention. They also described a reduced need to refer the children and their families to the hospital – indicating that decentralization "succeeded" within the frames of this intervention. In this analysis, I explore the intervention and seek to identify elements that facilitated the implementation process. A shared view of addressing an urgent problem, an extended knowledge base at the local level, access to the specialized level and an extended network of colleagues emerge as crucial facilitators of the implementation process. In sociological terms, I suggest that the material actualizes an influence of social capital.

**Thursday 10 September 2015 at 15:45 - 16:15**

Politics of Health  
PT006

### **Dialectics, Absence and Health Interventions: An Alternative to TINA**

*Scambler, G.*  
(Surrey University)

In this paper I draw on dialectical critical realism (DCR) in general, and the concept of absence in particular, to offer a non-orthodox slant on the sociology of health and health care. After giving a précis of DCR I argue that it opens up spaces for a 'new mode of interrogation' and offer a number of illustrations of its potential to yield novel agendas for substantive enquiry.

The bulk of this contribution will be devoted to making a case for DCR in relation to: (a) explanatory sociology, and (b) the politics of health interventions. In this context, three topics, or clusters of issues, will be addressed. The first focuses on the field of health inequalities and extends some of my own published arguments. The second looks at work on eHealth, referring especially to recent Norwegian research. And the third pick up on the notion of action sociology in relation to the health field.

The overriding aim of this paper will be to show that the philosophical theory of DCR carries considerable promise across a multitude of areas within the sociology of health and health care.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Theory  
PT006

### **What is at hand? Notes on the Cosmopolitics of Illness**

*Schillmeier, M.*  
(University of Exeter)

The experience of illness alters the various ways we are used and (are) expect(ed) to do things, how we feel, perceive, act and interact with others and our environment. Bodies affected by illness are not mere bio-medical facts of a disease, but affect the personal orderings of human beings as well as their social world (cf. Canguilhem 1991). The experiences trouble the practices and relations of our embodied life, unbutton social normalcy and realise it not as naturally given, but as vulnerable to uncertainty, contingency and change (cf. Schillmeier 2011). These processes unfold the realities of the cosmopolitics of illness. Drawing on ethnographic work that is concerned with the experience of dementia, this paper argues that illness not only draws attention to the

unsettlement of embodied human life, but also offers insights into the complex and powerful practices of normalizing embodied human relations.

**Wednesday 9 September 2015 at 12:45 - 13:15**

Experiences of Health and Illness

PX001

### **Patients on Patient Safety: Reinterpretation of Patient Safety Discourse**

*Scott, J., Heavey, E., Dawson, P., Waring, J.*  
(Newcastle University)

Patients' perspectives on patient safety have long been overshadowed by medicalised discourses of 'safety science', yet patient experiences can make unique contributions to safety improvement. This paper develops an account of patients' understandings of patient safety and considers how these views impact upon patients' willingness to engage in safety activities. It analyses 20 semi-structured interviews with patients who completed a safety survey following discharge from hospital. Three conceptualisations of safety were identified, each informed by patients' thoughts about who was responsible for their safety. First, there was no strong distinction between patient safety and safety in daily life; patients had a moral responsibility for their own safety through using common sense. Second, exposure to clinicians, other patients and visitors in healthcare settings induced additional risk which should be mitigated by staff and safety equipment, with safety the responsibility of staff and/or the wider institution. Third, safety was regarded as the positive co-produced outcome of staff and patients engaging with one another; staff are expected to keep patients safe, and patients expected to follow advice and give feedback. Having different perceptions of safety appeared to impact upon patients' readiness to engage in safety activities, and suggests the need for a new patient safety discourse. If patients perceive safety as entirely their own or the system's responsibility, they may be less inclined to engage in these activities, including reporting on their own safety, whereas those who saw safety as co-produced between patients and staff were more open to engage in safety activities.

**Friday 11 September 2015 at 10:10 - 10:40**

Health Policy

PT103

### **The New Public Health System and Obesity: The Confines of 'Decision Space'**

*Segar, J.*  
(University of Manchester)

Obesity is a growing Public Health (PH) issue in both wealthy and developing economies. It is associated with premature deaths and ill health leading to pressure on services, associated economic burdens and a concomitant increase in human suffering.

Obesity can be framed as a lifestyle matter, the result of poor choices around diet and physical activity. Nudge theory (Thaler and Sunstein) offers the view that all decisions are framed by context which can be designed to enable good or bad choices. Obesity can also be viewed as the result of broader structural factors which have been dubbed 'the obesogenic environment'. These environments have a particularly large impact upon the poorest in society.

Following the Health and Social Care Act 2012, PH functions moved from the NHS into local government. This move was applauded for placing PH in a position to tackle the social determinants of health. The PHOENIX project has been focusing on this reorganisation. This has been a multi-methods project including policy reviews, national surveys and qualitative interviews with PH officers and elected members.

Bossert's work on the decentralisation of healthcare systems is a useful way to examine the new PH system's approach to obesity. Bossert uses the concept of 'decision space' to explore whether decentralisation brings an expansion of choice and opportunity at the local level. Our data illustrate a complex picture where decision space is used to help nudge locals make healthy lifestyle choices. It also shows the limits of decision space in tackling the obesogenic environment.

**Wednesday 9 September 2015 at 16:15 - 16:45**

Ethics

PT103

### **'Explaining' Versus 'Understanding': What is the Role of Qualitative Process Evaluations in Interpreting Results of Randomized Controlled Trials of Complex Interventions?**

*Sheard, L., Marsh, C.*  
(Bradford Teaching Hospitals)

It is becoming increasingly common for trials to incorporate a process evaluation (PE) alongside outcomes (trial findings) and this trend raises important questions about the nature of the total findings that can be realised. Randomised controlled trials seek to

## Paper Abstracts

determine the effect of an intervention (does it work?). The desire is often for PEs to add nuance by also asking 'where does it work, how and why?'

We designed a qualitative PE for a large RCT of a complex patient safety intervention, tested across 33 hospital wards in the North of England. The RCT found no statistically significant difference between intervention and control wards and attention soon turned to the PE to understand why this was the case.

We present an overview of our PE: how a portfolio of qualitative methods was used to gather robust data about staff interaction with intervention components (x17 wards). Wards engaged with the intervention in a myriad of ways that we classify as 'consistent', 'partial', 'upward', 'downward' and 'disengaged'. These differences may explain why it was unlikely for intervention wards to show a distinct effect – they were not 'uniformly' different to the control wards and instead a number of other factors outside of the intervention were at play.

We fail to draw deterministic conclusions about the types of settings in which the intervention is likely to work, and will discuss whether this can ever be achieved for an evaluation of an intervention which is based on very complex models of cause and effect.

**Wednesday 9 September 2015 at 13:55 - 14:25**

Ethics  
PT103

### **Medical Research Decisions: Living with Duchenne Muscular Dystrophy**

*Skyrme, S.*  
(Newcastle University)

For my ESRC funded PhD I interviewed 9 boys and young men with Duchenne muscular dystrophy (DMD), a severe, degenerative condition affecting males, and one young woman with a less severe, degenerative muscular dystrophy. Medical research is working to find effective treatments to modify DMD and this clinical research often requires the direct participation of those with DMD. My research aim was to understand, from a sociological perspective how the participants thought they might make a decision to take part in medical research, and how their sociocultural and healthcare experiences influence decisions. What became apparent was that the participants tend not to 'ponder' medical research, as most are living with increasing levels of disability. However, I developed a range of scenarios to contextualise the subject, enabling some interesting discussions of life with DMD.

The participants described how parents play a key role as carers and advisers, with this relationship being likely to influence how decisions are reached; however, the participants also valued their own agency and independence within this familial dynamic. Other interesting points were raised about the ethics of placebo in clinical trials; a contentious issue amongst those advocating for more trials on DMD. My presentation would cover these key elements, including the ethical and the familial aspects of children and young people's decision-making.

**Friday 11 September 2015 at 10:45 - 11:15**

Health Policy  
PT103

### **Exploring the Efficacy of Infant-Feeding Policy**

*Smith, J., Jomeen, J., Hayter, M., Whitfield, C.*  
(University of Hull)

**Background:** Current UK Infant-Feeding Policy (IFP) advocates exclusive breastfeeding, being premised upon the ostensible health benefits of breastfeeding for mothers and infants. Breastfeeding is often a highly emotive issue for women, eliciting debate containing polarised views.

Contemporary IFP is an example of 'evidence informed policy formation' and is emblematic of the health policy landscape. The impact of current IFP in maternity services is under researched.

**Aim:** This study explored the impact of IFP upon Women, Midwives and Heads of Midwifery services in England between 2011-2012.

**Methodology:** A qualitative design exploring the experiences and views of IFP with sixteen healthcare professionals and six women. Data were analysed using Colaizzi's existential phenomenological method.

**Findings:** Themes arose across the participant groups that enhance understanding of the impact of IFP. For Healthcare Professionals the socio-political context of health and health-care system policy is multifarious but contains identifiable spheres. Themes identified included: Being with IFP, Discourses of Self-Determination and The Emotion work of Compliance.

**For Mothers:** Infant feeding remains emotionally fraught territory. Themes identified included: Adopting a Stance, Formulating a Vision, Processing the Dialogues of Infant Feeding, Being with the Reality of Infant Feeding, Regaining Selfhood and Seeking Companions.

**Discussion and Conclusion:** Foucault's analyses of power and governmentality were used to explore the 'Art of Midwifery' vs. the 'Art of Governance'. Lack of holism and neoliberal agendas dominating current policy landscapes may be detrimental in maternity care services as they compromise decisional autonomy for women and the role of midwives as advocates for women.

**Wednesday 9 September 2015 at 12:45 - 13:50**

Pecha Kucha  
PT007

## **Turning Traditional Interaction on its Head: What Happens when Patients Teach Doctors**

*Snow, R., Lewis, E., Salisbury, H.*  
(University of Oxford)

Although patient involvement is a buzzword in service delivery, research and healthcare education, patient-driven involvement, where patients themselves decide what clinicians should learn, is still relatively rare.

This presentation will inspire by showcasing examples from, and reactions to, up to four different patient-driven projects to teach medical students and qualified doctors. Examples will be described of our experiences in educating healthcare professionals using our own bodies, leading reflections on social media, setting the curriculum in print journalism, and by animating robots. We will describe the different responses to these projects and discuss what it reveals about society's concept of the expert patient, who is allowed to impart particular kinds of information, and the differences between "patient involvement" and "patient driven".

The audience will be encouraged to think about their own and clinicians' reactions to patient teaching inspired by discourses around hierarchies of knowledge, health literacy, the presentation of professional identity and the concept of the "sanitary citizen."

**Thursday 10 September 2015 at 16:20 - 16:50**

Experiences of Health and Illness  
PX001

## **Breast-cancer-isation Explored: Social Experiences of Gynecological Cancer in a Norwegian Context**

*Solbraekke, K. N.*  
(University of Oslo)

The growing critical interest in cancer seen from the patient's point of view (Wray et al. 2007, Ehrenreich 2009, Blaxter 2009, Willig 2011, Bell 2014) and claims about breast-cancer survivorship being the golden standard for all forms of cancer in contemporary English-speaking Western cultures is the context for this paper. An interview study of Norwegian women's experiences of gynecological cancer is used to explore whether this process is taking place in a non-English-speaking Western setting. Results shows that some parts of the women's accounts resonate well with the breast-cancer-isation postulate, that is, they feel obliged to think positively and be strong. However, obligations to display heroism are not as remarkable as in English-speaking Western regions, neither is the experience of social othering by friends and colleagues. This might partly be due to strong norms of social egalitarianism marking Norwegian culture and partly due to breast-cancer-campaigns not yet defining totally Norwegians norms of cancer survivorship. At the clinic and in in relation to the public sphere though, they experience gynecological cancer to be clearly in the hinterland of breast cancer. This leads to strong senses of the bodily cite of their disease, as well as the treatment they go through followed by heavy side-effect for their health and sexuality, being tabooed. Hence, as found in relation to cancer experiences in English speaking cultures, silencing the complex human and embodied nature of cancer seem to be a profound aspect of the Norwegian cancer discourse.

**Thursday 10 September 2015 at 09:05 - 09:35**

Embodiment and Emotion  
PT103

## **Organisational Emotionality of the NHS?**

*Spiegelhalter, K.*  
(University of Sussex)

This article presents empirical research on mindfulness-based interventions (MBIs) for staff working for Sussex Partnership Foundation Trust (SPFT) to aid the theoretical development of the field of 'emotional organisations', and the emotional dimensions of organizational environments (Lewis & Simpson 2007; Sieben & Wettergren 2010).

The field of the Sociology of Emotions has highlighted evidence from both the natural (Damasio 1999; 2005) and social sciences (Barbalet 1998; Fineman 2006) that emotions are inherent to rationality and rational decision-making rather than opposed to it as traditionally perceived (Sieben & Wettergren 2010). Emotions are framed as embodied, relational, and an integral part of the rationality of an organisation, following Barbalet, who has asserted the crucial role of emotions as the 'experience of involvement', situated within social relations which can then transform them and through experiencing emotions give rise to new ones (2002). Emotions can foster transformative cooperation through building relational strengths, and potentially expanding capacities at both individual and organizational levels (Sekerka & Fredrickson 2008). It is argued that such chain reactions contribute to construct 'emotional climates' (Rivera & Paez 2007).

MBIs aim to foster embodied experience and understanding, and can be the basis for an increase in organizational emotionality (Bolton & Boyd 2003). Learning from the mindfulness teacher training run through SPFT, and the evidence collected thus far on

## Paper Abstracts

ongoing benefits for managers, staff and patients, this article focuses on the NHS more broadly in the context of the focus on staff-wellbeing and compassion within the health service.

**Wednesday 9 September 2015 at 12:45 - 13:50**

Pecha Kucha  
PT007

### **Shiatsu Practitioners: Forging a Path Through a Landscape of Practice**

*Spurr, S.*  
(The Open University)

This paper presents the findings from a doctoral study of Shiatsu as a distinct type of healthcare practice. Situated within the sociology of the professions as the wider academic context, the study focuses on Shiatsu practitioners and the process of professionalisation in relation to complementary and alternative medicine (CAM). Neo-Weberian theory is used to examine the field of CAM, highlighting its marginalisation by the medical profession. What counts as legitimate knowledge is raised as an important question in relation to the process of professionalisation and CAM.

Ethnography and narrative inquiry form the basis of the methodological approach. Concepts of 'social positioning' and 'turning points' provide important theoretical considerations of the analytic framework.

Participants' pathways through a 'landscape of practice' highlighted key tensions and turning points in relation to a trajectory of 'Getting into Shiatsu' and 'Getting out there to practise Shiatsu', particularly in respect of the status of knowledge and earning a living as a Shiatsu practitioner. These tensions are discussed in the context of professionalisation, and highlight some of the wider structural factors – for example the interface of Shiatsu with the NHS, other CAM practices as well as society in general. The issue of marginalisation provides a connection between Etienne Wenger-Trayner's concept of landscapes of practice and neo-Weberian theory in relation to CAM practices. The experiences of participants in this study are potentially relevant to other practitioners not only in other marginalised emerging professions but also practitioners in more established professions.

**Thursday 10 September 2015 at 14:00 - 14:30**

STS  
PL005

### **Bridging to Transplantation with Ventricular Assist Devices: Hobson's Choice?**

*Standing, H., Rapley, T., MacGowan, G., Exley, C.*  
(Newcastle University)

Declines in the number of donor hearts available for transplantation has led to an increase in the use of ventricular assist devices (VADs) as a bridge to transplantation (BTT). BTT is the use of VADs to support those on the waiting list for a heart transplant thought too weak to survive until a donor heart becomes available. VADs are mechanical circulatory devices that support or replace the function of a failing heart. This qualitative study used semi-structured interviews (n=20) with a range of individuals living with VADs to explore their accounts of being offered and accepting a VAD.

The process of receiving a VAD appeared to be complex and potentially fraught with emotion. In order to accept the device individuals must come to terms with the severity of their condition and their closeness to death. Choosing to have a VAD implanted involves submitting to major open-heart surgery and the integration of a piece of medical technology; a 'non-self', into the body. Life, following VAD implantation becomes intimately linked with technology and recipients must learn to become essentially dependent upon the device to live. In spite of these considerations, a key feature of respondents' experiences appeared to be the sense that there was not a choice to be made about whether to have the VAD or not; it was a Hobson's choice. They perceived that they either had the VAD or died. They had chosen not to die, and as such the VAD, for them, was the inevitable, and only, recourse.

**Wednesday 9 September 2015 at 15:05 - 15:35**

STS  
PL005

### **Mitochondrial DNA: Negotiating Status, Ethics and Practice Within an Expert Community**

*Stephens, N., Dimond, R.*  
(Cesagene Cardiff University)

In February 2015 the UK parliament passed legislation making Mitochondrial DNA transfer legal subject to Human Fertilisation and Embryology Authority licencing. The move seeks to prevent the inheritance of diseases of the mitochondrial DNA by replacing the potentially unhealthy material in one woman's egg with healthy material from a different woman's egg during a process of in vitro fertilisation. These techniques became characterised in some debates as the 'three-parent embryo'. This paper reports an analysis of positions within the scientific and policy community on this development and as such contributes to the sociological literature

around biomedicine, publics and ethical boundary work. Interviews were conducted with key actors within the UK debate to focus upon the social construction of mitochondrial DNA transfer in terms of what it is, what it is for, and why it is acceptable. A focus on these issues unpacks a constellation of associations including laboratory technique and public acceptability. In terms of technique, we explore the boundary work around three approaches: pronuclear transfer, spindle transfer and polar body transfer. In terms of acceptability, we explore how publics are imagined and enrolled into promissory accounts. In drawing these together, the paper focuses upon mitochondrial DNA transfer as a socio-technical accomplishment.

**Wednesday 9 September 2015 at 14:30 - 15:00**

Ethics  
PT103

### **Challenges in Qualitative Inquiry: Judgements of 'Ethics' and 'Quality'**

*Stevenson, F., Dimond, R., Gibson, W., Pelletier, C., Chrysikou, V., Park, S.*  
(University College London)

**Background** - Research conducted within a healthcare setting generally requires ethical approval. We argue the methodological benchmarks with which research ethics committees are generally familiar and which form the basis of assessments of quality do not fit with the iterative goals of describing social processes/mechanisms and making visible the complexities of social practices.

**Our research** - We present a case study based on the challenges of gaining ethical approval and conducting a study of junior doctors' decision-making in an Accident and Emergency department. We suggest that there is an urgent need to re-think the ways that ethical issues are conceptualised. We argue that embedded in the current paradigm is a restricted notion of 'quality', which frames how ethics are developed and worked through. Specific, pre-defined outcome measures are generally seen as the traditional marker of quality, which means that research questions that focus on processes rather than on 'outcomes' may be regarded as problematic. We consider the need for an alternative 'iterative' paradigm and outline how this offers a useful starting point for moving forward.

**Conclusions** - We conclude that a 'one size fits all' standardisation of ethical procedures and approach to ethical review acts against the production of knowledge about healthcare and dramatically restricts what can be known about the social practices and conditions of healthcare. Our central argument is that assessment of ethical implications is important, but that the current paradigm does not facilitate an adequate understanding of the very issues it aims to invigilate.

**Wednesday 9 September 2015 at 14:30 - 15:00**

Lifecourse  
PL002

### **Non Invasive Prenatal Diagnosis (NIPD) and Testing (NIPT): Encounters with a Revolutionary Reproductive Technology**

*Strange, H.*  
(Cardiff University)

This work tracks the scientific and clinical development of two new, rapidly-progressing forms of prenatal testing: non invasive prenatal diagnosis (NIPD) and non invasive prenatal testing (NIPT). NIPD/T testing has quickly transitioned from research to clinical practice: tests are entering into everyday encounters with reproductive medicine, as practiced within antenatal care, fetal medicine and medical genetics.

As a location from within which the identification and elimination of disease prior to birth has become routinised and normalised, prenatal medicine raises multiple issues of sociological interest and concern.

The diffusion of NIPD/T into routine care, combined with the rapid and on-going expansion of the technology, simultaneously raises new issues and reinvigorates old debates around the social, ethical and cultural implications of prenatal medicine. This work interrogates such issues, building upon a four-year qualitative study of NIPD/T in the UK. Interviews with scientists, clinicians and public health experts, with early adopters and confronters of NIPD/T tests, and with pregnant women encountering routine prenatal care were conducted.

Ethnographic data collection of reports, clinical and scientific publications, clinical documentation, media, and online material was also conducted.

Analysis of this rich and varied dataset revealed a number of strong themes. Experts and patients debated test accuracy, the definition of diagnosis, and the processes of categorisation and sorting they witnessed as NIPD/T progressed. Reflecting on experiences with the technology, they interrogated biopolitically significant themes such as abortion, eugenics, and the commercialisation and commodification of reproduction. These accounts will be explored and their sociological significance highlighted.

## Paper Abstracts

Wednesday 9 September 2015 at 13:55 - 14:25

Teaching  
PT007

### **The Sociology of the Medical Student and the Sociologicalisation of Medical Education**

*Stronge, P.*  
(University of Durham)

I am surely not the first sociologist to have found themselves propelled into the field of medical education as much by market forces as by inclination, yet subsequently to have become intrigued by the singular sociology the situation of today's medical student itself presents. The teaching strand for first and second year medical undergraduates I lead at Durham University places – for a social scientist – superficially very welcome emphasis on engagement with societal context, on exploring difference, on confronting the vicious health impacts of social inequalities, on understanding perspectives other than the narrowly biomedical. Our approach even strategically mobilises qualitative social-scientific methodology as a key pedagogical device. An envisaged if partly tacit goal of all this would seem to relate to the production of rounded, unbounded and grounded professionals, in a word more sociologically-oriented practitioners. These will be better suited to an imagined future, a tomorrow where in parallel such qualities in 'tomorrow's doctors' are also presumed to be increasingly socially valorised.

However, the underlying progressive narrative this implies demands further probing. In my paper, drawing on auto-ethnographic experience as well as relevant literature, I intend to explore and problematise the apparent 'sociologicalisation' of medical education my strand involves from three angles. The first involves addressin inherent constraints imposed on this project by the immediate context, questions for instance of depth, breadth and duration. Second, the persistence – even resurgence – of 'pre-medical' positivism among students. Third and finally, the political/economic meta-context of 'in the name of health'.

Thursday 10 September 2015 at 14:35 - 15:05

Pharmaceuticals  
PT103

### **Buying Medicine from the Web: Problematic Patients or Capacitated Consumers?**

*Sugiura, L.*  
(University of Southampton)

There are a plethora of websites offering medicines for sale and increasingly people are exploiting the opportunities available. As online shopping becomes more ubiquitous medicines available to buy on the Web may be perceived as just another commodity. However, the provision and purchase of pharmaceuticals are typically regulated by national or state law and the sale of medicines online has made it easy to bypass such regulatory systems. Some people are choosing to operate in a way that benefits themselves, regardless of the rules that might normally stop them, and this has been problematised as risky behaviour by those with vested interests. Risks are framed in health, financial and criminal terms by pharmaceutical companies, regulators, and healthcare professionals who seek to police such actions, regardless of whether individuals view themselves with the same harm discourse. Whilst it may be illegal or illicit in some eyes, medicines online, nevertheless provide the potential for delivering important health services at a distance and reduce costs to remote communities. Yet, some consumers are presented as deviants, problematic consumers who are acting outside of authorised channels.

Presenting the findings of a three-stage mixed-methods study, this paper explores the sale of online medicine from the perspective of those engaging in these activities. The work of Erving Goffman and theories from the sociology of deviance are utilised to contextualise how online medicine consumers manage the labelling of deviancy and stigma.

Friday 11 September 2015 at 11:55 - 12:25

Lifecourse  
PL002

### **Living with Dying: Is There a Place for Hope in End-of-life Care?**

*Taplin, S.*  
(University Campus Suffolk)

From my practice experience as a social worker in end-of-life care, I am aware that, following a diagnosis of cancer, people face the enormous challenge of a threat to their existence and may use many different and varied approaches to reduce emotional distress.

Each individual travels a unique journey, depending, among other factors, on their social circumstances and support mechanisms. The way in which any of us cope with illness depends on our past experiences, characteristics and personality.

This paper will examine how, similar to Kubler-Ross's stage theory of dying, there exists a stage theory of hoping. It can help us to understand why some people seem to 'give up', others adopt a more combative approach to their illness and others seem to accept their terminal diagnosis. An appreciation of the person's life, their previous experiences, successes and failures, their social

interconnections and networks are all significant in the context of building a therapeutic relationship and treating the 'whole person' in health and social palliative care.

Based on the model developed by Ian Gawler, an Australian cancer survivor, and case studies from end-of-life care social work practice, this paper will explore how an understanding of this theory can benefit practice with people living with cancer to foster hope and promote well-being, even at the end of life.

**Thursday 10 September 2015 at 09:05 – 09:35**

Health Care Organisations  
PT111

### **Organizing Innovation in Healthcare: The Creative Practices Of Everyday Bricoleurs**

*Taylor, R., Fuller, A., Lyle, K., Halford, S.*  
(University of Southampton)

The challenges facing the healthcare system in England and Wales are well known. Taken together, an ageing population, widening health inequalities and comparatively poor health outcomes - in a context of severe financial constraint - demand a fundamental re-think of the organization and delivery of care. Whilst successive governments have pursued various top-down structural approaches to improving the performance of the NHS, it is increasingly recognised, both in organizational change research and by government itself, that creative solutions to the intransigent problems facing the NHS may come from its employees, whose knowledge of both patients and organizations might generate 'employee driven innovation'. This paper explores the tensions between the drive for centralised control and standardisation in the organization and management of the NHS, and the possibilities for localised innovation in the delivery of services. Drawing on three ongoing ethnographic case-studies, spanning primary, secondary, and community care, we argue that innovation emerges as practices of 'bricolage' whereby clinicians mobilise piecemeal networks from NHS resources, social capital, and personal resources, to achieve remarkable and transformative outcomes. Nonetheless, it is notable that these innovations are achieved in the margins of the healthcare system, either in addition to the 'day job' or outside the immediate structures of the NHS (for example, through the third sector). In conclusion, we consider the implications of these findings about the dynamics of innovation for the challenges facing the NHS.

**Thursday 10 September 2015 at 15:45 - 16:15**

Lifecourse  
PL002

### **'Caring at the Edge': Emerging Findings from a Case Study of Co-production in Care Homes for Older People**

*Taylor, S.*  
(University of Glasgow)

Modernity has brought many benefits (e.g. technological advances, material comfort, longer life expectancy and improved health). However, it is argued that we are now experiencing 'diminishing returns' from and 'adverse effects' of a modernist worldview. Within the context of care for older people, there is an emerging critique of the tensions between 'relational care' and a post-industrialist mechanistic culture. This paper will present findings from a case-study exploring how these tensions are being experienced in 11 residential care homes for older people which are seeking to shift to a culture of care based on co-production. Co-production, in the context of care, is about 'doing with' rather than 'doing for' and it places intrinsic value on building relationships. Firstly, narratives from care staff, care home managers and senior managers will be summarised. Then, a more philosophical lens will be taken to these narratives in order to show blind spots, contradictions and insights that might be missing from traditional analysis. Finally, considerations will be discussed in terms of the applicability of the emergent findings for the public sector more generally.

**Thursday 10 September 2015 at 09:40 - 10:10**

Patient - Professional Interaction  
PL001

### **Translation of Scientific Knowledge: A Patient and Public Involvement (PPI) Experience**

*Thetford, C., Byrne, P., Wang, A., Broadbent, D., Roberts, J., Gabbay, M., Harding, S.*  
(University of Liverpool)

The involvement of PPI within all aspects of research is a requirement of most funding bodies. The translation of knowledge between clinical experts and PPI members is often cited as a barrier to involvement. The implied and tacit sub-narrative is that scientific/medical knowledge is complex with conceptual models and theories that are represented textually and linguistically as beyond the intellectual grasp of non-experts. We report our findings from a series of consultative workshops on an NIHR funded Programme Grant on changing the eye Screening and Diagnosis intervals for people with diabetes (to detect changes which indicate diabetic retinopathy). Our 'expert' anxieties before the workshops focused on our presentation of bio-technical language, heterogeneity of disease progression and treatment, and the amount of information given to our PPI representatives. In contrast to

## Paper Abstracts

our anxieties, our PPI members requested more information on contextual factors, empirical epidemiological literature, risk assessment, aetiological and physiological information on diabetic retinopathy. We argue from a Public Understanding of Science (PUS) perspective that the translation of knowledge is often represented as challenging and associated with a deficit model of PPI engagement. We use our findings to present a model of PPI involvement which captures 'expert' anxieties around scientific/medical knowledge.

This abstract presents independent research funded by the National Institute for Health Research (NIHR) under the Programme Grants for Applied Research programme (RP-PG-1210-12016). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

**Friday 11 September 2015 at 10:45 - 11:15**

Patient - Professional Interaction

PL001

### **'Hands-Off Work': How Professionals Routinise Prenatal Screening and Diagnosis for Down's Syndrome in the Clinic**

*Thomas, G.*  
(Cardiff University)

It is widely recognised that Down's syndrome Screening and Diagnosis has become a 'normal' and taken-for-granted practice in UK prenatal care, yet few have explored how this routinisation is accomplished in everyday clinical practices and interactions. Drawing on an ethnography of two hospitals, I explore how Down's syndrome Screening and Diagnosis is organised, performed, routinised and, ultimately, 'downgraded' in three ways. First, the task of Screening and Diagnosis is relegated from consultants to midwives/sonographers who act as an unwitting 'mop-up service' (Bosk 1992). Screening and Diagnosis is categorised into a hierarchy of values and, in turn, is framed as polluting the purity of the (technical) clinical space, meaning that it is reclassified as a non-technical matter. Second, professionals construct Down's syndrome Screening and Diagnosis, inside and outside of consultations, as a routine affair via both social processes (e.g. its description as a 'simple test') and cultural materials (e.g. doors remaining open during consultations). Third, professionals downgrade Screening and Diagnosis as a tedious duty which does not permit the performance of an authentic or imagined midwife/sonographer role. For professionals, Screening and Diagnosis represents 'hands-off work' which is monotonous and cannot regularly offer the rewards of more 'interesting'/demanding activities. In short, I capture how Screening and Diagnosis for Down's syndrome becomes routinised and, in effect, depersonalised, trivialised, and downgraded via both human and non-human interactions, thus (re)accomplishing certain hierarchies and identities in the clinic. I conclude by highlighting the implications of this research for the social study of patient-professional interactions, genetic Screening and Diagnosis/testing, and the politics of reproduction.

**Thursday 10 September 2015 at 08:30 - 09:00**

Citizenship

PL006

### **Temporal Landscapes in Patients' Experiences and Expectation of Recovery from Serious Illness or Injury**

*Thomas, H., Earchy, S., Slaney, J.*  
(University of Hertfordshire)

This paper addresses patients' experiences and expectations of recovery following serious illness or injury. The phrase 'getting back to normal' is often used to describe the progress or extent of recovery and carries with it social expectations that people will recover and that this will be straightforward. Narrative accounts of illness suggest that the recovery may be more complex than this phrase suggests yet surprisingly little research has examined patients' experiences of this process. In addition, there has been comparatively little research on patients' experiences of injury compared with that of illness.

The paper presents analysis from the ESRC-funded project [www.gettingbacktonormal.org.uk/](http://www.gettingbacktonormal.org.uk/). It draws on secondary analysis of 165 qualitative interviews from four datasets: three on patients' experiences of heart attack, leukaemia and intensive care (n=120) from the archive of the Health Experiences Research Group, University of Oxford; and the fourth from the UK Burden of Injury Study (n=45). All interviews followed a similar pattern from recognition of a problem, through help-seeking to treatment and its effects.

The paper is informed by sociological work on time, described by Adam (1995) as a crucial but often overlooked dimension of social life. The analysis examines the ways in which time both structures the experience of recovery and acts as a resource for the generation of meaning. Different conceptualisations of time provide a useful framework for consideration of multiple dimensions of recovery (physical, emotional, social) and the ways in which external events, such a health check, may temporarily challenge the status of recovered health.

Friday 11 September 2015 at 10:10 - 10:40

Professions  
PL006

## Reconstructing Profession and Management: Primary Care Professionals in Finland

*Timmons, S., Windrum, P., Hyytinen, K., Maatta, H., Toivonen, M.*  
(University of Nottingham)

The sociology of professions has sought to move beyond a simple dichotomy between professionalism and management. In this paper we analyse, via a study of primary health care professionals in Finland undergoing substantial organisational change, how these professionals reconstructed contemporary notions of professionalism and managerialism. The professionals studied worked for a new service provider, established by a city government, which aimed to radically change how care was provided for people with chronic illness. In this turbulent organisational environment, conventional notions of professionalism (similar to Evetts' occupational professionalism) were heavily challenged. However, the professionals reconstructed their ideas and discourses about professionalism in response to these changes, without ever adopting an avowedly managerialist position.

Data were collected via participant and non-participant observation of meetings and implementation workshops, document review, and qualitative interviews

We will examine two issues in particular. Firstly, the way in which professionals used Evidence-Based Medicine as a way of resisting certain changes imposed by the management of the organisation, as predicted by Traynor (2009). Secondly, the role of geographical space and distance in determining how the relationship between professionals, managers and organisational change played out, with some striking differences between the contexts of the centre and the periphery.

Friday 11 September 2015 at 11:55 - 12:25

Critical Public Health  
PT007

## Who is Responsible for 'Obesity Epidemic'? Study of Adolescents' Beliefs Through Playdecide Participatory Event

*Timotijevic, L., Kugelberg, S., Zolotonosa, M., Gemen, R., Acuna-Rivera, M., McBarron, K.*  
(University of Surrey)

Governments across Europe have set up policy agendas to address childhood obesity epidemic, focused on increasing individuals' ability to make a "healthy lifestyle choice" and framed with a strong emphasises upon individual responsibility for healthy eating (Mayes, 2014). Limited evidence however exists about young people's beliefs about responsibility for childhood obesity epidemic. The current research set out to explore how young people discuss responsibility for childhood obesity epidemic, utilising an innovative engagement approach: PlayDecide. A series of PlayDecide engagement exercises (<http://www.playdecide.eu/>) were organised and facilitated by science museums on the topic of childhood obesity, with young people aged 13-18 recruited through schools in 2 European countries: UK (4 groups) and Spain (6 groups) (N=83). The thematic inductive analysis shows that personal responsibility is discussed through two concepts, previously developed by Feiring (2008): causal responsibility (circumstances that caused obesity); and prospective or forward looking responsibility defined as the responsibility to make choices in line with the goal of health. Causal responsibility for obesity is seen to rest with groups and institutions that provide conditions for healthy lifestyle such as family, school and ultimately the government. Prospective responsibility is indicated in the participants' rejection of behaviour change approach and the recognition of the practical constraints of achieving healthy lifestyle choice. They espouse diverse sets of values (over and above that of health) as key to the concept of "good life", which may not be in line with the values of healthy lifestyle and therefore lead the young to make knowingly risky choices.

Thursday 10 September 2015 at 10:15 - 10:45

Theory  
PT007

## An Apple (Watch) a Day Keeps the Doctor Away? Re-paternalising Health-Care By Delegation to Health Gadgets

*Tjora, A.,*  
(Norwegian University of Science and Technology)

With the now almost-total diffusion of smart phones and strong beliefs in the smart watch market accordingly, health apps (m-health) are becoming a significant field of utilisation of these technologies. Combining promises of big-data research opportunities and a chance for responsible consumers to better monitor their own health individually, the development is suggested by companies such as Apple and IBM to transform health-care forever. Introducing 'ResearchKit', Apple develops an open source software framework for developers to create health apps more easily. IBM Watson Health is concerned with devices that will 'capture enormous amounts of information about us, as humans' for the sake of medical breakthroughs. The combination of private consumer-oriented gadgets/apps and users taking the role of citizens being monitored by a (diffuse) system of big-data health-care companies, invites to a sociological discussion in which (material) affordances of technologies must be taken into account. Drawing

## Paper Abstracts

mainly on perspectives from the sociology of technologies, I suggest in the paper that the immediate sexiness of personal gadgets may increase the number of worried-well citizens and lead to larger social health inequalities. The strong privatized market of monitoring apps and services should be studied sociologically in more detail, by applying both theories of uses of technologies and on medicalization processes.

**Friday 11 September 2015 at 10:10 - 10:40**

Gender

PX001

### **A Visual Participative Inquiry into Young Women's Experiences of Cigarette Smoking: An Intersectional Approach**

*Triandafilidis, Z.*

*(University of Western Sydney)*

During the second half of the twentieth century in a number of Western countries, rates between men and women's smoking began to converge. In Australia, young women are taking up smoking earlier, and at times smoking more heavily than their male counterparts (Australian Institute of Health and Welfare, 2014). Although researchers have begun to explore the relationship between gender and smoking, we are yet to fully understand the way in which women's experiences of smoking are shaped by multiple, mutually constitutive identities. I will present preliminary findings from my doctoral research, which explores the way in which young women construct and experience smoking, anti-smoking campaigns and policies, and smoking-related stigma. I will be drawing on interviews conducted with 27 young women from a variety of social class, cultural and sexual identity backgrounds, with 18 of those women going on to take part in a photography activity and a follow-up interview. Using feminist Foucauldian discourse analysis and post-structural theory, I will unpack some of the key discourses, positionings and subjectivities that these women negotiated and adopted. Consideration will be given to the impact of these discursive constructions, and the implications this has for future tobacco control policy and practice.

**Thursday 10 September 2015 at 08:30 - 09:00**

Patient - Professional Interaction

PL001

### **The Video-gaze in Psychiatric Emergency Care**

*Trondsen, M., Tjora, A.*

*(University Hospital of North Norway)*

To solve the problem of limited availability of psychiatrists in rural areas, the University Hospital of North Norway established in 2011 a decentralised on-call system for psychiatric emergencies. Psychiatrists are accessible by telephone and videoconference 24/7, through (local) consultations with healthcare staff (typically nurses) and patients at three regional centres. With limited experiences and research on use of VC for psychiatric emergency consultations with patients, we have performed an explorative, qualitative study of this first Norwegian videoconferencing psychiatric emergency service in operation. Based on 29 interviews with patients, psychiatrists in the on-call system and healthcare staff at the regional centres, we have studied how VC consultations matter for patients, professional practice and cooperation in psychiatric emergency care. We found that VC consultations, during which patients were present, were chosen for complex and challenging situations when there were difficulties assessing the patient, difficulties deciding the level of treatment, and differing opinions regarding treatment or admission. Access to the VC system also increased the participants' experience of confidence in challenging psychiatric emergencies, by strengthening patient involvement, reducing uncertainty, sharing responsibility for decisions, and by functioning as a safety net even when VC was not used. Based on empirical research of this new video-conferenced service established in psychiatric emergency care, we address in this paper the negotiation between patient, healthcare staff (nurses) and psychiatrist. Within an interpretative sociological approach, we discuss how technologically mediated patient/provider(s) encounters may afford changes in the social dynamic of established roles within mental health care provision.

**Friday 11 September 2015 at 09:35 - 10:05**

Gender

PX001

### **'Between Ill and Not-ill': Exploring Women's Experiences after Treatment for DCIS**

*Trusson, D.,*

*(University of Nottingham)*

In this paper I will present preliminary findings from an ongoing study of women who have been treated for DCIS. DCIS (ductal carcinoma in situ) refers to non-invasive calcium deposits in the milk ducts of breasts which may or may not become cancerous. At the present time there is no way of knowing whether cancer will develop. Consequently, DCIS is treated in the same way as cancer, i.e. surgery to remove affected cells (lumpectomy) or the entire breast (mastectomy).

Blaxter (2010) highlights how diagnostic tests are increasingly able to identify potential diseases but in doing so create a dilemma of risks of acting and not-acting. Do women opt for surgery and live with the consequences? Or live with the knowledge that breast cancer may develop?

The women who took part in this study were interviewed after the initial shock of diagnosis and treatment were over. This presented an opportunity to explore complex emotions regarding the decisions they made, including changes to their body which could not be wholly justified as life-saving; but only potentially so.

The aim of the study is to increase our understanding of this condition which falls within what Blaxter (2010:132) calls the 'boundaries between ill and not-ill', in order to provide better information and support for women during and after treatment for DCIS..

**Thursday 10 September 2015 at 15:10 - 15:40**

Citizenship  
PL006

### **(In)hospitable Hospital(Ity): Hospital Visitors' Experiences of Liminality**

*Underwood, J.*  
(The Open University)

The central question posed by my phd is, 'What are the experiences of adult visitors to acute, NHS medical and surgical wards in England?' The more commonly researched areas of hospital-orientated inquiry often involve nurse and/or patients' experiences of specialist services (for example, intensive care, paediatrics or maternity). My focus is on hospital visitors to more general wards. I therefore supplement medical sociological knowledge by investigating how people experience the illnesses of hospitalised significant others.

Drawing on my empirical research, this paper demonstrates how features of liminality are manifest in hospital visiting. Everyday roles, identities, routines and accepted social customs are superseded by new demands, practicalities, uncertainties, anxieties and, often, forthcoming transitions in lifestyle, kinship group dynamics or roles.

I explore the value of liminality as an analytic lens through which to understand the experiences of hospital visiting and how hospital (in)hospitality features in those experiences. Participants' descriptions also cohere with van Manen's (1997) proposed four overlapping 'existentials' for understanding experiences: spatiality; corporeality; relationally; and temporality. My data demonstrates the liminal experience of segregation from the everyday and getting lost in vast hospitals (spatiality). Participants describe the physical challenges of liminality in 'the battle for chairs' upon which to sit (corporeality). Liminal 'invisibility' and loss of status is demonstrated in interactions with hospital staff (relationality). Time pressures are caused by the liminal experience of being "betwixt and between" tasks outside hospital and visiting restrictions inside hospital (temporality).

**Thursday 10 September 2015 at 09:40 - 10:10**

Theory  
PT007

### **Diagnostic Mysteries as Products of Medical Specialisation: The Case of Chronic Fatigue Syndrome**

*Ward, C.*  
(University of Nottingham)

Chronic fatigue syndrome or 'ME' (CFS/ME) is represented as a quintessentially mysterious illness in media such as the internet and in mainstream medical discourse. I argue that modern professional structures have been fundamental to the production of medical non-knowledge about CFS/ME. The mystery of CFS/ME is based on the assumption of a fundamentally physical disorder. However, no organ system is unequivocally implicated and the progressive specialisation of medicine and paediatrics, and the subspecialisation of neurology, together with the increasingly biological orientation of modern psychiatry, leaves CFS/ME and kindred 'medically unexplained' disorders without an appropriate professional 'jurisdiction' [1].

What appears to be a gap in scientific knowledge about a diagnosis such as CFS/ME can be conceptualised as the inability of the contemporary medical 'cosmology' (in Jewson's sense[2]) to accommodate an inherently ambiguous set of symptoms and circumstances. Neurasthenia, a nineteenth century category resembling CFS/ME, was strongly associated with the specialty of neurology. Its credibility in Britain and the U.S. declined sharply once neurology became more closely linked with neuroscience because the diagnosis could not be made within neurology's newly defined boundaries. What appears today to be unknown about CFS/ME can be seen as the converse of the knowledge claims of current medical and psychiatric specialties.

1. Abbott, A. (1988) *The system of professions*. University of Chicago Press

2. Jewson, N.D. (1976/2009) The disappearance of the sick-man from medical cosmology, 1770–1870. *Int J Epidemiology*, 38:622–33

## Paper Abstracts

**Thursday 10 September 2015 at 11:25 - 11:55**

Healthcare Organisations  
PT111

### **Understanding the NHS Diaspora: How Service Privatisation Impacts Upon Service Cultures**

*Waring, J,*  
(University of Nottingham)

In the wake of the global financial crisis, public policies increasingly look to transfer public provision of services to the ownership and management of the private or social enterprise sectors. In England, there has been systematic transfer and privatisation of public healthcare services to private sector provision; albeit still delivered under the NHS umbrella. This process has recently been interpreted as illustrating a 'public sector diaspora' to explain how cultural boundaries and affiliations are transformed through the processes of migration and re-settlement. This paper presents a novel theoretical framework of the 'public sector diaspora' and develops an ethnographic account of the transfer of doctors, nurses, clinical practitioners and healthcare assistance from a public NHS hospital to a private sector care provider. It shows how each group experienced distinct forms of migration, e.g. transfer being forced or voluntary; and also different experiences of resettlement, e.g. being welcomed or marginalised by private managers. Through exploring these divergent experiences the paper shows how inequalities in professional status, cohesion and solidarity influence how public sector workers experience and cope with processes of privatisation and the public sector diaspora. It also suggests that cultural change and blurring might occur less at the level of public-private sector, and more in terms of professional-business cultures.

**Thursday 10 September 2015 at 08:30 - 09:00**

Healthcare Organisations  
PT111

### **Transformational Change and 'Sensemaking': Examining the Integrated Care Programme for Older People**

*Warwick-Giles, L., Checkland, K.*  
(University of Manchester)

Large system change and integrated care has become an important part of the English Government's espoused policy surrounding NHS reform. This study explored large system transformation in the North of England, focusing on an Integrated Care Programme for older people. The programme affects multiple organisations and care providers. Qualitative research methods were used to explore how four different health and social care organisations were working together to implement a local integrated care programme. Weick's (1995) concept of sensemaking was used as a framework to examine the influences on partnership working, helping us examine assumptions about observed behaviours. Sensemaking has been used in the past to examine individual organisations in isolation. This paper aims to discuss how sensemaking can be used to explore how local organisations have made sense of national policy and implemented it locally. Successful joint working is based on historical working and relationships which have enabled organisational leadership and trust to be formed. A collective identity provides all organisations with an opportunity to develop a vision that is inclusive of their needs and expectations. Large scale transformation is complex and influenced by numerous local factors. These early findings highlight what factors can be seen to enable or inhibit local transformational change. This is an important contribution as actors and organisations within the health system, wrestle with the concept of integration and seek to understand whether and how far models can be transferred beyond a local context.

**Wednesday 9 September 2015 at 15:05 - 15:35**

Theory  
PT006

### **Locating Ludwick Fleck's Sociology of Medical Knowledge in the Sociology of Knowledge**

*White, K.*  
(Australian National University)

Many commentators - both in favour of and critical of Ludwick Fleck's *The Genesis and Development of a Scientific Fact* - have wondered at how he developed his sociology of medical knowledge. It is the case that his bibliography has scant references to sociologists of knowledge though he does mention Durkheim. In this paper I follow a lead given by Fleck; that in any period thought is directed by a thought collective of which the individual practitioner may have no knowledge of but still be shaped by. In the light of this argument Fleck's work can be seen as part of the sociology of knowledge of the 1930s: the work of Bachelard and Canguilhem in France; Mannheim in Germany; and C.Wright Mills and Merton in the United States. In the light of this thought collective Fleck's insights and developments of the sociology of medical knowledge are part of a wider stream of thought and his development less puzzling to understand.

**Friday 11 September 2015 at 09:35 - 10:05**

Health Policy  
PT103

### **Health Inequalities, New Public Health and Area-Based Initiatives: Redressing Ecological Disparities or Placing Blame?**

*Williams, O.*  
(University of Abertay Dundee)

Historically, public health has looked towards social and environmental explanations for the occurrence of illness and disease but increasingly new public health shifts attention to how individuals 'choose' to behave. Despite the current trend towards moral individualism, area-based initiatives (ABIs) have been popularly used by neoliberal governments to address social and ecological inequalities. In market-driven societies there is a longstanding 'inverse care law': health resources tend to be less readily available to those most in need. By highlighting the significance of structural inequalities, ABIs appear to acknowledge the problematic nature of approaching social issues as matters of individual moral responsibility alone. However, they also continue to draw heavily on the discourse of individualism which readily blames the victim.

ABIs are particularly susceptible to the wider health policy trend known as 'lifestyle drift': whereby policies aimed at addressing structural inequalities tend, over time, to adopt a behavioural approach. This paper draws from data collected during sixteen months of ethnography, involving observation, interviews with staff and participants and analysis of documents, in a deprived English neighbourhood where ABIs have promoted active-lifestyles and significantly increased local physical activity opportunities. The analysis shows that over time the relevance of initially identified barriers to participation experienced by local residents was largely ignored and institutional responsibility became contested. These findings inform an evaluation of the strategy of delivering ABIs in a market-driven, neoliberal society. Conclusions are drawn as to how research-based interventions could increase the robustness of future policies aiming to address health inequalities.

**Wednesday 9 September 2015 at 13:55 - 14:25**

Experiences of Health and Illness  
PX001

### **Using Bourdieu to Understand the Dynamics of Choice in Health Care**

*Willis, K., Collyer, F., Franklin, M., Lewis, S., Calnan, M., Gabe, J.*  
(Australian Catholic University)

People are increasingly expected to make a choice between public and private healthcare services in Western countries. These expectations range from whether to self-finance healthcare by taking out private health insurance, to the choice of private or public provider of health services. However their capacity to choose between services is assumed, rather than problematised in the policy and health services sectors. In this paper, we report on a three year study of the way people in Australia navigate the healthcare system, examining how choices are structured, perceived and enacted in particular social contexts. Bourdieu's concepts of capital, habitus and field are employed to capture the dynamics shaping the actions of individuals as they encounter the healthcare maze. Drawing on qualitative interviews with 74 participants we report on the choices they value and the choices they make. We find that while the choice to use private services is highly valued by some segments of the community, for others, 'choice' is neither relevant nor available. In a healthcare field where there is a public rhetoric about the value, and necessity, of choice, there is a differential capacity to make and enact choices in healthcare. We demonstrate that choices are structured according to differential access to economic and symbolic capital, and that this structuring is a dynamic process..

**Thursday 10 September 2015 at 16:55 - 17:25**

Health Policy  
PT111

### **The Role of interpreters in Shared Decision Making Consultations: A Discourse Analysis Approach**

*Wood, F., Phillips, K., Edwards, A., Elwyn, G.*  
(Cardiff University)

**Aim:** - Interpreters are necessary in consultations when patients and clinicians do not share a common language. They reduce errors, improve quality of care and outcomes, and increase patient satisfaction. However, consultations involving interpreters are complex. The interpreter is expected to be a patient advocate, act as a professional, and bridge cultural differences. There is an increasing move to shared decision making (SDM) within consultations, enabling clinicians and patients to reach a treatment choice together. Our research aims to explore how SDM is achieved in consultations using an interpreter.

**Method:** - Discourse analysis was undertaken on three consultations involving clinician, patient and interpreter. Consultations were from a musculoskeletal clinic where management of knee osteoarthritis was discussed with use of a decision aid to facilitate SDM. An independent translator transcribed languages spoken into English to allow in-depth analysis.

**Results:** - The roles of the interpreter as advocate, professional and cultural mediator were apparent. Examples from the consultations illustrate areas where difficulties arise in interpreted-consultations. The decision aid appeared another hurdle within

## Paper Abstracts

the consultation. Clinicians struggled to give clear instructions on the tool to interpreters, and interpreters did not translate the reasons for using the tool to patients.

Discussion: - Shared decision making is important in managing chronic conditions. However, in consultations where interpreters are used this is difficult to achieve. Improvements in discussion of decision aids may improve care in future. Clearer understanding on the parts of clinician, interpreter and patient are needed before shared decision making is possible.

**Wednesday 9 September 2015 at 14:30 - 15:00**

Experiences of Health and Illness

PX001

### **A Place to be Well: An Ethnographic Study of Health and Wellbeing at a Chinese Community Centre in the North of England**

*Wood, N., Sanders, C., Segar, J.*  
(University of Manchester)

This paper uses the notion of therapeutic community to explore wellbeing amongst a group of first generation Chinese migrants at a Chinese community centre in the north of England. Drawing from medical geography, the term 'therapeutic community' encompasses both the physicality and social dynamics of particular places in order to consider how place contributes to (or detracts from) the health of those within it.

The Chinese community centre is central to this research project, as an important place in the lives of its members, and as a research space or 'field'. This paper explores the ways in which the centre functions as a place where practices of wellbeing are enacted and maintained. The physical characteristics and day-to-day rhythm of life at the centre are considered, alongside ideas about identity, belonging and generational change, as expressed in conversations and formal interviews about family, migration and health.

The findings presented here are based on an ethnographic study carried out over 10 months. In addition to participant observation, 19 formal interviews have been conducted with members of the centre, the majority in English, and several in Cantonese using an interpreter.

The centre is the site of a therapeutic community where members enact their sense of identity and belonging through a range of communal activities. Occupying a place between life as it was (prior to migration) and life as it is now, the centre is a space where difficulties including illness can be managed and mitigated: a space in which people can be well.

**Wednesday 9 September 2015 at 15:40 - 16:10**

Health Care Organisations

PT111

### **Exploring the Boundaries: A Space and Place for Young People in the Hospital Setting**

*Wood, V., Farre, A., Parr, J., Reape, D., McDonagh, J., Rapley, T.*  
(Newcastle University, Institute of Health & Society)

Child and adult hospital services are often very distinct physical, social and organisational environments, orientated towards the provision of different types of facilities in which there are distinct ways of working. 'Young people' are an ambiguous category of patient whose needs may clash with the more formalised organisational structures that are usually employed when dealing with the category of 'Child' or 'Adult' patient. In this paper we focus on where the boundaries between child and adult services lie, both formally and informally, and how organisations manage the provision of appropriate healthcare for young people. We examine the tensions that exist at the intersections of these services and how, as a result, the space and place provided for young people may not be seen as a priority by some healthcare professionals. We will present research from a qualitative ethnographic study on Developmentally Appropriate Healthcare involving 65 interviews and over 1600 hours of time spent in the field holding informal conversations and conducting observations with NHS managers, clinicians and other healthcare professionals, taking place across three different hospitals in England (a District General Hospital, tertiary Children's Hospital and a tertiary Adult Hospital).

**Thursday 10 September 2015 at 14:00 - 14:30**

Professions

PT111

### **The Conditions and Properties of Health Professional Boundaries in Intensive Care**

*Xyrichis, A., Lowton, K., Rafferty, A. M.*  
(King's College London)

This paper reports an ethnographic study which examined health professional boundaries within three intensive care units (ICUs) in England in order to draw out the associated interplay of context-specific factors and social processes through which ICU clinicians organised and delivered life-saving care to critically ill patients. The research was conducted against a backdrop of international

political and public pressure for healthcare systems to deliver safe, quality and efficient healthcare. Like in many Western health systems, for the English Department of Health key to containing these challenges was a reconfiguration of responsibilities for ICU clinicians in order to encourage greater inter-professional work and a joined-up service provision under the guise of workforce modernisation.

Through the analysis of health professional interaction and discourse we examine the properties and conditions under which professional jurisdiction (Abbott, 1988) was negotiated and accomplished in day-to-day practice. We discuss how staff seniority influenced the nature of professional interaction and how professional boundaries were reproduced and reconfigured under conditions of routine and emergency work. In particular, we show that modernisation policy was diffused at the level of day-to-day practice and that professional boundaries were neither rigid nor infinitely negotiable but were dynamically shaped by the conditions and properties of interaction.

We conclude that in ICU, urgency and seniority have a part to play in shaping professional boundaries at the level of day-to-day practice. These findings should be taken into account by policy makers in the development of more refined and resilient ways of organising healthcare work.

**Thursday 10 September 2015 at 09:40 - 10:10**  
Experiences of Health and Illness  
PX001

### **Disease, Illness and Sickness: Three Dimensions of Illness Experiences in the Cases of Rare Disease Patients.**

*Yamanaka, H., Nojima, N.*  
(Osaka University)

Since 2013 we have been interviewing people with rare diseases about their experience of medicine, illness and social reaction to their sufferings. From 35 interviews with rare disease patients we identified some specific problems they encounter because of the rareness of their diseases. The first problem they face is the emptiness of the medical diagnosis. For the rare disease patients diagnosis has a symbolic meaning but has no substantial meaning in terms of treatment or prognosis. Some have never visited the hospital after they received their diagnosis as no effective treatment exists. The second problem is the difficulties in communicating their problems to others including medical professionals due to the lack of common language accounting for their sufferings. The social status of illness plays a significant role in this phase. The third problem is the relationship between diagnosis and patients' identity. For many of rare disease patients not getting a diagnosis but getting to know the other patients with the same diagnosis brings a significant impact on their identity transformation. The diagnosis itself is just a starting point or a clue from which they start exploring who they are. Patients remain in an unstable condition until they get to know the other patients. This causes a lot of sufferings to the patients. All of these problems indicate that the illness as is experienced by the patients need not only to be biomedicalized into disease but also to be socialized into sickness to obtain their proper positions of 'sick' persons.

# Foundation for the Sociology of Health and Illness

## Book Prize 2015



The FSHI book prize of £1,000 is awarded annually each September to the author(s) or editors(s) of the book making the most significant contribution to the sub-discipline of medical sociology/sociology of health and illness, and having been published over the three years preceding January 1 of the year in which the award is made.

We are very grateful to the external judges who joined members of the committee in the difficult task of judging the diverse selection of interesting books nominated this year. We thank Dr Donna Bramwell and Anika Baddeley as well as Professor Joan Busfield who joined the 2015 panel at the short-listing stage.

We are also reliant on members of the community nominating books. Please consider making a nomination for the next year if you have read something that excites or engages you! Thanks you to all of those who took the time to make a nomination this year.

You can see this year's short list on the next page, and read more on our webpage: <http://www.britsoc.co.uk/medical-sociology/foundation-for-the-sociology-of-health-and-illness-book-prize.aspx>

The 2015 prize winner will be announced at the conference dinner on Thursday, 10 September at the Galleria Restaurant, Roger Kirk Centre, University of York.