

# PAPER ABSTRACTS

Listed in alphabetical order by first author

**Thursday 12 September 2013**

**10:15 - 10:45**

Health Policy

Derwent Room 104

*Abeyasinghe, S.*

*London School of Hygiene and Tropical Medicine*

## **Evidence-informed Health Policy: Investigating how 'Evidence' is Framed and Applied within Public Health Institutions**

As a result of contemporary discourses and models of good governance, which emphasise objective and transparent decision-making, the idea of 'evidence-informed policy' has come to the forefront of discussions of the policymaking process. Recently, many areas of public policy have begun to embrace this idea. This has led policy-makers to look to the evidence-based medicine (EBM) movement for guidance. In part, due to the easy analogy with EBM, the application of notions of evidence-informed policy has been most pronounced within the field of public health. This paper is drawn from the London School of Hygiene and Tropical Medicine's ongoing project on Getting Research Into Practice (GRIP-Health). This project aims to both theoretically address the idea of 'evidence-based' health policy (through, for example, interrogating constructions, mobilisations, and applications of the concept of 'evidence') and to optimise the use of research evidence within political decision-making (through identifying practices and processes which tend to maximise the consideration of research by policy-makers). This paper articulates the present conceptual and methodological frameworks of the GRIP-Health project, and explores ways in which the tensions between the theoretical and normative roles of the project might be reconciled.

**Thursday 12 September 2013**

**09:40 - 10:10**

Pharmaceuticals

Derwent Room 002

*Abraham, J., Davis, C.*

*King's College London*

## **The Politics of Drug Safety**

The paper examines how the regulation of pharmaceutical safety has changed over time in the UK and the US since 1971 when pharmaceutical regulation was first introduced in the UK. The methodology is spatially comparative between the UK and the US and temporally comparative. Drawing on research from two ESRC-funded projects, a quantitative analysis of pharmaceuticals withdrawn from the market for safety reasons is presented, with particular reference to comparison of the periods 1971-1992 and 1993-2008. It is found that there are marked shifts in the comparative numbers and rates of drugs withdrawn over time between the two countries. Specifically, many more drugs have been withdrawn in the US in the later period. Using both qualitative and quantitative methods, social scientific explanations for these changes are then sought, which bear directly on the politics of pharmaceutical regulation. A number of hypotheses are systematically explored, such as: US regulators have become less tolerant of post-market drug risks; they are learning more from safety problems in Europe; there is less paternalistic regulatory culture in the US than UK; drug review times have been accelerated since 1992 causing approval of more unsafe drugs; and/or changes in broader institutional and political culture of US regulators has produced more permissive regulation regarding safety evaluation. The paper concludes by assessing the validity of these possible explanatory hypotheses.

**Thursday 12 September 2013**

**14:00 - 15:40**

MedSoc Committee Symposium

Derwent Room 028

*Akehurst, A. M.*

*University of York*

## **'Not the Idea of a Prison': Lunatic Asylum Architecture as Therapeutic Environment at the Early Modern York Retreat**

Between 1660 and 1820 European hospitals and asylums evolved from religious foundations - to increasingly secular, specialized, purpose-built machines for cure. Put crudely, responding to the late-seventeenth-century scientific revolution, at a pace determined by the specific religio-political climate, the altar was replaced by the operating table; the celebrant by the surgeon; and the architectural design reflected faith in science rather than faith in God. Foucault construed early modern hospitals as agents

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of social control and vectors by which the State intervened in private life through the imposition of a normalized health state. Recent research minutely anatomizes architectural innovation and its relation to those who produced and consumed it, extending Foucault's profound, if pessimistic, insights. Archival research into 2 famous York lunatic asylums illustrates the forces acting to generate innovations in early modern asylum design, and the mechanisms by which this architecture became normalized in society. The 'elegant and expensive' York Lunatic Asylum (1777) was criticized as an ostentatious waste of public money and transformed into a metaphor for a discredited political, cultural and imperial hegemony. The York Asylum has become the defining negative Other against which the radical, compassionate Quaker York Retreat (1792) is measured. Tuke's 1813 comprehensive illustrated account of the Retreat's establishment and therapeutic regime constructed it as a model and positioned Tuke as an international authority on enlightened asylum design. But Tuke's account has dominated the historiography and skewed Foucault's history. This paper shows the Retreat's innovative design emerged from a radically alternative intellectual context and cultural praxis.

**Wednesday 11 September 2013**

**15:40 - 16:10**

Professions

Derwent Room 036

*Albert, M., Kuper, A., Whyte, S.*

*University of Toronto*

### **Making Social Research on Health Legitimate: Social Scientists' and Humanities Scholars' Struggles for Legitimacy in Faculties of Medicine**

Funding agencies and research institutions in Canada and internationally have recently been restructured to promote the intensification of interdisciplinary research. These policies encourage the formation of teams, centres, networks and even whole domains in which intellectual communities seek to combine diverse methodological approaches. Such communities, organized around an explicit interdisciplinary ethos, have created many opportunities for social scientists and humanities scholars (SS&HS) within medical research. However, these opportunities come with accountabilities that may shift these scholars' knowledge production practices and legitimization strategies. SS&HS often become accountable to the evaluative mechanisms (e.g., promotion committees, performance reviews) of medical schools. Understanding the effects of the medical research culture on the academic practices of SS&HS is therefore a pressing priority. Our research project addresses the following two questions: How does working within the context of a faculty of medicine affect the knowledge production and dissemination practices of SS&HS? How do SS&HS manage (or fail) to gain academic legitimacy in that context? Thirty semi-structured interviews with SS&HS working in 11 faculties of medicine across Canada were conducted. Our findings suggest that most SS&HS see themselves as misfits or outsiders in their work environments. Most SS&HS find it challenging to gain legitimacy as the reward system has been designed by and for biomedical scientists. Many thus expressed concerns that trying to advance their careers as medical sociologists or medical humanists within this system structurally confines them in a position of inferiority and negatively impacts on the development of a social understanding of health-related issues.

**Thursday 12 September 2013**

**09:40 - 10:10**

Professions

Derwent Room 036

*Allan, H. T., Ball, E., Evans, K., Horton, K., Johnson, M., Magnusson, C.* *University of York*

### **Messy Learning or Incompetence? The Experiences of Newly Qualified Nurses**

Drawing draw on empirical data from the AaRK (Academic Knowledge and Recontextualising Knowledge) project, we explore how nurses integrate theoretical and practical knowledge. The idea of re-contextualisation has been developed by Evans et al (Evans, Guile et al. 2010) using an approach that concentrates on different forms of knowledge and the ways in which these are contextualised and 're-contextualised' in movements between different sites of learning. Using ethnographic case study methodology (Burawoy 1998) we have collected participant observation data (N=54), undertaken interviews with newly qualified nurses (N=28), healthcare assistants (N=10) and ward managers (N=10) across three hospital sites in England.

In this paper we explore how the transitional state of learning to be a newly qualified nurse may effect how care is delivered in general medical and surgical wards. We explore ideas around threshold concepts developed by Meyer and Land (2010) and in particular transition and liminality (Allan 2009), to understand how patient care may be delivered more or less successfully depending on how confident and competent newly qualified are in this transitional phase of their professional lives. We argue that understanding the transition from student to newly qualified nurse through the concepts of liminality and transition would require acknowledging that such periods where there is intense learning are often

messy (Cousins 2007). Of course this has implications for patient experience. This may be difficult following the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013; so-called Francis Report).

**Friday 13 September 2013**

**11:55 - 12:25**

Health Service Delivery

Derwent Room 104

*Allen, D.*

*Cardiff University*

**Redistributing Articulation Work: Business Process Improvement Methods and the Limits of Delegation**

This paper examines Patient Status at a Glance White Boards (PSAGWB) in the work of hospital nurses as one example of the introduction of Business Process Improvement Methods in healthcare. PSAGWB have been introduced widely in the NHS as part of the NHS Institute of Innovation and Improvement Productive Ward series. Drawing on 28 qualitative case studies of the articulation work (Strauss 1985) of adult nurses working in clinically-focused roles and theories of technology-in-practice, the analysis considers first, how far the coordination functions of human actors (i.e. nurses) can be 'delegated' to non-human actors (i.e. white boards) and second, the activities white boards 'prescribe' for nurses. In so doing, it seeks to contribute to current understanding of the effectiveness of different elements of business process improvement methodologies in healthcare contexts and their wider system effects, as well as underlining the importance of a thorough understanding of the work processes these technologies seek to transform if they are to change practice in the direction desired.

**Wednesday 11 September 2013**

**13:20 - 13:50**

Embodiment and Emotion

Derwent Room 049

*Amini, E.*

*St Aidens College*

**Embodiment, Sexuality & Agency: Exploring the Role of Embodiment in Sexuality of Iranian Menopausal Women**

Populations across the world are ageing rapidly. Although the menopause is considered as a sign of being old for women, most of the women who become menopausal are younger than 60. Another issue that merits consideration is that sexuality and sexual desire are accounted as an endowment for young and male people to enjoy, so elderly women are simply excluded from this list. Presenting this standpoint, this paper considers the sexuality of menopausal women in a sociocultural context, which has been effected by hegemonic masculinity. The research reported here considers the inter-relation of body, culture, and social structure as reflexive action rather than determined action which is singly formed by nature or structure. This research has been done in the context of a broader debate which explores the embodiment and agency in sexuality of Iranian menopausal women.

In this qualitative research, samples have been chosen from Iranian menopausal women and rich data elicited through the use of focus groups and individual interviews. On the basis of this research, the process of hegemonic masculinity was found to be the pivotal factor influencing the lives of Iranian menopausal women. These women believe that expressing sexual desire puts them in an inferior position. So, Women embody the gender norms in their sexuality, and deliberately ignore their desires in sexual relationships. Moreover, the relationship between body shape and sexual activity can clearly be seen. Thus, it can be concluded that hegemonic masculinity defines the sexuality of Iranian menopausal women.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Politics of Health

Derwent Room 037

*Andrews, N., Greenfield, S., Drever, W., Redwood, S.*

*University of Birmingham*

**Tuned In: Using Talk Radio as Site for Health Research**

Traditionally within medical research, African Caribbean communities and other minority ethnic groups are seldom heard due to their underrepresentation as participants in both clinical and qualitative investigations. Therefore it is important for health research to develop dynamic approaches that encourage involvement so that knowledge about these communities can be incorporated into developing and enhancing health service provision. This presentation will be based on an on-going

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medical sociology research project seeks to explore cultural narratives of embodiment, health and wellbeing within African Caribbean communities with a particular focus on female body shape and size.

As a subjugated group within society, African Caribbean women have developed alternative sites of knowledge affirmation which exist outside of the mainstream, thus creating alternative discourses of understandings of health and wellbeing. This research has identified liminal spaces within the African Caribbean communities where alternative knowledge is constructed. This paper will explain how talk radio exists as a liminal space in society and how such spaces are valuable sites for conducting health research. Research that has used talk radio as a data collection method with African Caribbean communities will be presented, where discussions on body shape and size for women of this ethnic group were conducted and the audience were invited to contact the radio station to contribute to the discussion. Thematic analysis of the radio transcripts show that a number of themes emerged using this method that further add to the existing knowledge in this area and may not have surfaced using more traditional research methods.

**Wednesday 11 September 2013**

**15:05 - 15:35**

Health Service Delivery

Derwent Room 104

*Angell, E. Tarrant, C.*

*University of Leicester*

### **Implementing Practice Responsiveness: Successes and Difficulties from the Perspectives of Policy-makers and Frontline Staff**

Recent policy calls for primary care organisations (PCOs) to become more responsive and patient-centred, enabling quality care for all. Implementing policy and delivering improved healthcare poses a significant challenge. This paper focuses on elites' (policy-makers) and PCO staff members' interpretations of responsiveness, their perspectives of successful implementation, and the difficulties that are experienced.

Elites felt that responsiveness was part of a high-quality service. Whilst frontline staff did not speak of quality in such explicit terms, there was a shared discourse that responsiveness was a way of meeting patients' diverse needs and preferences. Elites spoke of challenges implementing responsiveness policy arising from staff resistance and competing priorities on the ground. Their accounts suggested that implementation approaches should include communication, engagement, and incentivised targets, to drive cultural change. PCO staff also referred to targets, but as a hindrance. Primary challenges for frontline staff in developing responsive services included the barriers generated by levels of demand, patients' expectations, and the structure of primary care. Success required changing staff mind-sets and taking a visibly proactive approach, as well as being willing to be reactive to patients as they came through the door.

Implementing responsiveness in primary care is complex, and the perspective of elites and staff on implementation differ. Elites focus on engagement, but enactment on the ground remains patchy, mainly due to practical difficulties and lack of incentives. I will argue that successful implementation is most likely when stakeholder groups work together rather than maintaining a 'them-and-us' mentality.

**Wednesday 11 September 2013**

**12:45 - 13:15**

Professions

Derwent Room 036

*Annandale, E., Suhomlinova, O., Teasdale, N.*

*University of York*

### **Going Over to the 'Dark Side'? The Vulnerability of Medics who Manage**

When visualising the medical consultant, power rather than vulnerability is likely to come to mind. In this paper we transpose this to analyse the vulnerability expressed by consultants recruited into managing their peers. We draw on in-depth interviews with six consult-managers in a range of specialisms situated within a larger body of interviews with a range of other senior clinical-managers in two large English NHS hospitals (undertaken between 2010 and 2012).

In common with existing research, consultant-managers identified first and foremost as clinicians and experienced the managerial role as a time-consuming and difficult 'add on' to their clinical work. They were nonetheless motivated by the opportunity that management offered for developing clinical services. We focus here on the relatively unexplored and quite significant challenges that arose from the need to manage their peers in what is only a temporary, time-limited role. We found that their identity is not only 'suspended' but also questionable amongst their peers who might construe them as less credible for having gone over to the 'dark side'. This made managing difficult for them. The authority to sanction was hard to come by when powerful peers asked to do things differently could say 'well, make me'. We explore the vulnerabilities that this generated and also the strategies that they employed to

counter them, such as espousing an organisation-wide vision and drawing on their wider management team (of general managers and senior nurses) to counterbalance the force of consultant peers in order to get their managerial work done.

**Thursday 12 September 2013**

**10:15 - 10:45**

Complimentary and Alternative Medicines

Derwent Room 047

*Ayala, B., Rojas, P.*

*University of London, Goldsmiths*

**On Practices and Abstractions in the Social Study of Complementary and Alternative Medicines: An Embodied Research of the Practice of Lyengar Yoga**

This paper seeks to contribute to the study of complementary and alternative medicines (CAM) in medical sociology through an empirical engagement with the practice of one of its most widespread forms: yoga. We argue that although yoga practice has been tackled in social and cultural research, it has been done primarily in a disembodied way that understands it as a new and more insidious form of disciplinary power linked to neoliberal arts of government, or as a consumerist and individualistic choice in the context of a postmodern world. We propose that this scope presents important shortcomings since it turns yoga practice into just another example at the service of wider theoretical abstractions, erasing its chances to become challenging and interesting for our research practices. Instead, we suggest studying yoga in practice through an embodied engagement with practitioners. Drawing from open-ended interviews and participant observation with practitioners of the lyengar method of yoga in Chile, we propose to open up the complexities involved in its practice, and the novel, unexpected and heterogeneous ways in which it enacts new forms of body awareness, embodied selves, and lived experiences of pain and wellbeing. This way we seek to contribute not only to the study of yoga practice, but to a reconceptualization of the critical sociological research of CAM, one capable of tracing not only their normalising effects, but also the inventive dimension that they put at play creating heterogeneous versions of health, disease and selfhood.

**Wednesday 11 September 2013**

**12:45 - 13:15**

Experiences of Health and Illness

Derwent Room 056

*Banks, T.*

*Cardiff University*

**Square Pegs in Round Holes: How do Acquired Brain Injury Survivors Perform the Role of Patient in Rehabilitation?**

During rehabilitation, there seems to be a lack of fit regarding the organisation and allocation of resources for individuals with Acquired Brain Injury (ABI) and the ability of the patient to engage with them. Specifically, it appears that the biomedical framework used to assess and provide for ABI 'survivors' can discount and exclude particularly vulnerable persons most in need of care. Drawing on an ethnographic study of an NHS long-term rehabilitation hospital, I explore the rehabilitation experiences of ABI survivors with particular reference to access, participation, inclusion and identity-work, considering how Acquired Brain Injury struggles to allow patients to perform the patient role. In addition, I will consider how these experiences interact with the biomedical discourse of ABI and the formal organisation of rehab services, including assessment protocols and processes, the major social actors involved, and the structure and delivery of ABI rehabilitation provision. I will conclude by analysing how such developments point toward an understanding of how interactions between rehabilitation processes and identity-work play an integral role in constructing a sense of self and how this leads to decisions made regarding rehabilitation, how it impacts on the success of the rehab interventions, and ultimately, how it affects a patient's quality of life.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Pharmaceuticals

Derwent Room 002

*Bell, S. E., Figert, A. E.*

*Bowdoin College*

**Global Clinical Trials, Ethical Standards, and Pharmaceuticalization**

In the past decade scholars have developed the concept of pharmaceuticalization to analyze inequalities in the global development and distribution of pharmaceuticals. In previous work we argued that sociologists need to expand our thinking about the concept and processes of pharmaceuticalization by conducting studies beyond the West and by employing a postmodern theoretical lens (Bell and Figert

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2010, 2012). In this paper we focus on the role of global clinical trials – specifically ethical and research standards – in the pharmaceuticalization process. We review and problematize ethical variability and show how it simultaneously upholds and disrupts Western ethical guidelines for human subjects research. Further, we show how global clinical trials contribute to pharmaceuticalization. We use examples of ethnographic research in India (Sunder Rajan 2006, 2007) and Thailand, Uganda, South Africa and the United States (Petty and Heimer 2011) to show in addition (a) how sometimes universal standards and at other times variable standards for pharmaceutical clinical trials contribute to global health inequality and (b) how a postmodern framework helps to make these processes visible. Put simply, the outcomes of the clinical pharmaceutical trial process internationally do not fit standard modernist narratives of either exploitation or the ethical advance of scientific research. Pharmaceutical and clinical trial innovations are made possible by and at the same time foster major shifts in the global political economy that are especially apparent in the pharmaceuticalization process.

**Thursday 12 September 2013**

**14:00 - 15:40**

MedSoc Committee Symposium

Derwent Room 028

*Bell, S. E., Figert, A. E.*

*Bowdoin College*

### **Placing Care: Embodying Architecture in Hospital Care for Immigrant/Refugee Patients**

Hospitals are places where people, objects, and ideas meet and interact. In their physicality hospitals – and differentiated spaces within them (Mol 2002) – install routines in bodies by insisting on particular paths that bodies move along daily. These embodied routines become natural and invisible (Gieryn 2002). This paper explores the impact of the physical space, routines, regulations, and technologies on encounters between adult immigrant patients and caregivers in two outpatient clinics in one hospital in Maine, USA. It draws from 9 months of ethnographic research in 2012 that included following approximately 200 staff and 69 adult immigrant patients (including refugees, asylees, and asylum seekers) and the patients' interpreters. It identifies assumptions about patients, practitioners, and forms of healing embedded in the two hospital clinics; how the clinics' physicality establishes biomedical routines and ways of knowing in clinic staff and immigrant patients; and how their material infrastructure, symbolic meanings and human practices may and may not enable staff and patients to align the practice of biomedicine with cultural sensitivity.

**Friday 13 September 2013**

**11:55 - 12:25**

Critical Public Health

Derwent Room 006

*Bendelow, G.*

*University of Sussex*

### **'A Danger to Self or Others': Who Decides? Police use of Section 136 of the Mental Health Act in Sussex**

Public 'anti-social behaviour' is increasingly a major societal concern and police in England and Wales are empowered, under Section 136 of the Mental Health Act 1983, to detain individuals who are thought to be a danger to themselves or to others in public spaces. Use of these powers are widespread, but highly controversial as police are required to make judgements about mental health and to detain individuals who usually have not committed any crime. Section 136 has been under increased scrutiny over the last five years, as the rate of detentions has risen significantly at a national level, and rates in Sussex are as much as ten times higher than the national rate.

This study is funded by the British Academy in collaboration with Sussex Police and Sussex Partnership Foundation Mental Health Trust who have been jointly producing statistical information regarding s136 detentions for the last 10 years. The data consistently show that less than half of detentions result in admissions to mental health units, suggesting there are wide variations between police interpretations of emotional distress and the subsequent diagnoses of mental health professionals. Using a combination of secondary analysis of existing data and in-depth interviews with police, mental health professionals and members of the public, this study aims to provide an in-depth sociological analysis of the ways in which vulnerability and 'dangerousness' are perceived by the various actors.

**Friday 13 September 2013****11:55 - 12:25**

Methods

Derwent Room 047

*Bennert, K., Ryan, S., Hislop, J., Ziebland, S.**University of Oxford***The Tellability of Good Care: How do Patients Narrate Their Health Service Experiences?**

Narrative interviews are frequently used to examine patients' experiences of healthcare services. In the interview interaction, participants may present their views on positive and negative aspects of healthcare as explicit evaluations, but also in the form of 'small stories' (Bamberg & Georgiakopolou, 2008) that are embedded in the overarching illness narrative. This paper examines the different types of small stories patients employ to describe specific health service experiences.

The paper draws on data from a qualitative secondary analysis of three narrative interview collections from the healthtalkonline archive, University of Oxford (<http://www.healthtalkonline.org/>). We aimed to identify core components of good healthcare from patients' experiential accounts. In-depth interviews with 126 patients who had experienced myocardial infarction, Type 1 diabetes or rheumatoid arthritis were coded to gather instances of small stories relating to their experience of health services. These stories were then classified according to their performative characteristics, strategies chosen for emplotment and self- and other-positionings. This process was supported by NVivo qualitative analysis software.

The paper draws on selected 'small stories' to explore whether certain aspects of healthcare may possess greater intrinsic tellability (e.g. Norrick, 2005) than others and whether any systematic differences can be found with regard to the stories patients choose to tell in terms of emotional valence, intensity, and self-presentation. It will discuss the methodological implications of these findings for research that seeks to explore quality in healthcare via in-depth interviews.

**Wednesday 11 September 2013****13:20 - 13:50**

Politics of Health

Derwent Room 037

*Benzer, M.**University of Sheffield***QALY Politics**

The paper considers the political orientation and implications of the controversial quality-adjusted life year (QALY) framework. Organisations such as the UK National Institute for Health and Care (until recently: Clinical) Excellence (NICE) employ the QALY framework for cost-effectiveness assessments of health technologies which are meant to guide decisions about the distribution of scarce healthcare resources. The paper asks to what extent existing theoretical conceptions of biopolitics – notably of contemporary Western societies' dominant modes of conceptualising, evaluating, and managing human life and mortality – can elucidate the QALY framework's political orientation. The paper critically scrutinises the allegation that the QALY method forms a component of 20th century deathmaking projects. It then proceeds to examine the resonances between the QALY framework and what Michel Foucault has described as a liberal government of life. Finally, the paper investigates whether more recent theories of advanced liberalism and neoliberalism can shed light on the QALY method's political orientation. Current conceptions of biopolitics capture several key aspects of the QALY framework. Simultaneously this framework has the potential to sharpen our understanding of the politics of life of the early 21st century.

**Wednesday 11 September 2013****15:05 - 15:35**

Screening and Diagnosis

Derwent Room 047

*Berghs, M., Atkin, K., Dyson, S., Bennett, C.**University of York***Finite Fatherhood: Temporal Trajectories and Embodied Transitions in Testing for Sickle Cell**

Sickle cell is a genetic condition that mainly affected minority ethnic groups but due to migration and intermarriage has become one of the most common recessive 'disorders' in the United Kingdom. We present some findings from an NIHR-RfPB study about engagement with men and improving informed decision-making in screening for sickle cell. Men usually receive an invitation to get tested if their partners have been identified as genetic carriers during antenatal screening. Men thus related different trajectories linked to reasoning behind involvement and embodied engagement with medical

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professionals, astutely noting some of the paradoxes, inequalities and tensions between policy and practice. If men tested as carriers, the trajectories changed according to how genetic information and (bio) medical technology, such as prenatal diagnosis, was presented and understood. Engagement also became more emotionally and ethically complex but also paradoxically delimited, technical and temporal - affecting decision-making. Where once they had been infinite possibilities at the start of a pregnancy, men related having to refashion relationships to their partners and ideas of fatherhood in terms of the uncertainty of different tests, genetic information and technologies. Especially fathers who had children with sickle cell, noted that the visible hyper-vigilance espoused by policy as a 'good father' does not lie with the embodied acceptance of new technologies and medicine but in constantly questioning information and implications when such 'choices' are presented.

**Wednesday 11 September 2013**

**15:05 - 16:45**

Symposium

Derwent Room 006

*Bernays, S.*

*London School of Hygiene and Tropical Medicine*

### **Contributions to Hope: The Dilemmas Inherent in Examining and Describing the Experience of the 'Lucky' Ones**

Since the widespread availability of HIV treatment global policy and advocacy discourses have emphasised the significance of hope in the contemporary experience of living with HIV. However, whilst burgeoning access to anti-retroviral treatment (ART) has enabled millions of people to regain or sustain their health, the transformative effects of ART amongst HIV populations are not universally felt. Drawing on two qualitative case studies from very different epidemiological and regional contexts, one from Serbia with adults (2005-2008) and a study conducted in Uganda and Zimbabwe with children (2011-2013) this presentation engages with the methodological challenges involved in examining the concept of hope in relation to living with HIV on ART. In this paper I also consider how we, as social researchers, may approach listening to, interpreting and disseminating the experiences of PLHIV. This also includes the dilemmas we may face, through the dissemination of our findings, in contributing to development narratives around 'successful progress' and/ or 'the impossibility of positive change'. In doing so this presentation addresses broader methodological and ethical dilemmas in investigating 'fragile and in managing the risks that the research itself may expose the frailty of individuals' hopes.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Professions

Derwent Room 036

*Beynon-Jones, S.*

*University of York*

### **Re-thinking the 'Dirtiness' of Abortion Work: An Analysis of UK Health Professionals' Accounts of their Practice**

Workers' experiences of stigmatized aspects of healthcare provision are routinely theorised using Hughes' concept of 'dirty work'. A central concern of this literature is the mechanisms via which workers construct and maintain positive identities in the face of society's stigmatisation of their labour as morally, socially, and/or physically tainted. However, as several critiques have highlighted, this framework tends to generate an overly static conceptualisation of dirt, with the consequence that social constructions of particular forms of work as 'dirty' become reified. This paper reflects on the implications of such reification in a healthcare context that has often been characterised as a site of 'dirty', emotionally difficult labour by both sociological and nursing literatures: abortion provision. The analysis draws on semi-structured interviews with UK health professionals involved in providing medical and/or surgical abortion procedures and explores their reflections concerning the content of their day-to-day work. It argues that – in line with Douglas's insight that 'there is no such thing as absolute dirt' – the 'dirtinesses' (and 'cleanlinesses') of abortion work are constituted through context-specific sets of practices.



**Thursday 12 September 2013****15:10 - 15:40**

Methods

Derwent Room 049

*Boden, Z., Gibson, S., Owen, G., Benson, O.**SANE – Mental Health Charity***Listening to Ourselves to Better Understand Absent others: Methodological Challenges in Learning About the Suicide Process from those Bereaved by Suicide**

Understanding the experiential process of a completed suicide necessarily relies on second-hand accounts, and in our phenomenologically-informed grounded-theory study these came from the partners, parents, adult-children, siblings or friends of the deceased. This presentation will explore some of the methodological challenges which arose from this project, and how we sought to work within the limitations given by our topic of enquiry. To collect accounts we conducted interviews. Part of this process drew on the phenomenological concept of 'being-with'; listening as fully as possible to the participant, not just to their words, but attuning ourselves to their bodily way of being, and to the background mood more generally. During and after interview, we engaged in a process of critical reflexivity. One aspect of this was attending to the embodied intersubjective relationship between participant and researcher, and what have been called 'co-transferences'; the sensations shared between individuals. Through reference to several case-studies from our project, we will examine the ways in which our bodies signalled how we might proceed with analysis, and allowed us to develop a fuller understanding of the lived experiences leading to a completed suicide, despite the absence of first-hand accounts.

**Wednesday 11 September 2013****15:05 - 15:35**

Professions

Derwent Room 036

*Booth, J.**University of York***Tomorrow's Doctors' Framework and its Effects on Clinical Placements in Undergraduate Medical Education**

Both Timmermans and Epstein and Latour argue that it is easier to trace how the social is constructed at periods of innovation or when institutions are being built, before they are what Latour terms 'back boxed' (2005), and 'uncertainty and ad hoc tinkering' (2010 p.83) is hidden.

Tomorrow's Doctors 1993 was the first edition of the GMC's framework for undergraduate medical education, and it sought to deal with the problems of an overloaded curriculum and the pre-clinical/clinical divide, as well as to ensure students had more experience of primary care. It drew a distinction between a core curriculum described as 'a distillate of essential knowledge and skills' (1993 §30) that prepared graduates for their first jobs, and student selected modules (SSMs) which focus on 'the long term intellectual and attitudinal demands of professional life.' (1993 §24), but it retained the mode of learning in clinical placements (Stacey 1993, p. 113).

The paper examines how Tomorrow's Doctors' assumptions and distinctions have resonated in the curriculum for undergraduate clinical placements in a new medical school. Using Prior's notion of the 'vita activa' of documents (Prior 2008), it responds to Timmermans and Epstein's call for 'careful empirical analysis of the specific and unintended consequences of different sorts of standards operating in distinct social domains' (2010 p 69).

It will explore some of the consequences of an outcomes-based curriculum on the mode of learning in clinical placements and of the provision of 'the greatest educational opportunities' through SSMs. (1993 §24).

**Thursday 12 September 2013****09:05 - 09:35**

Lifecourse

Derwent Room 049

*Boydell-Wright, N., Buston, K., McDaid, L.**MRC/CSO SPHSU, University of Glasgow***'Personal Communities' and Safer Sex: A Qualitative Study of Young and Bisexual Gay Men in Scotland**

Successful HIV prevention among gay men has been linked to strong 'Community' responses to HIV and adherence to safer sex practices.

Ambivalence about the role of community has been identified among young gay men, and recent research has suggested that the concept of 'personal communities' may offer an alternative way of

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understanding sources of support and identification among gay men. This PhD research aimed to explore young gay and bisexual men's 'personal communities', and the role those within them (e.g. friends, family, partners and colleagues) may play in shaping men's safe-sex strategies. Thirty young gay and bisexual men, aged 18-29, took part in in-depth, semi-structured interviews. Interviews focused on exploring men's 'personal communities', and how they understand and negotiate safe(r) sex as part of sexual practice. Preliminary analysis suggests that men's personal communities are diverse and complex, highlighting the different roles that individuals within them may play in informing men's approaches to safer sex. How men think about and manage their sexual identity, particularly in the context of 'gay community', appears to play a role in how men discuss sexual health and safer sex. Areas of convergence and divergence between men's experiences of 'gay community/ies' and their own 'personal community' can be seen, suggesting the importance of supportive relationships with individuals, and connections with 'community', and community organisations. The implications for HIV prevention are explored with particular reference to whether different types of intervention are needed to address various parts of men's 'personal communities'.

**Thursday 12 September 2013**

**16:20 - 16:50**

Lifecourse

Derwent Room 002

*Boyle, G.*

*University of Bradford*

### **The creative Agency of People with Dementia**

People with dementia are assumed to possess weak or even no agency, particularly since existing agency theory prioritises rationality, language and dialogue as the necessary abilities to exercise agency. However, this paper examines the potential for basic agency in people with dementia and explores whether they express agency through more creative means, notably via embodied and emotional agency. In particular, the author considers whether people with more advanced dementia - who experience significant cognitive and communication challenges - can nonetheless manifest agency. In addition, whereas current sociological theory essentially views agency as an individualised process, the paper explores whether a relational concept of agency is more appropriate, particularly as people with dementia need support to exercise agency. The author draws on findings from a qualitative study of everyday decision-making by people with dementia which aimed to identify the role of social factors in influencing their involvement in decisions. The ESRC-funded study was undertaken in the North of England. The study highlighted that people with dementia who lack the ability to exercise deliberative agency (for example, through decision-making) can nonetheless demonstrate creative capacity for agency.

**Wednesday 11 September 2013**

**14:30 - 15:00**

Experiences of Health and Illness

Derwent Room 003

*Brady, G.*

*Coventry University*

### **Children, ADHD and Medication Management**

This paper focuses on a group of children and young people who are often subject to pharmacological intervention, namely, those that are diagnosed with the condition of Attention Deficit Hyperactivity Disorder (ADHD). The views of children and young people diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) have, until relatively recently, largely been neglected both in research and in practice. The emergence of the phenomena of ADHD can be regarded as productive, in that it provides an opportunity to reflect on cultural expectations of children. One such idea which can be used to conceptualise the active role that children play in responding to the designated label and to treatment with medication is the health care division of labour. The approach, most notably developed by Stacey (1984; 1988) is distinctive, through the inclusion of the contributions of both lay and professional, paid and unpaid carers, each participant being regarded as a social actor and all part of a social process. The analysis presented here prioritises children's lived experience, drawing attention to the ways that they actively 'take' responsibility for managing their physical, psychological and emotional well-being. The neglect of a tradition which asks children about their own experiences of ADHD is crucially bound up with the way in which children have been constructed in UK society.

**Wednesday 11 September 2013****15:40 - 16:10**

Experiences of Health and Illness

Derwent Room 056

*Bramwell, D. Sanders C., Rogers, A.**University of Manchester***Being Tightrope Walkers: The Emotional Consequence of Supporting People with Long-term Conditions in the Workplace for Employers and Managers**

Measures by the UK Government to get people with long-term health conditions into the labour force and off incapacity benefits present a challenge for employees and employers alike. However, little is known about employers and managers experiences of managing those with long-term conditions (LTCs), or what it means to support such employees in the social context of the workplace. This is important to explore given that research from the employee perspective frequently cites the importance of supportive managerial relationships as a determinant of a successful (re)entry to work.

Findings from semi-structured interviews with 40 employers and managers based in a wide variety of organisations, suggested that their role in supporting those with LTCs is one of a difficult 'balancing' act – hence 'being tightrope walkers'. Participants expressed a sense of conflict and discomfort arising from ambivalence between the obligations of their professional 'public' role and the 'private' feelings and values of their personal role. Where acting in the professional interest of the organisation, the law and other worker's is often in contradiction to personal feelings and values about the individual employee, their condition and maintaining professional integrity. This sociological ambivalence incurs an emotional consequence, manifest in feelings of guilt and fear etc., which as findings illustrated, undermine how participants approach supporting those with LTCs. Future research could utilise this to inform the development of a suitable intervention to support employers/managers in addressing socio-emotional factors related to employee illness, ultimately benefiting those with LTCs seeking to successfully (re)enter the labour force.

**Friday 13 September 2013****11:55 - 12:25**

Lifecourse

Derwent Room 003

*Brierley-Jones, L., Crawley, R., Lomax, S., Ayres, S.**University of Sunderland***Stillbirth and Stigma: The Spoiling and Repair of Multiple Social Identities**

The rate of stillbirth in the UK remains one of the highest in the developed world at 3.5 per 1000 live births, or 11 stillbirths every day. The experience of stillbirth has been shown to have a significant effect on the entire family, but particularly on maternal mental well-being. (e.g. Cacciatore, Schnebly, & Fr?en, 2009). Our study sought to investigate mothers' experiences surrounding stillbirth, in particular their opportunities to make, and later share, memories of their babies and the effect such opportunities had on them. Qualitative data was generated from free text responses to open-ended questions about memory making and sharing and professional and social support, which were embedded in an online demographic and mental health questionnaire. A total of 141 women, who had experienced a stillbirth in the UK in the previous 10 years, completed free text responses and the data was subjected to thematic content analysis. Stigma emerged as a central theme and consequently Goffman's work on stigma was used to provide an analytical framework. The data showed that stillbirth results in the spoiling of identities for women as 'patient', 'mother' and 'full citizen'. Our study confirms evidence that family members stigmatise mothers of stillborn babies (Murphy 2012) but shows that stigma also arises from interaction with professionals, friends, work colleagues and casual acquaintances which necessitates 'identity work'. Stigma reduces opportunities for memory sharing and this may help to explain contradictions within the literature regarding the mental health effects of memory making. (word count 244). Ageing; Death and Dying

**Wednesday 11 September 2013****12:45 - 13:15**

Health Service Delivery

Derwent Room 104

*Briggs, M., Manzano, A.**Leeds Metropolitan University***Active Listening in Hospital: Staff and Patient Perspectives**

Communication is at the centre of health care systems and delivery. Interpersonal communication skills are essential in all clinical encounters and the merits of listening are praised across a variety of fields in and beyond health and social care. Active listening (AL) is a communication skill which involves hearing, evaluating and responding to what is heard. The degree to which active listening may aid relationships

## PAPER ABSTRACTS

and recovery in a healthcare settings for patient and healthcare staff other than those in counselling services is still not widely documented empirically. This study explored the feasibility of implementing an active listening intervention for hospital patients by chaplaincy volunteers in the UK National Health Service.

Seven moderator-led focus groups were conducted among healthcare researchers and lecturers, nurses, patients, active listening tutors, active listening practitioners and chaplaincy volunteers (n=47) . Following a DVD demonstration of an AL patient/listener intervention, impressions were solicited to explore the acceptability and perceived effectiveness. Data analysis followed the framework approach. Results: Four main themes emerged from the data: (a) listening as a well-being generator, (b) spirituality, and public perceptions of hospital chaplaincy (c) benefits of AL being delivered by volunteers, (d) challenges of using a structured communication technique in inpatient and outpatient settings. Conclusion: Despite organisational barriers embedded in acute care, healthcare staff and patients reported positive attitude towards the introduction of AL in hospitals, albeit with reservations about how the effectiveness of a structured communication approach would be affected by the acute environment.

**Thursday 12 September 2013**

**16:20 - 16:50**

Teaching Medical Sociology

Derwent Room 006

*Brooks, L., Collett, T., Forrest, S., Greene, A., Kendall, K., MacBride-Stewart, S.*

*Keele University*

### **Sociology in Medical Education: State of the Art and Future Directions**

'Tomorrow's Doctors' (GMC 2009) is the most recent guidance from the General Medical Council to medical schools on the discipline-specific learning outcomes expected of medical graduates. This represents a spectacular success for sociology; reflecting several decades of work by sociologists to argue the case for the contribution of the social sciences to medical education. However, it also highlights some pressing needs: to establish what core knowledge and skills are necessary to meet the sociology learning outcomes, how these are best organised and delivered, and what obstacles and opportunities exist.

This presentation reports on findings from three regional workshops with social scientists from 24 medical schools across the UK. The aim was to bring people together to discuss their teaching practice with a view to: capturing the 'state of the art' teaching and assessment of sociology in medical education; explore views on the core elements of medical sociology and their relationship to the GMC outcomes; identify how the subject needs to develop with reference to these outcomes; discuss challenges and opportunities in the teaching and learning of sociology in medical education; and enhance professional, peer-support networks.

The findings presented here reflect on some of the key themes that emerged from an analysis of the workshops. These include: expertise, integration, curricula change, self-sufficiency, 'public sociology', genealogy, rationalization and critical thinking. We argue that while important advances have been made, there is a need for collective action to strengthen teaching and deal systematically with the challenges facing the discipline.

**Thursday 12 September 2013**

**12:00 - 12:30**

Lifecourse

Derwent Room 049

*Brown, S.*

*Durham University*

### **'I Think it Must Run in the Family': Multi-generational Households and the Decision-Making Processes Around Teenage Pregnancy and Parenthood**

The debate has shifted during the late 20th and early 21st century from regarding teenage pregnancy as a moral problem, due to the unmarried status of the mother, to positioning it as a social problem due to the age of the mother. Teenage pregnancy and parenthood have been viewed as overwhelmingly negative, a feature of deprived communities which needs to be 'olved' by technical and educational means. The cumulative risks of young parenting are framed in health terms as part of a discourse about social exclusion, disadvantage and inequality.

The purpose of this study was to investigate the experiences of young parents across the generations, embedded in local contexts and cultures in the north of England. The study takes a qualitative approach, using in-depth interviews with family members. Interviews were recorded and transcribed, and analysed using constant comparative methods.

None of the young mothers had planned to get pregnant, but decided to keep the baby because it seemed like the best option, they were encouraged and supported by their families, or because of strongly held beliefs about abortion.

For many young women, motherhood is an attractive choice and for some can be a positive turning point, although this is an unpopular view which has been rejected by politicians. In policy terms, in many Western countries, teenage motherhood is positioned as a 'problem' to be solved. There is, however, a mismatch whereby policy-makers regard it as a problem but those experiencing it do not.

**Thursday 12 September 2013**

**15:45 - 16:15**

Lifecourse

Derwent Room 002

*Buse, C., Twigg, J.*

*University of Kent*

**Clothing the Body in Dementia Care: Dress as a Form of Bodywork**

This paper explores practices of dressing, undressing, and managing clothes, as a form of bodywork in dementia care. Previous work has highlighted the significance of the concept 'bodywork' for understanding the practices of health and social care workers (Twigg et al 2011), and there is a growing body of literature on 'bed and body work' in dementia care settings (e.g. Chatterji 2006; Reed-Danahey 2001; Ward et al 2008). However, dressing and managing clothes has not been the focus of previous research. In examining these issues, this paper draws on findings from 'Dementia and Dress'- a qualitative and ethnographic ESRC funded study, which incorporates the perspectives of people with dementia, family carers and care-workers. Like other forms of bodywork, dressing and undressing raise issues around temporality; boundaries of intimacy and privacy; and quality of care. However, dress has unique implications for maintaining- or diminishing- the embodied identity and personhood of people with dementia. This becomes increasingly complex as dementia advances, and people with dementia can no longer choose their own clothing. There are also challenges around appropriate dress, and tensions between maintaining identity and dignity, and normalising the body. In addition, this paper explores the responses of people with dementia to this form of bodywork, and ways in which practices of dress and dressing are experienced, embraced or resisted.

**Thursday 12 September 2013**

**10:15 - 10:45**

Lifecourse

Derwent Room 049

*Campbell, A.*

*University of New England*

**Soothing Science: The Medicalization of Mothering**

In a society increasingly preoccupied with 'risk', parenting is frequently reduced to a set of epidemiological risk factors where aspects of parenting are conceptualized as being potentially catastrophic to the physical, psychological and emotional health of the growing child. On the surface the directives and advice flowing from scientific research on parenting seems only beneficial and educational, yet the regulatory effects on women, in particular, are difficult to ignore. Indeed the 'truths' of good/bad parenting come to be embedded in advice manuals, parenting books, educational initiatives, and public health approaches. This paper is not so much concerned about the veracity of such truth claims rather it is interested in thinking through some of the consequences of the medicalization process. While appeals to science obscure the extent to which mothering (and the meanings around mothering) is a site for political struggle, this paper seeks to make apparent the normalizing and disciplinary consequences of 'scientific mothering'.

**Wednesday 11 September 2013**

**15:40 - 16:10**

Mental Health

Derwent Room 003

*Carvin, K.*

**Coercion in the Community: Mental Health Service User and Professional Experiences**

Studies of coercion in psychiatry have focused extensively on the hospital setting but much less so on coercive practices in community settings where both informal (outside legal and policy provision or guidance) and formal (under the Mental Health Act) practices may be employed. Little is known about how these practices are experienced by service users or used by mental health professionals in England, especially since the introduction of Community Treatment Orders (a form of compulsory supervision which permits the rapid recall of service users to hospital for assessment and treatment).

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We conducted an extensive qualitative study of coercion in community psychiatry comprising interviews with 76 service users (including 26 with a diagnosis of psychosis who were on CTOs) and 25 consultant psychiatrists, and 6 focus groups with 48 mental health professionals. In this paper, I will draw on the findings of this study to consider how the shift from the hospital to the community (and indeed the private sphere) has impacted upon the nature, use and experience of coercion

**Friday 13 September 2013**

**11:20 - 11:50**

Ethnicity

Derwent Room 002

*Castro-Vazquez, G.*

*Nanyang Technological University*

### **Reproductive Technologies and Child Adoption in Times of Low-birth Rates and Pronatalism in Japan**

Within current pronatalist policies – subsidies to foster childbearing/child-raising and the promotion of a culture conducive to reproduction – against the 'crisis of ultra-low fertility rates' (Jones et al. 2009), this paper presents data from an ongoing research on intimacy and reproduction in Japan. From a symbolic interactionism perspective, the paper analyses the viewpoints of a group of Japanese mothers concerning the use of reproductive technologies and child adoption.

A set of two, 60-minute, semi-structure interviews were conducted with 56 Japanese mothers to explore the ways reproductive technologies are subjectively produced and practiced. 29-45 aged mothers were acquired through snowball sampling and interviewed in Kanagawa and Tokyo. 45 of the interviewed-mothers have used different forms of technologies, biomedical or otherwise, to induce reproduction; of them 15 have accessed to IVF. To facilitate rapport, conversations started by discussing the case of Seiko Noda a Japanese politician who got pregnant at age 50 through IVF.

In relation to subjectivity and practice, the paper shows how the ideology of the 'maternal instinct' (Ramazanoglu 1989) and the idea of the preservation of lineage help justify decision-making processes concerning the use of reproductive technologies. In line with official rhetoric and subsidies to boost reproduction, the desirability of bearing a child with one's own genes was a reason to resist child adoption, which entails a risk because 'deviance can be genetically acquired'. This has largely translated into an enhancement to the power of the ever growing fertility treatment industry but the impact on current birth rate tendencies remains unclear.

**Wednesday 11 September 2013**

**12:45 - 13:15**

Screening and Diagnosis

Derwent Room 047

*Chandler, A.*

*University of Edinburgh*

### **Unsettling Boundaries: The Medicalisation, De-medicalisation, and Re-medicalisation of Self-injury**

Sociological work on self-injury has suggested that in the 21st century, self-injury has become increasingly de-medicalised (Adler and Adler 2011). However, there are clear indications that a particular category of self-injury ('non-suicidal self-injury', or NSSI) is being securely medicalised (or perhaps, re-medicalised) by its inclusion as a diagnosis in the most recent iteration of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5, 2013). Sociology has long been engaged in critical analyses of psychiatric diagnoses, and particularly of the DSM. In this paper I contrast clinical and academic discourse about the nature of self-injury with the narratives of people who self-injure. In so doing, I attempt to unsettle some of the imagined boundaries between medical and lay understandings about self-injury. This analysis draws upon interviews with people who have self-injured (carried out between 2007-8; and in 2013); documents published by self-injury advocacy groups; and academic debate about the inclusion of NSSI in the DSM-5. There are important tensions between and within these accounts, which resist attempts to classify the practice as suicidal or non-suicidal; pathological or normal; psychiatric or sociological. I conclude with some reflections on the potential consequences of the formal medicalisation of self-injury.

**Friday 13 September 2013****09:00 - 09:30**

Lifecourse

Derwent Room 003

*Chapple, A., Ziebland, S.**University of Oxford***Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death**

Views differ on how far the subject of death has ever been taboo in Western Society. Walter (1991) has criticized the way the 'taboo thesis' has been presented, arguing that it has often been 'grossly overdrawn and lacking in subtlety'. Research suggests that suicide and other traumatic death may be particularly difficult for people to talk about or even acknowledge. We interviewed 80 people bereaved due to suicide, murder or other traumatic death and used interpretative thematic analysis to consider whether the 'death taboo' is evident in these bereavement narratives. People referred to suicide as a different, even stigmatized, death but we also found that those bereaved through other sudden and traumatic death felt that their reactions had to be contained and relatively silent: it was only socially acceptable to express their grief for a short period of time. The exception was those bereaved through terrorism, who seemed expected, even encouraged, to grieve openly and angrily. We conclude that the shock and suddenness of the death is tied up both with the circumstances of the death (suicide, murder, accident, terrorism) and the attendant consequences for the social acceptance of public displays of mourning.

**Friday 13 September 2013****10:10 - 10:40**

Risk

Derwent Room 037

*Chattoo, S.**University of York***On being a 'Carrier' of a Recessive Gene Disorder: The Politics and Power of the Liminal**

This paper will look at the social ramifications of the diagnostic category of a 'healthy carrier' through the theoretical lens of liminality, by analysing how men and women identified as carriers of sickle cell or thalassaemia (recessive gene disorders resulting in serious blood disorders) negotiate the notion of genetic risk within a particular biographical trajectory. In the UK, currently there are 240,000 sickle cell trait carriers (predominantly people of African and African-Caribbean origins) and 214,000 carriers of thalassaemia trait (largely people of Greek, Turkish, Cypriot and South and Asian origins). Even though carriers do not develop the condition, we know little about how the diagnosis impacts on their ideas about health, illness and social identity on one hand and state governed technologies of 'reproductive choice' (aimed at preventing the birth of potential babies with sickle cell and thalassaemia) on the other.

The paper is based on analysis from an on-going ESRC funded project (Jan 2012-Dec 2013), involving in-depth biographical interviews with a sample of over 50 carriers at different stages of their life-course, from different ethnic backgrounds, living in England. It will be argued that while a trait exists betwixt and between the medical and the social, being neither sick nor (not) healthy, the biographical and social context underpins the symbolic content of the term. Further, individual moral engagements with the notion of genetic risk reflect contrasting community based, political responses to the two conditions - both shaping and resisting state policies of governance aimed at prevention and control.

**Thursday 12 September 2013****08:30 - 09:00**

Experiences of Health and Illness

Derwent Room 056

*Cheraghi-Sohi, S., Jeffries M., Stevenson, F., Ashcroft, D., Rogers, A.***Explicating the Nature of 'Adherence Work' in Open Settings**

Previous literature surrounding lay adherence has focused on the problem of 'non-adherence' and located it firmly within the domain of the individual. In this study, we flip the 'problem' and place a focus on the work that people do when attempting to adhere to their medication. By focusing on those who have multimorbidity (MM) and are subject to polypharmacy, we aim to expand and inform a pre-existing notion of 'adherence work' developed in relation to a single condition with a view to providing an insight into the complexities of multiple medicine-taking in the realm of domestic settings. Furthermore, by drawing upon the concept of social networks, we also attempt to explicate the division of labour involved in medicine-taking, by asking who in an individual's network does what work, at what point and why.

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Participants with multiple conditions were purposively sampled and recruited from ongoing work as part of The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester. Preliminary findings suggest that participants appear to rely on developing 'medication infrastructures' within their homes with regimens becoming embedded into and around pre-existing routines. Adherence work in MM patients comprised of various discrete stages and multiple strategies in order to achieve the goal of 'completing' the regimen. The role of others forms a continuum of involvement, from simple acts such as reminding to 'others' performing all aspects of adherence work. Finally, network involvement is selective and limited to specific network members & reasons for this are discussed.

**Thursday 12 September 2013**

**12:00 - 12:30**

Mental Health

Derwent Room 037

*Clarke, J.*

*University of Nottingham*

### **'Where the Action is': Everyday Interaction Rituals of an Inpatient Psychiatric Unit**

Gossip, disagreements, jokes, sexual innuendoes, secret sharing, tears, sympathy, disassociation and storytelling all occur in a small courtyard designated for smokers on an inpatient psychiatric ward. Interactions in the smoking courtyard reveal the difference between what is said and what actually happens in practice during therapeutic interventions. Using narrative ethnography, this research studies the process of personal change within an inpatient therapeutic community (TC) for women with a diagnosis of personality disorder. The focus of this study is not the change outcomes; unlike like much of current mental health research, it prioritises the social processes of everyday interactions within a therapeutic setting. Yet it is not just smoking breaks, but numerous everyday interactional rituals that provide the means to understanding and explaining individual transformations. This paper adopts ritual theory as first suggested by Mead, Durkheim and Goffman to address how, and to what extent, individuals use social interactions to facilitate self-transformation. Three key community rituals are identified and explained: smoking breaks, ice/smells and community endings. These everyday interactional rituals are where social norms, social capital and power dynamics between clients and staff members are both explained and lived out. It is well documented that the process of change is non-linear and that outcomes without context can be misleading. By studying situations and their individuals, the subtleties of the change process are discernible amongst the various successes and setbacks that occur along the way.

**Thursday 12 September 2013**

**11:25 - 11:55**

Mental Health

Derwent Room 037

*Cleaver, K.*

*University of Greenwich*

### **Young People who Self-harm: Unpopular Patients?**

Earlier sociological work has clearly demonstrated that practitioners working in emergency services judge patients based on their reasons for accessing the service (Roth 1972, Jeffery 1979, Dingwall & Murray 1983), patients who self-harm being amongst those adversely judged. This body of work has contributed to the wider debates about popular and unpopular patients (Kelly & May 1982, Hill 2010). However this work focuses on adult patients, with little consideration given as to whether children and young people attract negative evaluations; findings from the limited research that exists are inconclusive and inconsistent (Dingwall & Murray 1983, White 2002).

This paper will consider findings from a mixed methods study which aimed to ascertain the attitudes of practitioners working in pre-hospital and hospital based emergency services, towards young people who self-harm. Findings from the study indicate that age, i.e. being a young person, influences attitudes towards self-harm - young people are less adversely judged as their self-harm is seen as symptom of distress, a coping mechanism or response to a stressor out with a young person's control. Nevertheless data from the interviews illustrated the difficulties and frustration the nurses and paramedics sometimes faced in managing the care of young people who self-harm. As a consequence constructions of 'good' and 'bad' patients as applied to young people who self-harm emerged. The paper will outline these constructions, consider them within in the wider debates around popular and unpopular patients, and their implications for the emergency care of and interaction with, young people who self-harm.



**Friday 13 September 2013****10:45 - 11:15**

Experiences of Health and Illness

Derwent Room 056

*Coffey, C., Ward, P., Wilson, C., Meyer, S**Flinders University, South Australia***Exploring the Role of Trust in Barriers to Colorectal Cancer (CRC) Screening among Different Population Subgroups.**

Disparities in colorectal cancer (CRC) screening participation rates, as well as barriers to and facilitators of the screening have widely reported. However the centrality of trust (and mistrust) as a key barrier and social process that underpins additional barriers remains largely unexplored. The objective of this research was firstly to explore the relationship between various dimensions of trust (and mistrust) and a bowel cancer screening program in culturally diverse and low-income (CALD) populations in South Australia (SA) and secondly, to explore the similarities and differences in trust (and mistrust) between and within these populations. Ninety-seven qualitative semi-structured interviews were analyzed from CALD and low-income groups by adopting the social theories of Niklas Luhmann as a conceptual framework. Important themes emerged including interpersonal and institutional trust, trust in oneself, risk, familiarity and privacy. Data falling outside the initial framework was not excluded allowing for novel findings distinct from trust to be analyzed including the notion of obligation. This study outlines that while similarities in the dimensions of trust (and mistrust) exist across the population groups with lower rates of participation and a bowel cancer screening program, there are important culture-specific differences that must be addressed if equitable screening is to occur.

**Wednesday 11 September 2013****14:30 - 15:00**

Experiences of Health and Illness

Derwent Room 056

*Combs, R., Sanders, C., Knowles, S., Kirk, S., Griffiths, M., Blakeman, T**University of Manchester***Identity Resistance, Life Changes and Care-giving: An Exploration of Perceived Roles and Responsibilities of Those Supporting a Family Member with Vascular Disease**

Carers provide regular unpaid support to family members, friends, or neighbours who are ill or disabled. Caring responsibilities can have a substantial impact on the emotional and physical health of the carer, but a sizable proportion of people in this category do not access the available benefits and support. This study aimed to explore how people who regularly assist someone with a chronic illness construct a carer identity and how these views influence their access to formal support.

In-depth semi-structured interviews were conducted with people who provide care for someone with vascular illness. The data show that participants grappled with changes to their lives brought about by the illness and their caring responsibilities. Participants had complex relationships with, and often resisted, the language and meanings associated with care-giving. Reasons for resisting a 'carer' identity included not measuring up to a perceived standard due to the increasing formalisation of caring work; worries about the impact a carer identity would have on the cared-for person's self-esteem; and concerns about the effect the transition from 'family member' to 'carer' would have on their relationship. In many cases, reluctance to accept the term carer restricted their access to outside help. The data suggest that the care of long term, self-managed conditions may be more implicit than in other illnesses, further impacting on perceptions of the carer role. However, the resistance was not universal; many employed language pragmatically as shorthand to communicate their experience and a minority were comfortable adopting the term.

**Thursday 12 September 2013****10:50 - 12:30**

Symposium

Derwent Room 036

*Compton, R.**King's College London***Medical Sociology and Climate Change**

Growing – though far from universal - public recognition that climate change may seriously threaten the quality and even viability of human life, has to some extent been reflected in the response by general sociology (e.g. Giddens, Urry), though arguably in a somewhat limited and tardy way. However, with honourable exceptions (Willis 2009), research and texts in medical sociology have continued to ignore climate change almost completely, even though the potential health impact has been addressed in major medical journals, and implications for health care recognized both by the NHS (nationally and in

## PAPER ABSTRACTS

specific services), and by supporting industrial sectors like pharmaceuticals. UK medical sociologists have largely failed even to assess such discussions of climate change's significance, let alone make their own - despite specific health and illness issues receiving scant attention in the mainstream sociological contributions.

In response to such an apparent lack of theoretical interest, avoidance of public engagement, and neglect of disciplinary opportunity, I aim to show how resources within the specialism have the potential to throw new light on a number of topics, for example: (i) the impact of climate change on health, (ii) its implications for the aims and organisation of health care, (iii) lay health and illness concepts and actions, (iv) expert accounts of health and illness, and (v) theory in medical sociology. I also show how resources developed elsewhere can both challenge and extend the existing analytical repertoire of the sociology of health and illness.

**Wednesday 11 September 2013**

**12:45 - 13:15**

Politics of Health

Derwent Room 037

*Coomber, R.*

*University of Plymouth*

### **Prejudice or Epidemiology: Public Health Concerns over Spitting in the Developing World**

This paper will look critically at the much assumed notion that public spitting carries with it the meaningful possibility of disease/virus transmission - particularly in much of the developing world. This will be undertaken primarily from Elias' concept of the civilising process and will argue that rather than understanding the many campaigns against public spitting as situated in epidemiological evidence it may be more fruitful to see them as 'moral' campaigns that have strategically chosen to append widely believed (and often unquestioned) notions of disease transmission as proof that public spitting is both disgusting and dangerous. With reference to field research carried out in 2013 on the nature of public spitting in India, Malaysia, Indonesia, Japan, South Korea, China and the UK it will be argued that public spitting takes many forms, proffers varying levels of acceptability and meaning but is increasingly being hijacked through an exaggeration of risk by political bodies and cultural movements concerned with the 'outfacing' image of their locale. As such, looked at through the lens of process and societal change rather than that of sensibility and risk it will be further argued that traditional local practices are being pushed out of existence by a will to civilisation and an internalisation of certain westernised manners.  
*Griffiths, M., Blakeman, T*

**Wednesday 11 September 2013**

**12:45 - 13:15**

Experiences of Health and Illness

Derwent Room 003

*Cooper, R.*

*University of Sheffield*

### **Medicine Addiction and Identity**

Drawing on recent empirical data and also the wider addiction literature, it is argued that the identity claims made by, or constructed around, individuals reporting addiction to licit (over-the-counter (OTC) and prescription) medicines may be distinct from other forms of addiction. The latter, as identified in the mainstream addiction literature, often also rely on definitions of identity that are framed around recovery, deficit and abnormal practices. Even if recent trends towards narrative approaches are accepted in the mainstream addiction literature, there remain important differences. It is argued that this contrast between licit medicine addiction and other forms of addiction (illicit, gambling, alcohol) can be viewed in terms of, and have wider implications for, treatment options, the morality of addiction, risk, control, consumption and personal and social identity. However, it is also important to recognise that 'licit' medicines are not a convenient catch-all label and that differences between prescription and OTC medicines in terms of consumption, iatrogenesis, blame, support groups and group identity are also important in framing this issue. In setting-up these differences and hinting at iatrogenesis for example, the aim is not however, to re-enforce a biomedical model of addiction with a causative origin or privilege autonomy and loss of control - but to argue that there are differences but which require a sociologically grounded perspective to be best understood.

**Thursday 12 September 2013****10:50 - 11:20**

Experiences of Health and Illness

Derwent Room 056

*Cooper, S.**University of the Witwatersrand***Explaining the Inexplicable: Narratives of Fibromyalgia Experience in South Africa**

This study investigated the experiences of people with medically ill-defined conditions in the South African context. Through a focused study of fibromyalgia (a musculo-skeletal pain disorder), the ways in which a patient draws on government, biomedicine, institutions, family and social networks to navigate their way through a contested and confusing illness experience was explored.

The study aimed to investigate the processes linked to legitimizing fibromyalgia as a disease and the individual as a patient as well as experiences of delegitimization that emerge in the face of uncertain prognosis and ineffective treatment options.

The study themes included: uncovering the dominant views of health and illness that contribute to the social construction of an illness experience, explaining the trajectory of fibromyalgia patients' illness experience through interactions with institutions, practitioners and social networks of family and friends. Understanding the ways in which diagnosis affords the patient entry into a legitimate social 'sick role' through the acquired medical label, and confirms their experience as medically and socially real, but then rejects their experience when biomedicine cannot adequately account for neither the causes, effects and treatment of the conditions was another aim of the study.

Exploring the role of diagnosis and prognosis as a site of contestation, legitimacy and uncertainty was a core aim included in the study. The main research methods utilized in were interviews and narrative diaries. This presentation will detail the preliminary findings of the research process thus far.

**Thursday 12 September 2013****17:30 - 18:00**

Lifecourse

Derwent Room 037

*Coxon, K., Sandall, J., Fulop, N.**King's College London***Choice, Constraint and Risk in Birth Place Decisions: How do Events During Pregnancy and Birth Influence Planned Place of Birth, in Current and Future Pregnancies?**

Choice of place of birth has been encouraged in English health policy for two decades, but most women still give birth in hospital labour wards. Existing literature proposes that birth place preferences can be explained by socio-economic class, culture and ethnicity, but few contemporary studies detail the experience of planning where to give birth or document the influence of risk discourse upon these decisions.

This longitudinal narrative study followed 41 women through pregnancy and the early postnatal period. A maximum variation sampling strategy led to recruitment of women with diverse backgrounds, parity and pregnancy risk profiles. Longitudinal analysis explored change and consistency in perceptions of birth place risk and safety, using concepts derived from sociocultural risk theories.

Women often did not feel they were in a position to decide where to give birth, particularly those who were less affluent or non-graduate, or whose experiences were mediated by discourses of clinical risk and individual responsibility. Most women planned to give birth in hospital and did so; following birth, they would usually do the same in future, even if their births were straightforward. The experience of hospital birth appeared to reinforce a risk-averse expectation that hospital, as a site of technological activity, was the most appropriate setting for birth. An alternative perception that technology posed risks either to 'normal birth', or to sensitive care during labour, motivated others to plan birth in non-hospital settings. These findings are discussed in relation to the ongoing international debate about place of birth in high-income countries.

**Friday 13 September 2013****11:20 - 11:50**

Experiences of Health and Illness

Derwent Room 056

*Crabu, S.**University of Padua***The Clinic Dates Laboratory: Bio-objectification of Human Research Subject in Cancer Clinical Trials**

As has been highlighted by the social studies of medicine, patients are increasingly subject to the epistemological subsumption of biomedical research processes. It should be noted that this process reflects the emergence of new biomedical fields within which the traditional boundaries between clinical practice and scientific research have been broken down.

In this contribution - based on ethnographic observation of an Italian laboratory of cancer pharmacogenomics and experimental therapeutics - I will investigate the clinical-experimental practices deployed on the body of the human research subject enrolled in a cancer pharmacogenomic trial. This clinical trial is addressed to define a new chemotherapy regimen customized on the genetic profile to treat colorectal cancer.

From an analytical point of view, it is fundamental to pay attention to the bio-objectification of patients' bodies which is articulated through their involvement in scientific R&D and clinical practices. As will be shown during the presentation, the bodies of the patients involved in the clinical and R&D activities are not static and immutable, but rather flexible and exposed to bio-objectification processes that represents them in terms of 'genes', 'metabolites' and so on. In this sense, the bio-objectification can be seen as the process by which the biological bodies of patients are abstracted and segmented into a set of biological entities in order to produce and stabilize a new therapeutic option. The reflection will show how the category of bio-objectification represents an analytical tool to understanding the relationship between laboratory life and clinical practices within which patients are becoming more involved.

**Friday 13 September 2013****11:20 - 11:50**

Health Service Delivery

Derwent Room 104

*Cramer, H., Hughes, J., Evans, M., Featherstone, K., Timmis, A., Hemingway, H., Deaton, C., Johnson, R., Feder,**University of Bristol***Working Across and Against Boundaries: An Ethnographic Study of Heart Attack Care in 10 UK Hospitals**

The fragmentation of medicine makes the care of some health issues, such as Non-ST segment elevation myocardial infarction (NSTEMI heart attacks), particularly challenging. Using the relational concept of boundaries, there are two main ideas of cooperation (e.g. Star and Griesemer 1989, Star 2010) and policing (e.g. Gieryn 1983) that relate to how people in organisations work together between different disciplines, roles and across spaces. This paper is based on the VICC study, an ethnographic study of 10 hospitals in England and Wales. This study showed that cross boundary working was needed to address the fragmentation of medicine and for good NSTEMI patient care to be achieved. For example, cross boundary care such as nurse prescribing and overnight cardiac registrar care extended traditional responsibilities for patients between staff, across physical ward spaces and normal working hours. Some attempts at cross boundary working such as remote telemetry did not seem to work in practice. Boundary policing generally seemed to be in opposition to cross boundary working and these examples were usually of poorer care, although there were exceptions. Boundary policing on a larger scale seemed to characterize the relationship between many larger tertiary hospitals and smaller district hospitals. The fragmentation of care into specialisms, the locations, layouts and adjacencies of hospital wards had consequences for patient care and responsibilities that some cardiology departments seem able to address and overcome more than others. Despite the recognition of the need to reduce boundaries, we explore their continued resilience and power in this setting.

**Thursday 12 September 2013****15:45 - 16:15**

Methods

Derwent Room 049

*Crang, C., Ngwenya, N., Barclay, S.**University of Cambridge***What is Important in Palliative and End of Life Care? Multiple Perspectives and Different Methods Help Understand Individual Experiences**

This paper considers a methodology employed to help understand the care, support and information needs of those with palliative lung cancer and severe COPD. One patient from each disease group, their carer/supporter, nurse and General Practitioner (GP) were recruited from the same GP Practice. Semi-structured interviews were undertaken with all participants, along with participant-generated (Pictor) charts concerning patients' experiences of both lay and health professional care provision. Pictor charts provided a way for participants' to voice their thoughts and feelings about their care. Longitudinal interviews with a subgroup of patients and their supporters provided additional information about potential transitions from palliative to end of life.

Recruitment was not without problems. 10 complete clusters of participants were recruited, four part-clusters (lacking a nurse or supporter), and 12 non-clusters (lacking a lung cancer patient, COPD patient, supporter, nurse or GP). In total 18 COPD patients, 22 lung cancer patients, 29 nurses or allied health professionals and 20 GPs were recruited.

The data has enabled comparisons to be made between the experiences of those with malignant and chronic disease as well as between GP practices. For example, what care patients found important, how health professionals and others provided care, the character of high quality care, what information patients needed and why it was not necessarily provided, the nature of transitions from palliative to end of life care and the differences between the two groups of patients. Within a changing NHS, the result should provide a basis for better care provision in the future.

**Friday 13 September 2013****09:35 - 10:05**

Open

Derwent Room 049

*Cronin, J., McCarthy, M.**Lancaster University***Dabbling with the Devil's Candy: A Life Course Perspective on the Food Consumption Stories of Obese Adults**

Rates of obesity continue to rise counter to the medicalization of the marketplace and consumers' preoccupation with thinness, diet and health. Furthermore, chronic obesity-related illnesses now threaten to reach epidemic proportions, placing heavy pressures on the individual, society and the economy. Using the work of Foucault and Bourdieu, this paper reports on findings from a series of narrative-biographical interviews conducted with 21 obese Irish adults to offer a confessional perspective on these consumers' relationships and experiences with food. We suggest the pathways that are conducive to weight gain are enmeshed in participants' life trajectories and everyday experiences across the domains of identity; context; and the body. Sub-optimal eating practices are discussed as central to the gendered habitus of mothering or 'being a lad', and construction of these relational identities is at odds with the engagement of certain technologies of self i.e. practices of self-care. Furthermore we reveal how socio-cultural environments and life stages come with their own site-specific habitus and transposable ways of consuming. Finally we consider how an amalgam of bio-social characteristics coupled with these dispositions frame how individuals use food in their responses to significant life occurrences. The findings contribute to the sociology of health and illness as they expand our understanding of obesogenic determinants. 'Obesogenicity' must be recognised as more than a construct of 'built' and social fields, and understood as embedded in the food norms, habits and practices that are embodied and reproduced across life stages and experiences. Implications for policy are discussed.

**Thursday 12 September 2013****14:00 - 14:30**

Health Policy

Derwent Room 104

*Dal Secco, A.**London Metropolitan University***Translating Gender-based Violence into a Public Health Issue: a Pilot Study of How Health Care Providers Identify and Manage Domestic Violence**

Background. Domestic violence is a human rights violation, which damages women's physical and mental health with long-term consequences also for their children. As in other European countries, in Italy about 30% of women have experienced domestic violence in their lifetime.

While domestic violence has been internationally acknowledged as a large and severe public health issue, the National Health System's capacity to deal with the problem has been poorly effective in terms of prevention and care. To address this issue in Italy, the Department of Equal Opportunities has recently issued a national pilot programme to assist victims of gender-based violence, delivering training to health care providers and setting up specialised services within the public health system.

Objective. To survey health clinicians participating in this national training programme and measure their clinical preparation and skills, knowledge and opinions in this field.

Method. A selected number of health settings within the programme have been contacted and filled a questionnaire Physician Readiness to Manage Intimate Partner Violence Survey, which was adapted from the UK to the Italian context, to analyse five areas: respondent profile, background, knowledge, opinions, and practices.

Results. 95 health care providers, including specialised doctors and nurses, responded. Clinicians proved comprehensive of abused women's difficult conditions and willing to offer them specialised support, though they expressed a need for further knowledge and resources to provide appropriate responses. Moreover, a focus on psychological explanations sustains a tendency to individualise the issue in detriment of integration with its gender and social dynamics.

**Friday 13 September 2013****11:20 - 11:50**

Risk

Derwent Room 037

*Dalrymple, J., Booth, J., Flowers, P., Lorimer, K.**Glasgow Caledonian University***A Qualitative Study of Late Middle Aged Heterosexual Adults' Negotiation of Partnerships Within the Context of Risks for Sexually Transmitted Infections.**

Adults aged 45-65 years are engaging in sexual behaviours within an environment in which the impact of the culture of the new ageing, Internet dating and pharmaceutical interventions for sexual dysfunction on their sexual experiences are as yet unclear. There is also sparse evidence on whether this 'baby boomer' generation view their sexual selves through ageist or gendered norms. There has, however, been a steady rise in sexually transmitted infection rates among the over 45 age group in recent years (Health Protection Agency, 2010). The development of effective sexually transmitted infection (STI) prevention interventions requires evidence on adults' negotiation of partnerships within the context of risks for STIs.

This paper describes a qualitative study of in-depth, individual interviews with heterosexual adults aged between 45 and 65 years, recruited from a large city NHS sexual health service, city council run leisure facilities and a social networking website. Thirty episodic interviews, addressing selected experiences over the course of participants' lives (Flick, 1997) were conducted to explore adults' approach to sexual risk at different life stages in order to identify possible generational, cultural and social influences. The role of alcohol and the gendered nature of sexual negotiations were considered within this study. This paper will describe the emerging findings around men's and women's perceptions of risk within new partnerships and key factors influencing sexual behaviour. The paper will conclude by considering potential future initiatives from the perspective of STI prevention interventions. *Hemingway, H., Deaton, C., Johnson, R., Feder,*

**Thursday 12 September 2013****09:05 - 09:35**

Complimentary and Alternative Medicines

Derwent Room 047

*Danell, J. A.**Umeå University***Negotiating Integrative and Complementary Medicine in the Public Domain**

In almost all western societies there are (more or less) distinct boundaries between conventional medicine and different forms of integrative and complementary medicine (ICM): from juridical boundaries on who is allowed to diagnose and treat patients to general opinions on what is considered as reliable medical or scientific knowledge. These boundaries are negotiated by very different actors (from researchers and practitioners to politicians and laymen), with help from different arguments, and are changing over time. The aim of this paper is to analyze how ICM is defined and negotiated in Swedish public documents. How are the boundaries of ICM and conventional medicine defined? What is conceptualized as problematic or in need of political intervention? What interests are in focus? What kind of solutions are suggested or implemented? The documents are restricted to government bills, submissions, committee reports, and laws from the Swedish parliament, from the 1980s until today.

The results indicate a clear shift in the use of terms, but also contradictions and ambiguity on how to draw the boundaries. Some of the recurrent problems are formulated in terms of risks/side effects of treatments, deficient public health care, societal costs, unequal conditions between ICM and public health care, and difficulties for patients to value or compare ICM treatments, which has led up to general goals of integration, equal conditions, and patient security. Some of the suggested solutions are legislative changes, integration of ICM in public health care, support of ICM research, and an official ICM register.

**Thursday 12 September 2013****14:35 - 15:05**

Inequalities

Derwent Room 036

*De Maio, F., Llovet, I., Dinardi, G.**DePaul University***Chagas Disease in Non-endemic Countries: 'Sick Immigrant' Phobia or a Public Health Concern?**

In recent years, the literature on neglected tropical diseases (NTDs) has advanced in significant ways: there is a renewed sense of urgency in World Health Organization reports, new specialized journals have been launched, and advocacy groups are leveraging social media to gain attention to the burden of NTDs around the world. But as the literature in this field develops, there is a danger of an important split between (a) work that recognizes the profound geopolitical patterning of NTDs, and focuses accordingly on structural factors that lead NTDs to thrive in some areas of the world and not in others; and, alternatively, (b) work that 'securitizes' global health and thereby focuses on the 'risk' posed by NTDs to population in non-endemic countries. Our work examines this schism through the example of Chagas disease, the most important parasitic disease in Latin America. Our analysis questions the implications of the increasing attention given to this disease in non-endemic countries.

**Thursday 12 September 2013****16:55 - 17:25**

Inequalities

Derwent Room 036

*Dikomitis, L., Birks, Y., Oliver, S., Macleod, U.**University of Hull***The Effect of the NHS Reforms on Health Inequalities: Example from the Humber Area in the North of England**

This paper deals with the new NHS structures through the prism of health inequalities, and explores the progress of the move of public health to local authorities. Prior to the recent NHS reforms, public health related initiatives were commissioned by the Primary Care Trusts (PCTs), based on local needs assessment and analyses of health inequalities. The PCTs have been replaced by the Clinical Commissioning Groups (CCGs), which have many challenges to face as they take on commissioning responsibility and liaison over public health issues with local authorities and the new Health and Wellbeing Boards (HWBs). New relationships and partnerships will need to be forged between organisations which have hitherto had only limited contact. This is particularly true of local responses to health inequalities; a key issue for the Humber area where this research was conducted.

## PAPER ABSTRACTS

Methods - 25 in-depth semi-structured interviews with respondents from the four shadow CCG boards and shadow HWBs in the Humber area were conducted between October 2012 and February 2013 and analysed via thematic coding.

Findings - In this paper we present an analysis of how the dynamic between the new institutions, CCGs and HWBs, influences strategies to reduce health inequalities. We focus on the cultural divide between the different organisations and groups of professionals (clinicians, managers, local politicians and lay board members) involved. In doing so, we highlight the different ways in which each has dealt with the new clinical leadership and how each group has its own understanding of health inequalities.

**Wednesday 11 September 2013**

**15:40 - 16:10**

Politics of Health

Derwent Room 037

*Dimond, R., Bullock, A., Stacey, M.*

*Cardiff University*

### **Smart Phone Technology as Mobile Information Resource: The Changing Pace and Place of Professional Socialisation and Patient Care**

This presentation reports on the transformative potential of mobile technologies in medical work, revealing the practical challenges of medical education combined with ward based practice. Two issues are explored: the role of mobile resources in professional socialisation and the production of mobile etiquette in medical spaces.

The Wales Deanery funded 'iDoc-project' supports newly qualified doctors by offering an internet-free package of medical textbooks with cross-text search facility for use on a smartphone. This aims to assist the transition from medical school to workplace, a period associated with high levels of stress and depression and increased patient mortality.

Users of the resource complete a baseline questionnaire and submit at least two case reports which detail specific instances of mobile use. The 135 case reports submitted so far contain rich and detailed stories of the benefits and challenges of mobile technologies. The reports suggest that 'just-in-time' information resources can support transition by increasing confidence in decision making, greater efficiency, generating independence and improved patient care. Mobile resources are also being used to 'clue up' before engaging with seniors, improving conversations and enabling newly qualified doctors to access a higher level of professional engagement.

However, considerable challenges and tensions are also revealed. As a 'bottom up' technology, junior doctors are not gaining tacit knowledge of how to integrate mobile resources with patient care through contact with their seniors. Uncertainty surrounding the etiquette of mobile use has the potential to become a barrier between doctor and patient.

**Thursday 12 September 2013**

**14:35 - 15:05**

Lifecourse

Derwent Room 037

*Dolan, A., Lomas, T., Hartshorne, G.*

*University of Warwick*

### **Men, Masculinity, and Infertility: Towards a Theoretical Understanding of Men's Experiences of Infertility and its Treatment**

In the UK, it is estimated that infertility affects one in seven couples. Male-factor infertility accounts for around one-third of all infertility problems and contributes to an additional one-third of cases where the cause is attributed to both male and female factors. However, research which takes account of masculinity in relation to infertility is in its infancy and tends to be retrospective in nature, with men reflecting on their experiences of infertility from the vantage point of having assumed a parenting role, either through IVF, adoption or donor insemination. Consequently, expressions of active desire for a child and the potential for pain concerning failure are missing. Previous studies have also not explored the views and attitudes of health care professionals concerning masculinity and how these may mediate men's experiences when undergoing infertility treatment. This paper draws on evidence from a qualitative study which investigated how men experience infertility and infertility treatments, whilst they were in the process of undergoing treatment. The study also explores the experience of health care professionals working with men undergoing infertility treatment.



**Wednesday 11 September 2013****15:05 - 16:45**

Symposium

Derwent Room 006

*Doyal, L.**University of Bristol***Shaping a Social Science Perspective on the Pandemic: a Preliminary Overview**

This presentation will provide a brief introduction to the themes that need to be explored in making sense of life with HIV across a range of settings. The focus will be on the mix of conceptual and methodological questions that are raised in trying to make sense of individual experiences of HIV in local settings within a global context. How can we explain the nature of different epidemics as well as the marked inequalities in the fate of those who are positive within the same settings? How can an intersectional perspective help to make sense of these variations? These themes will be explored through an examination of different aspects of life with HIV: changing narratives and identities, labour and livelihoods, altering sexual practices and renegotiating reproduction and parenting.

This presentation will be based on Doyal L (2013) *Living with HIV and Dying with AIDS: inequalities and human rights in the global pandemic* <http://www.ashgate.com/isbn/9781409431114>

**Thursday 12 September 2013****09:40 - 10:10**

Health Care Organisations

Derwent Room 003

*Doyle, E.**University of Edinburgh***Healthcare at the Boundaries: Understanding the Role of NHS 24**

NHS 24 is a 24-hour helpline providing assessment, triage and where necessary, referral to out-of-hours services in Scotland. There are a number of challenges when situating the role of NHS 24 as a healthcare provider, and these are best understood in the context of its organisational history. It is available 24 hours a day, but is most commonly understood to be an out-of-hours service; people should call if symptoms are too urgent to wait for a GP surgery to open, but are not discouraged from calling for advice and reassurance. Data from my PhD research suggests that both service providers and service users have somewhat ambiguous understandings of the role and purpose of NHS 24, which in some cases leads to anxieties about what might constitute 'appropriate' service use. However, NHS 24 has high satisfaction ratings, which suggests that this ambiguity does not prevent the service from effectively meeting the needs of callers. This paper responds to recent calls for medical sociology to re-engage with the sociology of organisations. I explore the idea that NHS 24's location at the boundaries of primary, emergency and self-care and at the boundaries of different social worlds may be creating a new space which allows people to interact with health services in a way which meets their individual needs.

**Thursday 12 September 2013****12:00 - 12:30**

Health Policy

Derwent Room 104

*Dumbili, E.**Brunel University***'Drink Responsibly', Die Irresponsibly? An Exploration of How the 'Lion is Lying with the Lamb' in Alcohol Advertising, Marketing and Promotion in Nigeria**

Globally, alcohol consumption and alcohol-related problems are increasing rapidly, especially among young people, due to factors such as sophisticated alcohol marketing and easy availability. In Nigeria, alcohol marketing and availability are pervasive due to non-regulation, thus giving rise to increasing alcohol use among young people. Nigeria is among the 30 countries globally with the highest per capita consumption and second in Africa, while its females' consumption ranks first. It is among the 10 countries globally with the highest road traffic accidents traceable to alcohol misuse, yet without a corresponding alcohol policy to date. As part of an on-going study, this paper examines brewers' role in alcohol misuse among Nigerian youths. It adopts a public health perspective to analyse the consequences of the unregulated alcohol adverts, marketing, promotion, 'social responsibilities' and sponsorship by alcohol producers in Nigeria. It argues that these have resulted in misconceptions about alcohol-related benefits among Nigerian youths and discusses the consequences for the contemporary Nigerian society. The paper questions the rationale behind the brewers' drink responsibly campaign and the recent inscription of alcohol by volume (ABV) on product labels by Guinness Nigeria. It argues that these are attempts to silence policy formulation or to encourage ineffective ones. The paper concludes that to reduce alcohol-related problems in Nigeria, there is an urgent need to regulate alcohol adverts, marketing and availability through effective policies.

**Friday 13 September 2013****09:00 - 09:30**

Health Service Delivery

Derwent Room 104

*Dyb, K.**University Hospital of North Norway***Do Telestroke Disrupt Professional Identities and Inter-professional Relations?**

New information and communication technologies have far reaching implications for the organization and delivery of health care. The use of telemedicine is promoted in political strategies and policy documents worldwide. Telestroke is the specific term used for the application of telemedicine in stroke treatment. In Norway, stroke is the third most frequent cause of death and the most common cause of severe disability in adults. Timely treatment and hospitalization in specialized stroke units are essential to reduce mortality in the acute phase and disability after stroke. Lack of stroke experts in non-urban areas is a challenge to high quality treatment in Norway. Telestroke has been implemented to transfer expert knowledge to small hospital with limited neurological services. However, telestroke is not only a tool to provide expert treatment to rural stroke patients; it also contributes to new communication patterns and new ways of organising working life. A process of change is evolving; involving identities and relations between professionals on the one hand, and communication systems and technologies on the other. We explore how telestroke might disrupt established communication routines and professional identities. The argument is worked through a case study of two telestroke services, and shows that while telestroke is considered a success at one local hospital, the story is rather different at the other. Our analysis reveals how practices and performances of telestroke are tied to the practices and performances of local differences, and how telestroke offers new possibilities for knowledge formation and ownership, professional roles and inter-professional relations.

**Friday 13 September 2013****11:20 - 11:50**

Lifecourse – Death and Dying

Derwent Room 003

*Dzeng, E.**University of Cambridge***Understanding the Changing Nature of the Physician Patient Relationship Through the Do-Not-Resuscitate Decision Making Process: A Comparison Between the US and UK**

In the United Kingdom, recent controversies surrounding end of life care, such as with the Liverpool Care Pathway, highlight increasing demands for autonomy in health care decisions and a growing lack of trust in the medical profession. Drawing from the works of Eliot Friedson, John McKinlay, and Marie Haug, I explore how deprofessionalization and consumerization have compromised the physician's ability to maintain power in individual patient interactions. Loss of physician authority shifts decision-making power towards patients at the expense of physician control over clinical decisions. These factors may contribute to problem of overtreatment, of which overly aggressive treatment at the end of life is exemplar.

Using the example of the Do Not Resuscitate (DNR) order, I discuss how decisions made between physicians and patients, reflect changing power dynamics and threaten the physician's ability to act in the best interest of their patient. I will make comparisons between the UK and the United States, where this professional social transformation arguably occurred decades ago. An increasing prioritization of choice and patient autonomy over clinical judgment, has contributed to spiraling health care costs in America and threaten to do so in the UK. Furthermore, prioritizing unrestricted choice in medical care at the expense of clinical judgment, forces physicians to perform futile therapies that they may believe are harmful to the patient and ethically unacceptable.

**Thursday 12 September 2013****14:35 - 15:05**

Lifecourse

Derwent Room 002

*Ellis, C. L.**University College Dublin***Recognising Identity among Those with Chronic Illness**

The forecast for chronic illness has projected that an additional 523,000 people will suffer from a chronic illness by 2020 (Institute of Public Health, Ireland). This paper aims to display that recognising identity among those with chronic illnesses can lead to improvements in quality of life. The case study is the chronic autoimmune illness systemic lupus erythematosus (SLE), where relief is reliant on the management (Greco et al. 2004) and coping strategies (Bricou et al. 2006) of the individual. SLE places the individual's performance within daily life in uncertainty, where status, roles and routines fluctuate,

effecting the individual's well-being socio-economically. This paper will examine how social frameworks (relationships, employment and healthcare) contribute towards well-being and life quality, providing insight into the social identity of the individual with SLE and the subjective experiences of this chronic illness. The issue of chronic illness is both personal and social which makes the issues an ideal subject for sociological study, as it provides a concrete route to understanding the interaction between 'private troubles and public affairs' (Mills 1959). The research will provide insight in how the individual with SLE adapts and accultures to their new identity, due to performance and role change, examining their perspectives and experiences as the individual with an illness that is triggered by social stressors (Avitsur et al. 2006; Stonjanovich 2010; Roussou et al. 2011) live within a stressed economic climate.

**Wednesday 11 September 2013**

**13:55 - 14:25**

Politics of Health

Derwent Room 037

*Ellis, K., Polzer, J., Rudman, D., Kothari, A.*

*University of Western Ontario*

**Health Research and Knowledge Translation in a Knowledge Economy**

Proposals for funding of health research in Canada generally require an explanation of how research results will be translated into knowledge that will lead to improved health and health care system for Canadians, and/or useable information for clinical or policy decision makers (i.e. 'knowledge translation'). In this presentation, I examine how three prominent discourses related to health and health care, financial accountability, and economic prosperity contribute to the construction and positioning of knowledge translation as a technology of governance for health research in Canada. Informed by a governmentality perspective, I draw on findings from a critical discourse analysis of key public documents pertaining to knowledge translation from the Canadian Institutes of Health Research (CIHR). Specifically I consider how knowledge translation becomes positioned as a technology through which the value and use of health research is discursively constructed in ways consistent with the expectations created with the three dominant discourses: 1) a 'gap' between health research findings and their application health care; 2) the need to demonstrate financial accountability related to a return on investment in health research; and, 3) ensuring economic prosperity and global leadership for Canada through innovation and commercialization of health research. The relationship of these findings within the context of new public management practices in Canada will also be considered.

**Wednesday 11 September 2013**

**14:30 - 15:00**

Professions

Derwent Room 036

*Exworthy, M., Hyde, P., McDonald-Kuhn, P.*

*Royal Holloway, University of London*

**'Stuffing their Mouths with Gold'? Resistance to Reform of Doctors' Bonuses**

Medical power is pervasive but one aspect which has remained relatively neglected (in policy and research) is doctors' pay. We examine professional power in terms of the ways in which doctors have been able to sustain control over pay. We elaborate theoretical perspectives on professional power in terms of clinical excellence awards, the 'financial bonuses' which are paid to about half of all hospital specialists and which can be as much as £75,000 per year in addition to NHS salary. These awards were established at the outset of the NHS and since then have remained largely untouched by policy reform and also relatively under-researched. Through a textual analysis of responses to a recent review of doctors' pay, we examine the arguments used by professional, managerial and governmental stakeholders in defending or reforming these awards. We argue that doctors have maintained strong uni-professional networks and have permeated organisations at all (policy and clinical) domains. The effect has been to nullify any reform to their 'bonuses' which is seen as an explicit threat to their power. This case-study illustrates the enduring and flexible power of the medical profession in the UK.

**Thursday 12 September 2013****16:55 - 17:25**

Patient - Professional Interaction

Derwent Room 047

*Farooq, G. Y.**University of Manchester***Interactions Between Marginalised Patients and Marginalised Doctors: A More Reciprocal Relationship?**

While different theoretical perspectives on doctor-patient encounters have been put forward, what is agreed among sociologists is that medicine acts as an important institution of social control. Nearly all theorists on the doctor-patient relationship have described the way in which powerful groups in possession of medical and scientific knowledge have been privileged over others. Criticism of these standard theories have centred on their tendency to focus on the micro-properties of interactions of doctors and patients rather than incorporating an analysis that includes the macro-level social and political context within which such encounters take place. Almost all existing studies focus on the powerful positions that the medical practitioners hold and portray patients as disadvantaged in one way or the other.

This paper presents the empirical evidence from in-depth interviews with 27 overseas-trained South Asian general practitioners in the UK which shows that the standard theories concerning socio-cultural dimension of western medicine do not necessarily apply to the experiences of overseas-trained South Asian general practitioners in their interaction with patients. The asymmetry in power relationships in the clinical discourse is reversed when this encounter is between a white patient and an overseas-trained South Asian migrant doctor as both bring an imperial element into the encounter. The specific UK contexts such as post-industrial towns and inner-city locales serve as spaces where identities of practitioners and patients are simultaneously negotiated against a backdrop of the legacy of the empire. The insights into their relationships show that they are characterised by reciprocity than medical dominance.

**Friday 13 September 2013****10:45 - 11:15**

Open

Derwent Room 049

*Fergie, G., Hilton, S., Hunt, K.**MRC/CSO SPHSU, University of Glasgow***Engaging with Diabetes and Mental Health Content Online: Young Adults' Perspectives on Sharing Experiences Through Social Media**

Social media are increasingly being used by individuals and organisations to create and share online content about health and illness. Tweets, status updates, comments, images, video clips and blogs convey varied insights into personal experiences of health and illness, self-management strategies and new research and innovations. To explore the ways this online health-related content is interpreted and appropriated, and the impact of online information-seeking on experience, 40 young adults, aged between 18 and 30, with experience of either diabetes or a common mental health issue took part in in-depth, semi-structured interviews. Our preliminary analysis of the data produced suggests the complexities inherent in people's expectations and perceptions of online content about both diabetes and common mental health issues. The social media environment is both dynamic and intricate and negotiating it seems to involve various considerations around the presentation of identity and health and illness. Conceptions of expert and lay knowledge, expectations of individual differences and commonalities, and management of identities all seemed to impact how the young adults perceived and used online health-related content.

**Thursday 12 September 2013****16:20 - 16:50**

Patient - Professional Interaction

Derwent Room 047

*Fielden, S., Ledger, A.**University of Leeds***Professionalization of Patients: What is the Problem?**

The language of involvement, collaboration and partnership has been a central part of public policy for the past 15 years (Glendinning et al., 2002, Powell & Dowling, 2006). Within healthcare specifically this has led to an emphasis on patient and carer involvement in education, research and service development in order to improve health care services and patient care (Department of Health 1999). Increased and varied involvement has resulted in concern from some quarters that patients are viewed increasingly as professionals, an identity deemed separate and distinct from that of patient (Wright and

Rowe, 2005; Cowden and Singh, 2007 and Jha et al. 2009). The assumption is that as patients become professionalized through repeated involvement, their narrative loses elements of authenticity. This study will draw on two studies, which explored patients' experiences of involvement in medical education. Our interviews revealed the benefits of involvement for patients' wellbeing and their interactions with health and social care professionals, as well as the importance of peer support and training for their development. These findings put into question assumptions that 'professionalization' poses risks to students' learning, to the wellbeing of patients, and to interactions between patients and professionals. We will argue that further sociological research is needed to test these assumptions. A Bourdieuan analysis of patient educators may be particularly helpful in understanding patients' development through involvement initiatives and the changing relationships between patients and professionals.

**Thursday 12 September 2013**

**10:15 - 10:45**

Health Care Organisations

Derwent Room 003

*Field-Richards, S. E., Timmons, S., Noke, H.*

*University of Nottingham*

**Lean on me: Nurses' Emotional Work and Labour in Lean Times**

Background: Lean Thinking (Lean) is a management philosophy originating from the Japanese automobile manufacturing company, Toyota. Lean has been applied widely within the NHS as a means to address the financial, quality and safety challenges that it faces. Implementation requires that traditional NHS culture and ways of working be challenged and evidence suggests that Lean is changing the way in which healthcare is physically and socially organised, managed, structured and delivered. Emotional work and labour, together with the related concepts of caring and compassion, have been highlighted as pivotal components of nursing care, identity and culture. Whilst currently high on the public and professional agenda, there is a dearth of research examining the way in which Lean interacts with and affects opportunities for the expression of these elements within nursing practice, the nature of their manifestation in the context of Lean healthcare and the resulting professional implications.

Aim: To provide a conceptual and empirical analysis of the interaction between Lean and nurses' emotional work and labour.

Methodology: A seven month ethnographic study of nurses working on three wards at an NHS Trust, employing methods of observation and semi-structured interview.

Contribution to knowledge: Findings hold particular relevance for the sociology of professions. Themes of professional identity, collectivity and culture, boundary work, negotiations of power, role, status, and the changing nature of professional knowledge and work, are drawn upon in order to provide a contemporary insight into the profession of nursing in the context of organisational change.

**Friday 13 September 2013**

**10:45 - 11:15**

Critical Public Health

Derwent Room 006

*Fletcher, I.*

*University of Edinburgh*

**Is Poverty Really Healthier? Contemporary Obesity Science, 'Traditional' Diets and the Nutrition Transition**

Dominant accounts of present-day public health are framed in a broad historical narrative that emphasises the importance of a number of 'transitions' most notably the demographic and epidemiological transitions. These accounts underline the idea that we live in a time of both particularly good health, and of specific forms of degenerative illness that can be attributed to 'modernity'. Modernity is understood rather vaguely as a condition of economic and material plenty that is quite distinct from the constitution of earlier 'traditional' societies. In my presentation, I will demonstrate how obesity science – knowledge about the causes, effects and treatment of excess bodyweight - has added to this narrative the further concept of a 'nutritional transition'. The nutrition transition results from processes of modernisation and industrialisation, and leads to both an increase in the amount of food available, but also a shift from healthy traditional diets and patterns of activity to more harmful lifestyles and forms of consumption. Through an analysis recent British and international public health nutrition reports, I will describe some of the ways in which the narrative of this transition was constructed in the work of a specific coalition of research scientists and clinicians. In so doing, I seek to demonstrate that other, more political, accounts of obesity and chronic disease might be seen as alternative and more appropriate ways of framing the health problems that confront industrialised societies.

**Thursday 12 September 2013****15:45 - 16:15**

Teaching Medical Sociology

Derwent Room 006

*Forrest, S.**Durham University***'Really Useful Knowledge': Teaching Learning About Key Concepts in the Sociology of Medicine and Health in the Context of Medical Education**

Changes in the regulations around medical education which foreground knowledge about the behavioural and social sciences in requirements for qualification as doctor in the UK reflect multiple influences. The changing nature of society – particularly aging populations and concerns about the relationship between lifestyle and health – the commitment and energy of sociologists to enhancing the profession's response to patient and population experience and need, and emerging recognition of the social basis and context of health and ill-health among the healthcare professions.

As a consequence, knowledge and understanding of the ways that health is socially determined and particularly the links between social and health inequalities is central to the agenda set out around the contribution of medical sociology to medical education.

This presentation draws on scholarship around pedagogy in the UK and Australia to describe and critically examine one approach to teaching and learning around these issues involving students engaging in placement-based learning in non-clinical, community-settings.

Alongside describing how these programme are organised, their content and structure I will seek to explore questions about the kinds of sociological knowledge that this emergent pedagogic practice draws on and the kind of knowledge about sociology that it seeks to progress among non-subject specialist students. I will also examine the risks and opportunities posed to students as learners and sociologists as teachers in engagement across their disciplines and examine what impact we believe this practice has and ask how we might reasonably expect to assess it.

**Thursday 12 September 2013****10:50 - 12:30**

Symposium

Derwent Room 036

*Fox, N.**Durham University***Health and the Environment: Shall We Change the Subject?**

This paper argues that sociological discussions of health and the environment have been constrained by an anthropocentrism that privileges human health, human bodies and human experience. While still informed by a public health sensibility concerning enhancing human health, I consider how an ecocentric or anti-humanist perspective can re-think the interaction between health and environment. I show that environment can usefully be thought of as an assemblage, within which bodies, things, ideas and social formations affect and are affected, with no privilege accorded to the human elements. 'Health' consequently must be considered relationally: not as an attribute of an individual, but as concerning the capacities for interaction that are produced in the assemblage of bodies, animate and inanimate objects and social formations that is 'environment'.

I use this approach to consider three environmental issues (city transport, water management, anthropogenic global warming), to show how human 'health' may emerge as a 'by-product' of a sustainable approach to environmental challenges. I suggest that this supplies a distinctive public health approach, with policy implications for the shaping of sustainable health services.

**Wednesday 11 September 2013****15:05 - 15:35**

Pharmaceuticals

Derwent Room 002

*Gabe, J., Coveney C., Williams, S.**Royal Holloway, University of London***Prescriptions and Proscriptions: Moralising Sleeping Pills**

The pharmaceuticalisation of insomnia is a contentious issue. Sleeping pills get a 'bad press' due to their potential for addiction/dependence and other side effects, including increased mortality risks. Expert bodies have long advised that prescription hypnotics should only be used to treat severe cases of insomnia, in low doses and for short periods of time. Despite efforts to reduce hypnotic prescribing in primary care, long term prescribing is still common and prescription rates remain fairly stable. Relatively little qualitative sociological research has been conducted into how people who have been prescribed sleeping pills understand and negotiate their use in the context of their everyday lives. We draw on

focus group data to elicit collective views on and experiences of hypnotic use across a range of social contexts. We found that our respondents drew on a variety of moral discourses which functioned to allow them to present themselves as responsible and reflexive users/non-users, to rationalise their patterns of use and to justify modifications they made to their treatment regimes. Our paper contributes to recent sociological work on the pharmaceuticalisation/ de-pharmaceuticalisation of everyday life and the consumption and consumerism involved in medicine in the UK today.

**Thursday 12 September 2013**

**08:30 - 09:00**

Complimentary and Alternative Medicines

Derwent Room 047

*Gale, N.*

*University of Birmingham*

**Making a Living (or Not) as a Complementary Medicine Practitioner: The Role of Social Networks**

In the context of a global financial crisis, pressure to reduce healthcare spending and ideological drives (in many centre right-leaning governments, such as the UK's) to shift responsibility for health from the state to individuals, complementary and alternative medicine (CAM) has retained a small but enduring position in the overall health system. Little is known about practitioners of CAM - their professional practices, their financial aspirations, their personal ambitions or how they are coping with this period of 'austerity'. I conducted ethnographic interviews and observations with 20 osteopaths and homeopaths in the UK for a study examining the experiences of mid-career graduates from CAM training courses. The research question was: After graduation, how do homeopaths and osteopaths negotiate building a career that is personally and financially sustainable, and continue to develop their professional knowledge and skills? In this paper, I analyse the data that were related to practitioners' social networks. In the absence of established career structures and in the context of a preponderance of independent working in CAM occupations, I describe the extent to which they are able to build a sense of professional community (including seeking referrals and new clients, continuing to develop their professional knowledge and finding like-minded people for emotional support). I analyse the extent to which CAM practitioners can be seen to be participating in a 'community of practice' (CoP), what the characteristics of that CoP are, how it compares to other health-related occupations and what implications this has for the embodied experiences and identities of the practitioners themselves.

**Thursday 12 September 2013**

**10:15 - 10:45**

Experiences of Health and Illness

Derwent Room 056

*Gallagher, S.*

*University of East London*

**Expert-ism and the Sequential Issues of Resilience: In an 'ME World'**

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a working case definition for a chronic illness underpinned by medical contestation and socio-cultural debate (Carruthers et al, 2011). Extensive medical and political deliberations exist in relation to naming and framing this illness. The current study has employed Foucauldian strategies in order to trace the particular events and structures that produced the sick body and the eventual constitution of the diagnosed subject. This paper is based on two diagnosed 'severe' ME life histories and their photo-elicited diaries (PEDs). The overall aim explores how they negotiate and synthesise political and medical discourses and social practices in relation to their life experiences of becoming and living with a diagnosis of ME. A critical discourse analysis (Fairclough, 2003) provided a framework to analyse language and meaning. A transdisciplinary approach focused on various elements taken from the overall narratives which reflected the literature in the field of chronic illness. Drawing on the socio-historical context the life stories/PEDs offered a means to investigate the rhythmic and often metaphoric sequence of discourses and social practices in which shifting identities and dominant ideologies constituted the performance of being healthy/unhealthy subjects. The analysis also goes some way to argue that the turn in medicine from Cartesian to psychosocial approaches has displaced the boundaries of ownership from merely the objectified medical gaze to include subjective accounts of chronic illness, where the patient is no longer in compliance, but in concordance with medicine constituting the chronically ill as accountability for their own prognosis.

**Thursday 12 September 2013****14:00 - 14:30**

STS and Medicine

Derwent Room 003

*Gardner, J.**Brunel University London***Generating Bodies of Data: Clinical Assessment Tools & Measuring Clinical Outcomes of Deep Brain Stimulation in Paediatric Neurology**

In order to generate evidence of clinical therapy's effectiveness, investigators rely on clinical assessment tools to extract numerical data from the material bodies of patients. Using interview and observational data, this presentation explores the activities of a multidisciplinary clinical team as it attempts to measure the effectiveness of a new medical therapy: deep brain stimulation for children with a motor disorder called dystonia. Members of the team argue that the standard assessment tool within neurology for measuring dystonia fails to capture improvements that are meaningful for patients; they have therefore adopted what they believe to be a more useful assessment tool from occupational therapy. By comparing the two tools, this presentation will argue that clinical assessment tools can be seen as constructed perceptual systems that render the disease and the body intelligible in specific ways: while some assessment tools tend to perpetuate the biomedical model of disease, others, such as the tool adopted by the team from occupational therapy, enact a less-reductive form of disease and the body. This presentation will demonstrate that a sociological exploration of clinical assessment tools can provide important insights into the way in which the body, health and illness are rendered intelligible in clinical practice.

**Thursday 12 September 2013****10:50 - 11:20**

Mental Health

Derwent Room 037

*Georgiadis, A.**Peninsula College of Medicine and Dentistry***Offenders', and their Practitioners', Perceptions of Common Mental Health Problems and Care**

In Pierre Bourdieu's theory of practice social agents' accumulation of capital frames cultural practices and tastes that serve to manifest social class inequalities. Offenders are a socially excluded population with increased mental health needs and low access to health care services who frequently come from different social backgrounds compared to practitioners involved in their care.

To explore offenders' thoughts and emotions that lead practitioners to impose a diagnosis of anxiety and depression. How practitioners understand offenders' thoughts and emotions and relate them to diagnostic manual definitions?

100 semi-structured one to-one interviews were conducted with offenders recruited through prison and probation services to assess previous and current mental well-being difficulties. 10-15 were purposively selected on screening positive on validated schedules for mental health problems as defined by DSM-IV/ICD-10 criteria. Interviews were audio recorded and transcribed verbatim. A thematic analysis is being undertaken examining offenders' and practitioners' 'talk' to explore the applicability of the Bourdieusian concepts of habitus, field and capital and appraise any contrasts in perceptions regarding offenders' mental well-being and care.

Initial findings indicate that offenders' and practitioners' different social backgrounds, coupled with diagnostic manuals definitions, impact on the ways in which anxiety and depression are conceptualized by each group; this leads to inequalities in accessing health care services.

Pierre Bourdieu's theory of practice offers an alternative theoretical and praxiological way of understanding social class inequalities and their manifestation in offenders' health care. Further exploration of its applicability to a wider range of offenders' health care services is required.



**Friday 13 September 2013****10:45 - 11:15**

Ethnicity

Derwent Room 002

*Ghillani, F.**Oxford Institute of Ageing***Transnational Bodies: The Effects of Migration on the Dynamics of Body and Self**

When approaching old age, women face bodily changes that can represent a source of discontinuity in their lives. Moreover, women are constantly exposed to the social pressure of compelling

stereotypes and their bodies are subjected to deep observations and regulations. The way individuals use, perceive and conceptualize their bodies is heavily affected by the cultural environment they inhabit through the process of socialization. Several studies have suggested that the socialization of the body mainly takes place during youth but only a few have explored if and how this process continues during adulthood and later life.

This study aims to analyse if the exposure to new social norms and meanings during adulthood can affect the conceptions of the body acquired during youth and generate a different perception of ageing.

Interviews were carried out with two groups: -

- Women, aged 59 to 73, born in a small Italian village, who moved to London in their adulthood;
- Women, aged 60 to 72, born in the same village and still living there.

All subjects were exposed to the same social conditions in their youth and are becoming older in two different social environments.

Delving into their day-to-day bodily practices and experiences, participants have given insights on the dynamics of body and self and formulated concepts of acceptance, adjustment and adaptation.

Substantial differences have emerged between the two groups, reflecting the influence of the two distinctive social contexts and the relevance of migration as a meaningful Life-Course transition.

**Thursday 12 September 2013****11:25 - 11:55**

Experiences of Health and Illness

Derwent Room 056

*Gibson, B.**University of Sheffield***Semantic Displacement and the Market: the Case of Dentine Hypersensitivity**

The study of the origins of accounts of illness is a core area that requires further exploration in the sociology of health and illness. Previous work on dentine hypersensitivity has sought to explore the form and structure of everyday communication about the condition and discovered that it was better described as a health condition, to be expected, and not something to worry dentists about. A remaining problem from this work was to try and establish where these accounts originated from. This paper reports the findings of a conceptual history exploring changes in the pool of meaning of dentine hypersensitivity. The emergence of the concept reflected changes in the semantics of dental treatment whereby normal pain reactions during treatment (dentine sensitivity) became distinguished from unwanted overreactions (dentine hypersensitivity). As an unwanted overreaction, the concept of dentine hypersensitivity developed to occupy a semantic space outside of the direct concern of dentistry. Because of this position, the concept remained disputed and undefined. The development of the concept, therefore, reflected a fragmentary process around which it was difficult to fashion stable identities. It was only after the intervention of the marketplace that the condition became properly defined. By then it had been displaced from the concerns of dentists.

**Thursday 12 September 2013****16:55 - 17:25**

Experiences of Health and Illness

Derwent Room 056

*Gibson, G.**Newcastle University***Intersections between Ageing, Gender, Masculinity and Chronic Illness: Men's Experiences of Living with Parkinson's Disease**

Reporting the results of a PhD study investigating 15 men's experiences of living with Parkinson's Disease (PD), this presentation will explore the roles ageing and gender play in the experience of chronic illness. Drawing on a phenomenological, narrative methodology, this presentation explores how

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men negotiated the changes PD brought their sense of self as men who were ageing. Men's experiences of PD were interpreted using gendered expectations of an ageing body and a masculine older age. Men described PD and its effects on their bodies through either a premature and therefore unnatural form of ageing, or alternatively as an expected consequence of an older age characterised by biological and social decline. Men's judgements of PD and ageing also intersected with their expectations of gender, in which PD posed a threat to men's masculine status. However, by telling stories about their illness, men could re-negotiate and where necessary reassert their masculine status, demonstrating that despite PD's effects they successfully remained 'men'. How well men responded to these changes to their sense of an ageing masculinity had key implications for their continued well-being and quality of life, providing us with insights into how age and gender sensitive PD services can be developed. Attendees of this presentation will gain insights into the continuing importance of gender in the lives of older men. In addition, attendees will be able to further consider how ageing and gender shape men's judgements about the experience of chronic illness, including PD.

**Thursday 12 September 2013**

**10:15 - 10:45**

Professions

Derwent Room 036

*Gilbert, L.*

*University of the Witwatersrand*

### **'Re-engineering the Workforce to Meet Service Needs': Exploring 'Task-Shifting' in South Africa in the Context of HIV/AIDS and Antiretroviral Therapy**

This article explores the major trends in the South African health workforce in the context of HIV/AIDS and analyses their potential impact on the professional work and status of nurses and doctors. The Human Resources for Health Strategy for the Health Sector 2012/13-2016/17 document, in addition to a wide range of secondary material, is used to depict the shifts that have taken place in the SA health workforce as a response to the un-met health needs and demands emanating from HIV/AIDS. Such response is particularly challenging in the context of limited-resource settings and inadequate public healthcare services. Therefore, there has been an urgent need to come up with inventive ideas to mobilise all available resources to curtail the spread of the epidemic as well as to cope with the provision of ART to large numbers as quickly as possible. Adopting a critical-analytical approach, this article draws attention to three such ideas: task-shifting, the training of new mid-level workers, and the use of members from the community in a variety of roles as 'community health workers'. Although these ideas are not new, they acquire acute poignancy in the context of HIV/AIDS in South Africa today. They also provide an interesting case study through which to interrogate arguments advanced in the sociology of the professions about 'medical dominance', 'occupational monopoly', 'laymanisation' and the potential challenge to medical authority and power that may have occurred alongside shifts in professional boundaries.

**Friday 13 September 2013**

**11:20 - 11:50**

Open

Derwent Room 049

*Gimlin, D.*

*University of Aberdeen*

### **'Too Good to be Real': The Obviously Augmented Breast in Women's Narratives of Cosmetic Surgery**

Although consumers and physicians alike have long described the goal of aesthetic surgery as the production of an 'improved' but still 'natural looking' body (Pitts-Taylor 2007), interviews with American women who had cosmetic surgery between 1990 and 2007 suggest that the 'artificial' is becoming increasingly prevalent within consumers' narratives of breast enlargement. In this presentation, I will discuss that change in relation to processes of conspicuous consumption, the growing cultural emphasis on continual self-transformation and the increasing normalisation of cosmetic modification. Following Fraser (2003), the analysis conceptualises consumers' accounts not as the reflection of 'reality' or a 'true self', but instead as indicators of the kinds of options, expressions, assumptions and perspectives that are available for use in communication about cosmetic surgery. My presentation also draws upon feminist writings about the social construction of 'breastedness' (Young 1992) in femininity; in so doing, it seeks to provide insight the cultural significance of breasts that are 'too good to be real'.

**Thursday 12 September 2013****14:00 - 14:30**

Methods

Derwent Room 049

*Girling, M.**Newcastle University***Improving the Normalization of Complex Interventions: the Everyday Work of Translating Theory into Something Accessible, Useable and Countable**

Normalization Process Theory (NPT) provides a framework for understanding how a new intervention becomes part of normal practice. Initially, NPT grew from a series of qualitative studies; it was developed into a model and then into a mid-range theory and an online toolkit. Over this time, we have outlined the very practical, behind-the-scenes, work we have undertaken to develop NPT. The objective of this next phase is to attempt to develop a structured questionnaire that will measure processes of implementation, embedding and integration.

In this paper we outline the initial stages of questionnaire development in the NoMAD study. We explore the mundane work that included rounds of item development, local and national project meetings, cognitive interviews with a range of actors, questionnaire appraisal techniques and on-line feedback. We outline the emergent tensions in creating questions that are accessible to respondents yet remain coherent to the theory. We also document the dilemmas encountered in operationalizing questions across different sets of settings (health and education) and actors (intervention developers, evaluators and providers). Finally, we explore how we have reflexively used NPT to challenge and guide our implementation of the NoMAD study. The next step is to use survey methods to test the utility of the measure across six health care interventions.

**Thursday 12 September 2013****10:50 - 12:30**

Symposium

Derwent Room 036

*Gislason, M.**University of Sussex***The Wicked Problems of Ecological Health Research and Practice**

Public health challenges in the anthropocene era are often global in reach and local in their impact. Whether due to newly-emerging infectious diseases (many of which are zoonotic), environmental toxicity, food-borne illnesses, or non-communicable diseases associated with poverty and urban decay, the interplay between social and ecological factors is at the root of many contemporary disease burdens. Yet, while healthy ecosystems are required to support healthy humans and animals, the challenges of how to translate these insights into new educational, health and research practices are mounting.

This paper discusses ways of studying health issues as coupled social-ecological issues, and draws illustrations from work being conducted within the newly emerging field of 'ecological health', which is grounded in the use of ecosystem approaches to health research and practice. I focus on some of the 'wicked problems' that emerge when working from the premise that human, animal and ecosystem health are inextricably linked. Wicked problems are issues which are complex, multifaceted and multi-causal, and which shift as solutions are put into play, often leading to the generation of a new series of unanticipated complications. Working within this type of complexity requires addressing health and illness at the interplay between social, economic, political and environmental factors and forming novel partnerships that reach far beyond the scope of traditional public health practices, remits and even logics.

**Thursday 12 September 2013****16:55 - 17:25**

Lifecourse

Derwent Room 002

*Gjernes, T., Måseide, P.**University of Nordland***Dementia: An Interagency Approach**

The aim of this paper is to develop an analytical frame for a Norwegian qualitative research project called 'Collaboration systems in the protection of citizenship for persons with dementia.' It is a comparative study of dementia within different national welfare systems. Dementia refers to lesions of the brain. In Deleuze's terms, it is a neurological condition belonging to a 'body with organs.' However, dementia is also a social category with social meanings and consequences. It merges with issues concerning personhood, self, and citizenship and with social surroundings, and it is enacted in various contexts by multiple professional and lay agencies. As a social category dementia belongs to relatively

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complex systems of agents and agencies, including the individual so diagnosed. In this perspective dementia belongs to what Deleuze called 'a body without organs.' Accordingly, the demented may be conceived of as sick, get care and gain personhood or citizenship depending on the multiplicity of relationships s/he may be involved and integrated in, and how these relationships are managed. This means looking at dementia not as a condition of an individual's brain, but as social processing of identity and a body-biography trajectory developing over time within various contexts and networks of agents and agencies. The purpose of the project is to compare how dementia 'becomes' within the social complexities of collaborative systems as they are affected by different welfare systems.

**Wednesday 11 September 2013**

**13:20 - 13:50**

Professions

Derwent Room 036

*Goldman, J., Reeves, S., Wu, R., Silver, I., MacMillan, K., Kitto, S.*

*University of Toronto*

### **Interprofessionalism in Discharge in General Internal Medicine**

Governments and hospital administrators are concerned with patient discharge from hospital, assessing efficiency through the measurement of length of hospital stay, readmission rates, and medication and discharge summaries. There is less attention being awarded to understanding how health care providers interact with each other and practice in relation to discharge within the context of professional boundaries, clinical processes, and organizational and government structures. This paper reports on an ethnographic study using theories of medical dominance and negotiated order to explore the meanings that different professional groups bring to the topic of discharge in general internal medicine and how their behaviours, and in particular their interprofessional practices, reflect these different interpretations. This analysis is undertaken with attention being given to the role of power in the form of professional power differentials and power as exercised through hospital and government directives. Observations were undertaken in various spaces in the general internal medicine ward including nursing stations, medical team meetings, nursing meetings, morning care rounds, and interprofessional care rounds. Semi-structured interviews were conducted with individuals representing the different professional groups in the ward. Hospital and government documents on discharge were analyzed. This presentation will illuminate the social processes and structures that come into play in understanding interprofessionalism and discharge in general internal medicine within a Canadian context.

**Thursday 12 September 2013**

**11:25 - 11:55**

Lifecourse

Derwent Room 049

*Graham, M., Bryar, R., Kendall, S.*

*University of Hull*

### **'Like it's Not Just Me I'm Thinking of Now it's a Child ... It's Another Person': Teenage Fathers, Teenage Fatherhood.**

Interest in teenage fatherhood in the United Kingdom has a relatively recent history and follows in the wake of an intense focus on teenage motherhood. However, much of the attention given to youthful fatherhood has centred on how young men can be persuaded to engage in 'responsible' sexual activity, thus preventing unplanned children, and for those young men who have fathered children, how they can be obliged to fulfil their 'duty' to support their children. This view of young fathers as parents by negligence with little commitment to being involved with their children, has left little space for other ideas of young teenage men in relation to fatherhood to take hold. Consequently, knowledge about young men's expectations and intentions about fatherhood, and their fathering practices, have been slow to unfold and gain attention.

This paper presents findings from a larger two year longitudinal qualitative study of teenage parenthood. It focuses on the fathering practices of a group of teenage men who chose to support their pregnant partners and to be involved with their children. The young men had a strong desire to be 'good' fathers to their children. Fatherhood is meaningful and important as an ideal and represents a marker of responsibility and a transition to adulthood. Young fatherhood is challenging, yet it is also a generative experience. This paper contributes to a discussion on young contemporary fathering practices. It also considers what interventions might best support young fathers as they take on their roles as co-parents to their children.

**Wednesday 11 September 2013****14:30 - 15:00**

Health Service Delivery

Derwent Room 104

*Grant, S., Guthrie, B., Entwistle, V.**University of Dundee***The Role of Organisational Routines in the Safety of Laboratory Results Handling in UK General Practice: an Ethnographic Study**

The handling of hospital laboratory results within UK general practice is a complex socio-technical process involving the interaction of information technology (IT) systems and multidisciplinary professional teams. While various components of the results handling process are automated through electronic IT systems, numerous human steps involving teams of doctors, nurses and reception staff are also required, with each step open to potential error. One approach to examining collaborative processes in health care has been through the study of organisational routines as both structuring devices ('the ostensive routine'), and as processes that evolve through the agency and choice of individuals through socio-technical interaction ('the performative routine') (Pentland & Feldman 2005). The aim of this paper is to examine and compare the 'ostensive' and 'performative' results handling routines across four UK general practice using ethnographic methods in order to identify individual and inter-professional contributions to patient safety across a range of practice cultures. An ethnographic approach combining 1,386 hours of participant observation of everyday practice work, 62 interviews and documentary analysis was employed across the four practices, which differed in terms of organisation, ethos, and the patient population served. This paper seeks to contribute to current understandings of the importance of everyday organisational routines for patient safety. In particular, it shows that different practice cultures prioritise different legitimate outcomes at each stage of the results handling routine, and that greater analytical focus should therefore also be placed on the co-creation of safe practice within healthcare organisations.

**Friday 13 September 2013****09:00 - 09:30**

Risk

Derwent Room 037

*Green, J. M.**London School of Hygiene and Tropical Medicine***Darkness, Ontological Security and Wellbeing: Public Views and Public Understanding**

Across the UK, local authorities are reducing street lighting to reduce costs, address energy use and reduce light pollution. Like many policy interventions, these schemes are likely to have impacts across a number of determinants of health and wellbeing, including road injury risk, crime and fear of crime, feelings of safety and security and sleep quality. These potential wellbeing outcomes feature explicitly as expressed concerns in local public consultations and media coverage around proposed street light reductions. However, analysis of these data, in tandem with the household surveys and ethnographic interviews conducted as part of the NIHR-funded LANTERNS project, also suggest some rather more deep seated concerns about lighting reductions. These relate to the ontological threats of darkness, as an archetypal space of fear, and the threat to wellbeing from the symbolic 'failure' of public governance to 'keep the lights on'. Street lights are a taken for granted element of modern urban life, with their significance as indicators of affluence, good governance and modernity unnoticed until disrupted by a proposed or actual 'switch off'. This paper reflects on the differences and relationships between the 'objects of concern' evoked by public views expressed in consultations, and those tacit understandings that emerge from qualitative analysis. The latter are not necessarily more valid, or more useful, as indicators of 'good outcomes' for policy makers. However, the differences suggest an adequate assessment of the 'public understanding' of individual and collective risks to wellbeing requires a range of methods to elicit different kinds of understanding.

**Friday 13 September 2013****10:10 - 10:40**

Experiences of Health and Illness

Derwent Room 056

*Green, T., Macleod, U.**University of Hull***Patients, GPs and Cancer Screening: Opening the Floodgates?**

In the UK patients usually first present to their GPs with potential cancer symptoms; these interactions can be seen as the 'battle ground' for the interaction between public/patient and the NHS with respect to the understanding of symptoms, presentation and GP response, all of which are important in ensuring earlier diagnosis. Primary care is therefore the focus of considerable research and policy activity in this area. There is also a relationship between general practice and screening programmes: cervical

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screening is conducted in general practice and the target included in the Quality Outcomes Framework (QOF). Breast screening and bowel screening are organised centrally, although some breast screening letters are distributed from general practice. GPs also receive requests from patients for prostate screening, and NICE guidance is available to them regarding the appropriate response to such requests. However, although research to date has included a GP perspective in cancer specific studies, there is limited investigation of how increased public awareness of cancer symptoms and the availability of different screening programmes impact GPs' practise. In drawing on data from 55 semi-structured interviews with GPs in England, this paper examines respondents' understandings of their gate-keeping role with respect to cancer awareness, screening and early diagnosis, and examines their attitudes to screening and their opinions of the role of primary care in supporting screening coverage. In so doing, the paper highlights the particular challenges GPs encounter positioned as they are at the interface of secondary care with respect to their patients and screening for cancer.

**Thursday 12 September 2013**

**17:30 - 18:00**

Patient - Professional Interaction

Derwent Room 047

*Greenfield, S., Litchfield, I., Bentham, L., Lilford, R.*

*University of Birmingham*

### **'Ring in a Week and See if the Results are Back ... If They Are Abnormal I Will Contact You Anyway': Test Result Communication in Primary Care: a Staff Perspective**

One of the most common primary care consultation outcomes is the GP ordering a laboratory test (e.g. blood glucose, cholesterol) for a patient. For good clinical outcomes and patient satisfaction tests must be carried out as requested and results fed back to GP and patient. We use theoretical conceptions of 'place' (Rapport, 2007) and the 'meanings of places' for individuals (Andrews, 2006) to examine data from 4 focus groups which explored general practice staff perceptions of current test result communication systems' strengths and weaknesses. Our data revealed a complex process involving a range of unconnected stakeholders and geographically discrete locations and enabled us to map a number of different test result communication routes. We identified a number of 'waiting' and 'failure' sites on the test result journey which could lead to delays and suboptimal or lack of communication of results. We found the meaning and perception of the test result process can differ markedly between healthcare professionals, administrative staff and patients as they each view it from a different start and end point. No study practice had a fail-safe system to ensure results reach patients or clinicians, in all but the most serious cases patients are advised to initiate result communication by contacting the practice themselves. We conclude current pathways are informal with no 'one size fits all' method for communicating all test results because clinical urgency/importance and patients' needs (emotional, cognitive) vary considerably. Although modern software systems (SMS, emails) could help streamline the process, patient confidentiality remains a concern.

**Thursday 12 September 2013**

**08:30 - 09:00**

Mental Health

Derwent Room 037

*Griffith, L.*

*University of Oxford*

### **Finding a Language for Mental Distress: Narrative Accounts of Psychosis**

Over the last two decades in scientific, sociological and popular discourse about the aetiology of mental health problems, Western psychiatry has (re)gained its dominance largely through the increasing prominence of the causal role of biogenetic factors in mental health. In contrast, accounts from people who have been diagnosed with severe and enduring mental health problems provide a complex and sometimes seemingly disorganised picture of the nature and aetiology of the distress they have experienced. Attempts to rationalise these experiences so that they can be understood within clinical frameworks, can significantly detract from the accuracy and validity of personal experience. The challenge is to more effectively frame and communicate peoples' distress, and in turn, establish what can be done to alleviate it.

Through the investigation of personal narratives collected for Healthtalkonline in Oxford, this paper examines how people have come to understand their distress, and crucially how this may have changed over time. In particular, the evidence highlights that by engaging with psychiatric services, a 'rational vocabulary' is overlaid onto individual experiences of people's suffering. This paper examines how this rational vocabulary is absorbed and modified in accounts of psychosis, engagements with mental health services, everyday life and recovery. Drawing on the work of Skultans (1998) and other about the personal meaning of suffering, the 'cultural grammar' through which people give voice to their pain is critically examined.

Skultans, V. (1998) *The Testimony of Lives: Narrative and Memory in Post-Soviet Latvia*. London: Routledge.

**Friday 13 September 2013**

**10:10 - 10:40**

Methods

Derwent Room 047

*Grønning, I.*

(NTNU)

**Being a Good Spy: Legitimizing Access in Web Based Observation**

Observing online forums may challenge the ethically concerned researcher, but still a relevant methodological approach for medical sociologist in studies of eHealth etc. On basis of a positive response to observing an online weight-loss forum (from the forum administrators) information about my project on obesity was posted online. Within a few days I received more than 20 replies, including a few participants expressing serious concern and requesting more information. Some felt like they were being surveilled and did not appreciate my presence. Would observing the forum anonymously lead to better data? How do we deal with online participants' scepticism to Internet-based research, while maintaining a high level of research? The presentation draws on the evolving discussion between researcher and participants to discuss the complex issue of research ethics (i.e. informed consent) in studying health-related use of the Internet.

**Thursday 12 September 2013**

**16:55 - 17:25**

Health Policy

Derwent Room 104

*Håland, E.*

*Norwegian University of Science and Technology (NTNU)*

**Enhancing Cooperation and Collaboration Between Primary and Secondary Care Through a Competence Network**

The need for integration of health care services and collaboration across boundaries is highlighted as a major challenge within health care in many countries. Hospitals and municipal health care, as well as other health care service providers, need to collaborate across organisational and disciplinary boundaries. In Norway, the introduction of The Coordination Reform in 2012 is addressing this issue. It is argued that patients' needs for coordinated services are not being sufficiently met and that there should be more cooperation and better, more efficient coordination between health care services. Also, the reform instructs the municipalities to be responsible for a larger share of the total health care services. This implies new challenges regarding competence. Health personnel, public health workers, patients and relatives need to learn new skills and need to collaborate in new ways. Following this, a competence program addressing obesity, involving an obesity clinic at a regional hospital and 30 municipalities in the region, has been established. The aim of this cooperation is to contribute to competence development and local activities to prevent obesity. In a research project following this program, we investigate how this program can enhance cooperation and collaboration between primary and secondary care, with a special focus on implications for competence development.

Relevance to medical sociology: Health service delivery is a well established topic within medical sociology. This paper aims to contribute to the understanding of how collaboration between different health care service providers can be established.

**Thursday 12 September 2013**

**16:20 - 16:50**

STS and Medicine

Derwent Room 003

*Hale, R., Dingwall, R., Van Tam, J.*

*University of Nottingham*

**The Bioethics of Healthcare Worker Influenza Immunisation**

It has been contended that there is an 'empirical deficit' in bioethics. Sociology can provide an empirical examination of bioethical issues and help bioethicists to gain a better and more detached understanding of bioethical transactions and 'ethical moments'. In addition to a sociological perspective, it has been argued that ethical questions benefit from the application of an actor-network theory (ANT) approach. In particular, an 'after-ANT' approach, which does not suffer from the same value-neutrality of early ANT in the 1980s, provides a fruitful way forward. This paper provides an examination of the bioethical issues around healthcare worker influenza immunisation, including mandatory vaccination, the duty of care, the duty not to harm, the duty to treat patients, resource allocation and rationing of vaccination, and the gendered nature of this immunisation programme. As a sociological analysis, this paper considers the social nature of bioethical issues and frames them in their sociological context. For example, the social

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factors that affect HCWs' access to influenza vaccines and information, differences among health profession groups, and the associations between bioethical issues and policies around HCW influenza immunisation. By applying an ANT approach it can be revealed that an influenza vaccine is a biotechnological actor, in a network, which has embedded in its scripts normative values and discourses of individual and professional responsibility for healthcare workers. Empirical data artefacts will be presented, in the form of transcript extracts, from interviews and focus group discussions with informants, to capture the ethical moments around influenza immunisation of healthcare workers.

**Wednesday 11 September 2013**

**15:40 - 16:10**

Embodiment and Emotion

Derwent Room 049

*Hallowell, N., Badger, S., Lawton, J., Foundation for Genomics and Population Health (PHG)  
Richardson, S., Caldas, C., Fitzgerald, R*

### **'I Still Don't Get Any Sensation of Feeling Hungry but I Do Have a Wee Thing Just in My Throat there, it Starts To... I Call it a 'Triffid!' ' Experiences of Hunger: Embodiment and Disembodiment.**

Between 30%-50% of cases of Hereditary Diffuse Gastric Cancer (HDGC) are caused by mutations in the E-cadherin gene. CDH1 mutation carriers have an earlier than average age of disease onset, and greatly increased risks of developing stomach cancer. Individuals identified as at-risk, either because of their family history or as a result of DNA testing, need to make decisions about risk management, whether they will have risk-reducing surgery (total gastrectomy - RRG) or continue screening. This retrospective study interviewed 42 patients, 27 of whom had undergone RRG. In this paper we will reflect upon the impact of surgery on bodily integrity and look at people's experiences of living without a stomach. The paper will focus upon eating post surgery, and discuss the ways in which surgery impacts upon feelings of hunger and satiety. We will demonstrate that following surgery, hunger and satiety constitute disembodied experiences that need to be re-embodied. Finally, we will argue that the process of re-embodiment of these supposed 'physiological' states raises a number of issues about the nature of hunger and satiety. These will be interrogated using a Wittgensteinian (1952) framework which sees internal states as necessarily grounded within public criteria.

**Friday 13 September 2013**

**09:35 - 10:05**

Ethnicity

Derwent Room 002

*Halsall, J., Wankhade, P., Cook, I.*

*University of Huddersfield*

### **Ethnic Minorities and their Health Needs: Crisis of Perception and Behaviours**

There is considerable evidence to suggest that racial and ethnic disparities exist in the provision of emergency and wider healthcare. The importance of collecting patient ethnic data has received attention in literature across the world and eliminating ethnic and racial health inequalities is one of the primary aims of health care providers internationally. The poor health status of certain racial and ethnic groups has been well documented. The improvement of racial and ethnic disparities in health care is at the forefront of many public health agendas.

This paper addresses important policy, practice and cultural issues confronted by the pre-hospital emergency care setup. This aspect of care plays a unique role in the healthcare safety net in providing a service to a very diverse population, including members of ethnic and racial minorities. Competent decision making by the emergency care practitioners requires patient-specific information and the health provider's prior medical knowledge and clinical training. The paper reviews the current ethnicity trends in the UK along with international evidence linking ethnicity and health inequalities. The study argues that serious difficulties will arise between the health provider and the patient if they come from different backgrounds and therefore experience difficulties in cross-cultural communication. This adversely impacts on the quality of diagnostic and clinical decision making for minority patients. The paper offers few strategies to address health inequalities in emergency care and concludes by arguing that much more needs to be done to ensure that we are hearing the voices of more diverse groups, groups who are often excluded from engagement through barriers such as language or mobility difficulties.



**Thursday 12 September 2013****15:10 - 15:40**

Patient - Professional Interaction

Derwent Room 047

*Hamilton, D., Heaven, B., Thomson, R., Wilson, J., Exley, C.**Newcastle University***Multidisciplinary Team in Head and Neck Cancer and the Patient Voice**

Head and neck cancer confers a poor prognosis and patients face complex treatment choices. It is increasingly expected that patients are involved in decisions about their care, however, in some areas of healthcare this is problematic. In the UK, cancer treatment decisions are made by a multidisciplinary team (MDT). We aimed to critically analyse the working of the MDT and associated clinic in three specialist cancer centres. Ethnographic methods were used in this study including non-participant observation and formal and informal interviews with staff and patients pre- and post-treatment. Data generated were analysed using constant comparative methods. Analysis focused on the interactions of the team with one another and with the patient and their interpretation of the process and outcomes of decision making

The complexity of head and neck cancer makes patient involvement vitally important but difficult to implement. There was often lack of agreement about the nature of, and possibility for, 'shared decision making' in this setting. Value judgements which form the basis of the decision were often made on the patient's behalf and the lack of reliable information about treatment outcome and risks led to uncertainty and conflict in the MDT meeting, often not acknowledged or expressed to patients. This acted as a barrier to active palliation and had a detrimental effect on patient expectations and informed decision making. This paper explores these individual and organisational challenges to engaging patients in MDT decision making and discusses possible ways of addressing them.

**Friday 13 September 2013****09:35 - 10:05**

Risk

Derwent Room 037

*Harden, J., Tonberg, A., Duncan, S., Chin, R.**Edinburgh University***Young Adults' Perceptions of Risk from Sudden Unexpected Death in Epilepsy (SUDEP)**

In 2011, a joint Fatal Accident Inquiry (FAI) into the deaths of two teenage girls recommended that most people diagnosed with epilepsy be informed of the risk of sudden death from epilepsy (SUDEP). The FAI highlighted particular issues about communicating risk to teenagers and the self-management of epilepsy in young adults. The research reported in this paper was commissioned by the Scottish Government, and carried out by Epilepsy Scotland and the University of Edinburgh, to address the views of young adults currently diagnosed and living with epilepsy, in particular: their perception of risks relating to epilepsy and specifically associated with SUDEP; their views on, if and how information about SUDEP should be acquired, exploring their independent information seeking and the delivery of information by healthcare professionals. We carried out qualitative interviews with 25 young adults with epilepsy, aged 16-30 years. Our findings suggest that young adults have a pervasive sense of fatalism about their views on SUDEP prevention, which was in sharp contrast to lengths they went to in order to achieve control over the other aspects of their epilepsy in everyday life; SUDEP was often 'bracketed off' from the rest of participants' epilepsy experience. In this paper we reflect on our findings in the context of wider debates about risk perception, discourses around control and responsibility for health, and engagement with expert discourses.

**Thursday 12 September 2013****14:35 - 15:05**

Health Policy

Derwent Room 104

*Harrington, B.**Northumbria University***Broken LINKs?: The Transition of LINKs to Healthwatch**

The Francis Report (Francis, 2013) highlighted how the local patient and public involvement organisation, LINKs, failed to provide an effective patient voice in relation to Mid Staffordshire NHS Foundation Trust helping to perpetuate poor patient care. Among the general contributing factors identified were the rate of change in NHS structures, loss of organisational memory, and poor relations with other organisations. In April 2013 patient and public involvement organisations were reorganised replacing LINKs by Healthwatch. This paper presents findings from a small qualitative pilot study carried

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out since March 2013 into the transition from LINKs to Healthwatch in the North East. The research included interviews with LINKs organisations, documentary analysis and observation.

The paper considers findings in the context of changes in patient and public involvement, concerns about the rate of change or 'churn' in public sector health organisations (Hunter, 2006), and the need for 'An organisation with a memory' in order to reduce risk for future patients (Donaldson, 2000). The 'legacy events' for LINKs members and the government's stated intent to have evolutionary change between LINKs and Healthwatch show a concern to preserve that memory. However, it remains to be seen how evolutionary the changes are in practice, and how far organisational memory (Pollitt, 2009) is retained.

Preliminary findings indicate that far from all LINKs seamlessly 'evolving' into local Healthwatch organisations, there have been impacts on function during the transition. The paper reflects on contributing factors including relationships with other organisations, and the implications for health policy.

DONALDSON, L. 2000. An organisation with a memory - Report of an expert group on learning from adverse events in the NHS chaired by the Chief Medical Officer. In: HEALTH (ed.). London: The Stationery Office.

FRANCIS, R. 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 1: Analysis of evidence and lessons learned (part 1). London: The Stationery Office.

HUNTER, D. J. 2006. The tsunami of reform: the fall and rise of the NHS British Journal of Healthcare Management, 12, 18 - 23.

POLLITT, C. 2009. Bureaucracies remember, post-bureaucratic organizations forget? Public Administration, 87, 198-218.

**Thursday 12 September 2013**

**12:00 - 12:30**

Health Care Organisations

Derwent Room 003

*Hedlund, M., Bodil, J., Magnussen, L., Magnussen, M. University College of Nord-Trøndelag*

### **Who Cares? Self-help Groups and Empowerment**

This research was focused on the study of self-organized self-help groups for people struggling with mental problems or disabilities. Some participants in the self-help group shared mutual experiences of minor mental health problem; experience of work-rehabilitation treatment or disabilities. The study adopted a salutogenic orientation to health and empowerment when investigating experiences from participants in self-help groups. The salutogenic orientation then referred to Antonovsky's concept of Sense of Coherence (SOC). The investigation is based on interviews with participants of from 24 informants from different self-help group types, and the data were analysed according to a Grounded Theory approach. The results illustrate that mutual support, development of change and shared participatory experience benefit and stimulate empowerment among participants. These core categories promote a salutogenic development of health and sense of coherence among participants of self-help groups. Moreover, empowerment provides them with feeling of strength, force and power to share burden of troublesome life circumstances. Participation in self-help groups can empower participants in various ways, and participants of self-help groups formed a type of modern agency, a place where one can find individuals struggling with the same issues as oneself, and use the experiences of peers in self-help groups to find ways to deal with self-governing capabilities. Yet another aspect found, was that self-help groups is part of a new health promoting strategy to shape people to take responsibility of their own health development through self-therapeutic methods.

**Thursday 12 September 2013**

**10:15 - 10:45**

Pharmaceuticals

Derwent Room 002

*Hendrick, R.*

*University of Edinburgh*

### **Managing or Hiding Conflicts of Interests in Medical Journal Publishing? An Analysis of the Current System of Self-regulation**

Evidence has shown how journals, which report the results of clinical trials, can be used by the commercial industries as vehicles for marketing products, rather than providing honest evaluations of the evidence.

This research focuses specifically on conflicts of interest, which can result from relationships between the different actors (journal editors, researchers, medical writers and sponsoring companies) and affect

the content of articles. This ultimately can impact upon public health, as journal articles lead to policy decisions and influence prescribing practices.

These relationships, and the conflicts of interest that result from them, therefore need to be managed effectively so that, where possible, bias does not slip into the articles, or to at least ensure that audiences are aware of their existence and can judge the discussion accordingly.

To date, this has been largely handled through a system of self-regulation. Professional organisations, such as the ICMJE, COPE and ISMPP, have developed a variety of policies to deal with conflicts of interest, as have individual journals. However, at least to some degree, these organisations are directly financed, or financially dependent upon, commercial industries. This therefore suggests that there are reasons to be cautious about their policies.

This paper is based on empirical research and critically analyses a sample of these guidelines in order to investigate how they both conceptualise and respond to conflicts of interest resulting from commercial industries' involvement in medical publishing in academic journals. This analysis is supplemented by interviews with key actors in the field.

**Thursday 12 September 2013**

**10:50 - 11:20**

Complimentary and Alternative Medicines

Derwent Room 047

*Hiadzi, R. A.*

*University of Ghana*

**Seeking Biological Parenthood Via Herbal Treatments: The Issue of Unmet Needs, Beliefs and Experiences of Ghanaian Infertile Couples.**

Some countries in sub-saharan Africa have been rightly labeled by some authors as the infertility belt of Africa owing to the high rates of infertility in those countries. Ghana can be said to be one such country recording an infertility rate of 15% (Donkor and Sandall, 2009). Due to the Ghanaians' pronatalist orientation, the negative consequences of involuntary childlessness are strongly felt by those affected. Such affected members of the society therefore adopt various observable treatment-seeking strategies including herbal medicines in an attempt to achieve conception and thus avoid the stigma associated with childlessness. Being a developing country with its associated characteristics of significant levels of illiteracy coupled with the majority of citizens found within the low and middle income status, it is not surprising that herbal treatments will be the preferred alternative for the ordinary Ghanaian infertile couple. This study explores the nature of the decision making process, the constraints faced and the utilization of herbal treatments by the contemporary Ghanaian infertile couple en route to achieving desired conception. The respondents for the study are selected from a private herbal clinic located in the capital, Accra. Based on qualitative in-depth interview data, this study illuminates the ways in which herbal medicines are adopted by the contemporary Ghanaian infertile couple to engender childbirth. The study highlights and provides the experiences and various cultural explanations that underpin the usage of this infertility treatment-seeking method.

**Thursday 12 September 2013**

**11:25 - 11:55**

Health Policy

Derwent Room 104

*Hilton, S., Wood, K., Patterson, C.*

*MRC/CSO SPHSU, University of Glasgow*

**Implications for minimum unit pricing advocacy: what can we learn from UK newsprint coverage of key claim-makers in the alcohol policy debate?**

On May 24th 2012, Scotland passed the Alcohol (Minimum Pricing) Bill. Minimum unit pricing is a legislative intervention intended to raise the price of the cheapest alcohol to reduce alcohol consumption and related harms. Communications and political sciences literatures offer a theoretical framework to investigate how competing frames about policy issues are presented in the news media from key claim-makers. Content analysis was conducted on seven UK and three Scottish national newspapers between 1st May 2011 and 31st May 2012. Relevant articles were identified using the electronic databases Nexis UK and Newsbank. A total of 262 articles were eligible for detailed coding and analysis. This paper attempts to map out the dynamic interplay between media framings from key claim-makers of what constitutes the alcohol problem and the arguments for and against minimum unit pricing in the months leading up to the passing of the legislation, with a view to informing policy advocacy.

**Thursday 12 September 2013****14:35 - 15:05**

Methods

Derwent Room 049

*Hindhede, A. L.**Steno Health Promotion Center***The Mediating Role of Social Networks in Health Promotion in a Danish Vulnerable Urban Neighbourhood**

Setting-based interventions have been widely acknowledged as a way forward in health promotion aiming at fostering participation and empowerment, and contributing to a reduction of health inequalities. However, initiating participation among vulnerable subgroups face many difficulties.

This paper explores new ways of mobilising and incorporating local knowledge and resources. The study was conducted in a marginalised neighbourhood of a provincial town in Denmark with several health promotion activities driven at the municipal level. The study identified social networks of residents who participated in these activities but in addition the social networks of groups who met regularly to practice hookah smoking, groups who met to read the Quran, and groups who met to drink beer. Data collection method included questionnaires, walking interviews, and participatory mapping to identify perception and experience of both egos and alters concerning health-related decision making. The data analysis focused on centrality measures of network data (Freeman, 1979), the flow of influence as well as clusters and cliques in the personal networks (Scott, 2000).

The study uncovered centrally positioned individuals in the marginalised neighbourhood. In-depth interviews with these were conducted on their views and understandings as potential resources for asset-based and locally adapted health promotion and as social catalysts (Rütten et al, 2007). The paper concludes that social networks constitute an important and partly untapped resource in health promotion initiatives as 'structures of opportunity' as they mediate and moderate the harsh circumstances of people's lives and their lived experiences of health and wellbeing.

**Thursday 12 September 2013****16:55 - 17:25**

Lifecourse

Derwent Room 037

*Hinton, L., Knight, M., Locock, L.**Oxford University***Impact of Severe Life-Threatening Complications in Pregnancy on the Partners of Women Affected**

Childbirth is a major and, most often, happy life event for women and their families. Maternal mortality is now very rare, but 'near-miss' (life-threatening) complications still occur in around 1 in 100 births, and are monitored by the UK National Maternal Near-miss Surveillance Programme. As part of the programme, a qualitative study of experiences of life-threatening conditions in pregnancy or childbirth was undertaken, which explored the immediate and long-term effects for both women and their partners.

Narrative interviews were audio recorded with 49 individuals (38 mothers, 10 fathers, 1 lesbian partner) who have experienced 'near miss' events. Interviews were conducted across the UK between 2010-2012. Transcripts were analysed using a qualitative interpretative approach, combining thematic analysis with constant comparison so that data was explored for anticipated and emergent themes. Overall findings are available on [www.healthtalkonline.org](http://www.healthtalkonline.org)

This paper focuses on the analysis of partners' experiences, as reported both by themselves and the women.

All the partners interviewed were deeply affected by their partner's near miss event. For some it had a profound impact on their long-term mental health. When the results of this study were published on Healthtalkonline, and covered in the mainstream news in April 2013 (newspapers, radio, TV and online) there was heated debate suggesting fathers should 'man up', and not whinge about having to watch their partners give birth. The gendered debate overlooked the severity and brutality of what the men had witnessed. We present findings on partners' experiences and discuss the discourse of (social) media reactions.

**Friday 13 September 2013****10:45 - 11:15**

Methods

Derwent Room 047

*Hislop, J., Ryan, S.**University of Oxford***Enabling Inclusion? Reflections on Using Focus Groups with 'Seldom Heard' Groups to Explore Views on Good Healthcare**

The perspectives of 'seldom heard' or 'hard to reach' groups in research are essential to gaining a broader understanding of health experiences. Yet as researchers with deeply embedded assumptions about research, our lack of confidence to move beyond the 'comfortable space' of traditional methods and recruitment practices may ensure that some groups remain excluded.

Here we reflect on our experiences of conducting focus groups with six 'seldom heard' groups (young men, Irish Travellers, older people, drug users, migrant workers, and people with learning difficulties) to explore their views on what makes a good experience of health care. We examine the logistics of setting up and running the focus groups including recruitment and access, gaining informed consent, choosing and adapting activities, and encouraging participation.

As importantly, the paper is about our journey as white middle class researchers as we reflect on the process and practice of running focus groups with these groups. Using video, audio and written clips we discuss the challenges we faced and the mistakes we made as we negotiated the gap between researcher and researched. We consider our expectations that participants will know how to conform to the focus-group game of turn-taking and co-construction of stories, our choice of language with its nuanced meanings, and the appropriateness of activities.

By accepting our 'otherness' and questioning our expectations as researchers we can move a step closer to enabling meaningful engagement with 'seldom heard' groups in health research.

**Thursday 12 September 2013****08:30 - 09:00**

Professions

Derwent Room 036

*Hjertstroem, H., Sandaunet, A.G.**University of Tromsø***Reconstructing the Professional Position: Public Health Nurses' Approach to Seriously Obese Children and Their Parents**

This paper explores how a group of Norwegian public health nurses approach seriously obese children and their parents in order to support them in establishing a more active and healthier life-style. The public health nurses were part of a research intervention in which a counseling program was investigated for its effects on BMI and quality of life among seriously obese children. Our analysis is based on in-depth interviews with 9 public health nurses that conducted the counseling of the families, and on participant observation of summary meetings where the public health nurses shared their experiences with the project group at the regional hospital. Five dimensions emerged as crucial in the public health nurses' approach to the families: identification of their own position towards the family, identification of the resources of the family, establishing awareness on constructive choices, positive reinforcement and practical support. The research provides insight into how health professionals respond to contemporary expectations of leaving the expert position and to redirect attention to the resources and knowledge that health care users themselves can activate in their response to a health problem. Our argument is also that the public health nurses enter a position as 'professional facilitator' that supports suggestions of a reprofessionalization in contemporary health care.

**Friday 13 September 2013****09:00 - 09:30**

Open

Derwent Room 049

*Holland, P., Collins, A.**Lancaster University***Barriers and Facilitators to Remaining in and Returning to Work: Experiences of People with Musculoskeletal Disorders**

Tackling health-related worklessness is a government priority. Unemployment and economic inactivity are high among people with musculoskeletal disorders (MSDs), yet worklessness is less strongly associated with pain and other physical symptoms than with the organisational setting and culture within which individuals work. This pilot qualitative study explored the employment experiences of people with rheumatoid arthritis, a chronic auto-immune disorder with painful and fluctuating symptoms. The study

## PAPER ABSTRACTS

explored organisational, and other, barriers and facilitators to remaining in work or returning to work after long-term sick leave. In-depth interviews were conducted with 11 men and women who were employed when first diagnosed with rheumatoid arthritis.

All participants still in employment reported struggling to stay working. Flare-ups and fluctuating symptoms caused uncertainty about the ability to cope at work. At first onset, discussions with rheumatologists about whether to remain working, and how to achieve this, were rare. Support from employers was crucial for remaining in work, in particular their willingness to modify participants' working environment, tasks and hours. Employers with personal experience of disability were more willing to offer workplace modifications. Homeworking enabled office-based employees to continue working, although some employers were reluctant to offer it. In fear of sick leave policies which punish work absence, some participants delayed their return to work from sick leave in case further leave was needed. Relationships at work were important: colleagues could provide much-needed support, yet several participants reported being bullied by co-workers or managers. Becoming self-employed was one way to overcome workplace discrimination and organisational barriers and continue to be productive.

**Wednesday 11 September 2013**

**14:30 - 15:00**

Embodiment and Emotion

Derwent Room 049

*Holliday, R., Bell, D., Jones, M., Probyn, E., Sanchez-Taylor, J.,  
Cheung, O., Hunter, E.*

*University of Leeds*

### **Beautyscapes: Exploring internet use amongst cosmetic surgery tourists and agents**

According to the British Passenger Survey around 60,000 people from the UK travel abroad for medical treatment each year and it is estimated that up to 70% of these travel for cosmetic surgery. Without the internet it is doubtful that cosmetic surgery tourism (CST) could exist. Patients access information on surgeons and surgical procedures, destinations, accommodation and travel via infomercial sites such as Treatment Abroad and So Feminine as well as the websites of particular clinics or specialist CST travel agents. In addition Facebook groups and internet discussion sites are key to supporting patients throughout the processes of surgical decision making, surgical experiences and evaluating the results of their surgeries, providing up-to-the-minute commentaries on the progress of patients, making the surgical experience transparent for other potential patients. At the same time such sites offer an opportunity for clinics both to advertise and facilitate 'self-help communities', lessening the burden on individual agents in caring for and providing information to their patient-customers. Facebook groups also bring potential travelling companions (known in Australia, for example, as 'Boobie-Sisters') together, lessening the need for surgical travel accompanied by resource-poor partners or relatives. However, the dual function of such websites as both support group and marketing device brings to the fore inherent tensions and contested meanings of the sites that we will explore in this paper.

**Thursday 12 September 2013**

**17:30 - 18:00**

STS and Medicine

Derwent Room 003

*Hollin, G.*

*University of Nottingham*

### **New Order, No Order, Disorder: Heterogeneity in Autism**

The modern conceptualisation of autism is perhaps best characterised by the term 'heterogeneity'; the claim that, both intra- and inter-personally, autism is fractured, different, and indefinable. In this talk I will seek to achieve two goals. Firstly, and based upon documentary evidence, I will briefly trace the emergence of heterogeneity to the mid-1990s and show how this moment marked a decisive break from the discourses of the 1980s. Secondly, and considering evidence from interviews conducted with cognitive (neuro)scientists, I will examine different constructions of heterogeneity and show the term itself to be heterogeneous, with at least two competing constructions of heterogeneity evoked during interviews. Firstly, 'epistemic heterogeneity' locates difference within the diverse scientific methods, classifications, and theories examining autism. For example, the categorical rather than dimensional approach to diagnosis utilised within DSM-IV may lead to diverse conditions being 'lumped together' as autism giving the appearance of a single, disordered, autism. A second, and more dominant, construction is that of 'aleatoric heterogeneity' whereby difference is seen to reside within the autistic condition itself. Examining this concept of aleatoric heterogeneity in more depth it will be argued that, in the construction of autism as an aleatory heterogeneous condition, the disordered state of the psychological sciences is reflected back upon, and reified within, the disease classification itself. The conclusion is that autism is, to a significant degree, a construct of the psychological sciences.

**Thursday 12 September 2013****10:15 - 10:45**

Mental Health

Derwent Room 037

*Holman, D.**University of Cambridge***Social Class, Mental Illness Stigma and Mental Health Literacy: Unpacking the Relationships and Implications for Service Use.**

The relationship between social class and mental illness stigma has received little attention in recent years. At the same time, the concept of mental health literacy has become an increasingly popular way to frame knowledge and understanding of mental health issues. British Social Attitudes survey data present an opportunity to unpack the relationships between these concepts and class, an important task given continuing mental health inequalities. Regression analysis centred on a depression vignette, with schizophrenia and asthma vignettes used for comparison, is used to undertake this task. The National Statistics Socio-economic Classification (NS-SEC), education and income are used as indicators of class. A number of interesting findings emerge. Overall, class variables show a stronger relationship with mental health literacy than stigma, and in turn literacy is more strongly associated with intentions to seek professional help. The relationship is gendered such that, for example, men's understanding of depressive symptoms are mostly consistent regardless of class status, whereas it is mainly women in lower class positions who show less understanding. Interestingly, class shows more of an association with stigma for an asthma vignette than it does for both depression and schizophrenia vignettes, suggesting that mental illness stigma needs to be contextualised alongside physical illness stigma. Education emerges as the key indicator of class, followed by the NS-SEC, with income effects being marginal. These findings have implications for targeting health promotion campaigns and increasing service use in order to reduce mental health inequalities.

**Thursday 12 September 2013****16:20 - 16:50**

Health Policy

Derwent Room 104

*Houle, J. A., Albert, M.**École de santé publique de l'Université de Montréal***Turf War Among Medical Specialties: The Case of Medical Oncology in the Province of Quebec, Canada**

This research project focuses on the struggle between two medical specialties for the control over chemotherapy treatments. In Quebec, Hematologists historically provided all chemotherapy treatments. However during the late 1970s, a group of Internists were trained in the US and obtained their Board in Medical Oncology. Back in Quebec, they sought recognition by Quebec's College of Physician (CPQ) for their training. In doing so they impinged on the Hematologists' territory and a struggle between the two specialties started.

The study triangulates interview data and archival documents. Interview data consist in a purposefully constructed sample of 30 oncologists and archives were provided by CPQ. Using Bourdieu's concept of "field", analysis focuses on the strategies developed by both groups to gain and/or maintain predominance.

Results show that during the 1980s hematologists had enough power to stop the recognition of Medical Oncology as a new specialty, to maintain control over the field, and to keep internists in a subordinate position. However in the early 1990s, internists changed their strategy and allied themselves with the political field. This added power shifted the power relationship with hematologists and enabled internists to have Medical Oncology recognized as a new specialty.

This study supports the literature stating that the logic of the medical field is not the only one at play when it comes to the evolution of medical care. Medical care can also be influenced by other social fields, including the political field.

**Friday 13 September 2013****09:35 - 10:05**

Methods

Derwent Room 047

*Hudson, N., Culley, L., Law, C., Mitchell, H., Denny, E.**De Montford University***Conducting Dyadic Research in Chronic Illness: Men, Women and Endometriosis**

Despite a growing literature on the value of couple data in studies of particular social phenomena, individuals still constitute the basic unit of analysis in most qualitative research. This paper explores the complexities of carrying out dyadic research with couples living with endometriosis.

Endometriosis is a common enigmatic gynaecological condition. There is no known cause and the primary symptom (pain) does not correlate with the observable extent of disease. Endometriosis has a huge impact on the lives of women, but despite the chronic, potentially disabling and gendered nature of the condition there is little work on the psychosocial impact on couples. The ESRC-funded Endopart study was designed to explore the experience of heterosexual couples living with endometriosis and included detailed face-to-face interviews with 22 heterosexual couples. Men and women were interviewed separately, in most cases simultaneously by two different interviewers.

Through a reflexive account of the research process, the paper explores the rationale for dyadic research and discusses the practical, ethical and methodological challenges of using a dyadic approach. In particular, it assesses the complexities of using solo rather than joint interviews identifying both advantages and difficulties at the level of data collection and in relation to dyadic data analysis. Despite ethical and interpretive complexities, it is argued that this approach allowed participants to articulate perceptions and experiences considered to be relationally or emotionally highly sensitive, permitted men's accounts to be heard unmediated by women's participation and has allowed a unique insight into how couples navigate this common chronic condition.

**Wednesday 11 September 2013****13:55 - 14:25**

Methods

Derwent Room 002

*Jamie, K.**University of York***The Pharmacy Gaze: Narrating the Body in Pharmacy Practice**

Despite an increasing focus on the body and 'body work' in medical sociology, the body in pharmacy practice has not been extensively examined. This paper argues that the body is a central feature of pharmacy practice as it is within the body that medicines act and through the body that the effects of medicines become known. Moreover, the increasing role of community pharmacists in public health practice has broadened the ways in which practitioners in this setting engage with bodies, necessitating new forms of body work.

Drawing on semi-structured interviews with 10 hospital pharmacists and 10 community pharmacists in England, this paper examines the construction of patient bodies, and the work undertaken upon them, by pharmacy practitioners in these two settings. It is argued that pharmacists cultivate a particular way of seeing and managing bodies given their expertise in pharmacology, which is conceptualised here as the pharmacy gaze. Common to the pharmacy gaze in both of these practice contexts are the notion of complexity, as a way of narrating the body, and the generation of algorithms, as a way of managing the body's complexity and risk. This paper untangles the particular relationship that pharmacists have with bodies and examines the ways in which complexity and algorithms are played out in the performance of these divergent forms of pharmacy work.

The paper concludes by examining the potential future of body work in pharmacy, particularly the integration of 'dirty' work.

**Thursday 12 September 2013****10:50 - 11:20**

Lifecourse

Derwent Room 049

*Jones, K.**University of Exeter Medical School***Men, Medicine and the Death of their Child: Ambivalent Transition to Fatherhood**

The effects of stillbirth and neonatal death on mother's mental health are well documented yet, academic accounts of men's experiences of perinatal loss have remained relatively unexplored. There is even less in the way which conveys the meaning of this form of loss when faced with negotiating the transition from being an expectant father to bereaved parent for men, or of the way in which this is



mediated by previously held expectations concerning pregnancy and birth generally. By drawing upon in-depth qualitative interviews conducted as part of a larger study on both men and women's grief following stillbirth and neonatal death, this paper explores the way in which the dominant discourses of our culture such as medicine together with expectations mediate men's sense of identity following the death of their child.

Men's narrations reveal the challenge in re-negotiating modernist representations of birth and ideas about the ability of medicine to intervene to prolong life. For men in this research, the death of their stillborn child or child who died on the neonatal unit represents a biographical disruption and a grief which continues to be felt over the life course. This research on men's grief following pregnancy loss uncovered several themes including loss of identity, marginalisation and neglect of their bereavement needs. Men's narrations are more than a reflection of their bereavement experiences. They are about a death and a loss of predictability which are endemic to late modern times and to which the self stories which proliferate throughout the narratives, are one response to uncertainty.

**Wednesday 11 September 2013**

**13:55 - 14:25**

Professions

Derwent Room 036

*Joynes, V.*

*University of Leeds*

**Professional Identity in an Interprofessional World**

This paper proposes that conceptualising and understanding 'professional identity' in the health and social care (H&SC) professions is more important than ever. The drive towards interprofessional education (IPE) and working, that is where more than one profession works with and learns from each other (CAIPE 2002), is ostensibly being undertaken with the aim of improving teamwork between professionals and ultimately improving standards of care. This push towards 'interprofessionalism' assumes that H & SC professionals have distinct professional identities ('doctor', 'nurse', 'social worker' and so on) but there is a growing recognition that in order for interprofessional initiatives to work, more attention needs to be paid to the way in which individual professionals perceive and experience the boundaries between professional groups' (Cameron 2011). Drawing upon the results of 30 interviews undertaken as part of a PhD, this paper will present the findings of research exploring how both academic and practicing H&SC staff perceive their own and others' professional identities, and how this relates to the interprofessional environment in which they are expected to teach and work. Particular consideration is given to the way in which many respondents identified themselves as a 'specialist' or belonging to a 'sub-group' of a profession, as opposed to feeling they had an identity defined by an overarching professional label. Attention will then be paid to the implications of this work for preparing students to work in interprofessional teams.

**Thursday 12 September 2013**

**16:55 - 17:25**

STS and Medicine

Derwent Room 003

*Kazimierzak, K., Skea, Z.C., MacLennan, S.J., Entwistle, V., N'Dow, J.*

*University of Aberdeen*

**Thinking With Care About Care Practices: Prostate Cancer Management Plans and the Doing of 'Good Care'**

In recent years the notion of care has emerged as a matter of concern for social sciences: on the one hand, as an object of inquiry which demands careful attention and articulation (Mol et al. 2010); on the other hand, as a certain way of thinking which highlights the ethico-affective dimensions of everyday practices (Puig de la Bellacasa 2012). In this paper, we link these two approaches as we attempt to 'think with care' about practices involved in the planning of care in localised prostate cancer.

Drawing on the findings from a recent ethnography of urological cancer services, we focus on a case study of one patient diagnosed with localised prostate cancer to explore how care is planned, or rather how a particular care plan is enacted in concrete practices and through diverse socio-material arrangements which include the patient, his friends and family, and health professionals, as well as diagnostic tests, laboratories, medical researchers and clinical guidelines.

Following the patient through various interactions with healthcare professionals and services, we retrace what is made to matter in the planning of care: who speaks and acts, and who is silenced, what counts as compelling evidence, and what is rendered irrelevant. In the process, we attempt to explore and articulate what – in concrete practices, rather than in normative models of clinical behaviour – constitutes good care, and how it is (or is not) achieved in the shifting tensions between different versions of the 'good'.

**Wednesday 11 September 2013****13:55 - 14:25**

Embodiment and Emotion

Derwent Room 049

*Kerr, A., Till, C., Ellwood, P.**University of Leeds***Feeling Responsible: The Affective Labour of Biomedical Research**

Scientists and clinicians working in biomedical research and innovation, particularly those in ethically complex fields like reproductive and regenerative medicine, engage in a range of affective labours as part of their research. Sociologists have tended to explore how they negotiate the role of research participants and patients through the active management of their own feelings of empathy and compassion, moral positioning and care. But these affective labours are also mediated by processes of audit and research management, processes which configure what it means to 'feel responsible' as a researcher. Drawing on ethnographic research with a large biomedical research group in a UK University, in this paper we explore how researcher's feelings about their responsibilities for research and innovation were performed and articulated in the course of their work, focusing in particular on how they cared about themselves, their patients, colleagues and institutions in project meetings and reflexive accounts of their practices. In conclusion, drawing on theories of emotional and affective labour, we reflect on the 'managed hearts' of biomedical researchers and the role of social scientists in demanding these kinds of labours from our colleagues in biomedicine.

**Friday 13 September 2013****10:45 - 11:15**

Risk

Derwent Room 037

*King, C.**University of Edinburgh***Health Visiting Practice as Performance: Assessing Risk and Vulnerability**

Over the last decade, the changing policy context of health visiting practice has shifted the focus of health work with new parents from working with all families to working with those considered to be the most vulnerable. This paper uses Butler's concept of performativity to explore how vulnerability is framed, managed and categorised within health visiting practice. The analysis draws on the accounts of 16 health visitors and 20 mothers interviewed as part of a PhD study. The study explored health visiting and mothering practices following the implementation of Health for All Children in the UK. It considers the gendered nature of health visiting work where health visitors, who are predominantly female, work mainly with mothers. In addition, the role of class in opening up and closing down what is recognised as vulnerability is explored. Taking the two strands of gender and class, the paper considers the implications of these for mothers and their families (while recognising that there are also implications for the health visiting profession) by considering the role of gendered and classed bodies in demarcating the vulnerable from everyone else. The paper draws to a conclusion by considering the implications of this phenomenon for the provision of meaningful support for families with young children.

**Friday 13 September 2013****09:35 - 10:05**

Health Service Delivery

Derwent Room 104

*Kitto, S., Peller, J., Moulton, C., Grant, R., Gallinger, S.**University of Toronto***Enhancing the Quality Improvement Outcomes of the CCO HPB Community of Practice.**

In 2007 the surgical quality improvement (QI) intervention Cancer Care Ontario Hepatic, Pancreatic and Biliary Tract Community of Practice (CCO HPB CoP) was formed during the wake of provincial regionalization of HPB services. Despite being conceptualized within the literature as an educational intervention [1], CoPs are increasingly being adopted in healthcare as QI initiatives [2-3]. This exploratory qualitative study examines the relationship between QI and educational aspects of the CCO HPB CoP to gain insight into the (un)intended impacts of regionalization and the CoPs formation as a governing body, on the active participation of the CoP members in the CCO HPB CoP. Using an interpretivist framework, in-depth interviews explored participants' perceptions and experiences of their involvement in the CoP. Additionally, a discourse analysis of CoP documents was conducted. Analysis of the data was guided by three bodies of literature; CoP, sociology of professions and governmentality. A key theme identified was the existence of operational tension between the dual purposes of the CoP as a governing activity and education intervention. This tension contributed to member resistance to this

governing exercise expressed through inactive and/or marginal participation by many of the surgeons in the CoP.

References 1. Wenger E. *Communities of practice: Learning, meaning, and identity*. 1998: Cambridge University Press. 2. Li LC, Grimshaw JM, Nielson C, Judd M, Coyte PC, Graham ID. Use of communities of practice in business and health care sectors: A systematic review. *Implementation Science*, 2009, 4(1): p. 27. 3. Fung-Kee-Fung, M, Goubanova E, Sequeira K., Abdulla A, Cook R, Crossley C et al. Communities of practice to facilitate quality improvement initiatives in surgical oncology. *Quality Management in Health Care*, 2008, 17(2): p. 12.

**Wednesday 11 September 2013**

**13:20 - 13:50**

Screening and Diagnosis

Derwent Room 047

*Kitzinger, C., Nettleton, S., Kitzinger, J.*

*University of York*

**Diagnosing the 'minimally conscious state': The social construction of disorders of consciousness**

This paper draws on recent theoretical advances in the sociology of diagnosis (Jutel & Nettleton 2011) to analyse the social construction of 'the minimally conscious state' (MCS). The definition of this medical category, and its diagnostic criteria, have developed in the last decade (since Giacino et al 2002) to name the condition of brain-damaged patients who display discernable, but inconsistent, evidence of consciousness such as to distinguish their condition from 'coma' and the 'vegetative state' (VS). The boundaries between these three different disorders of consciousness have become unstable in recent years as medico-technological developments (notably fMRI scanning) have altered the parameters of what is clinically 'discernable' (Dyer 2013) and diagnoses are regularly contested in practice by patients' relatives, and in courts of law dealing with insurance claims and treatment decisions. This paper analyses in-depth semi-structured interviews with 40 relatives and 10 clinical and legal experts to explore ways in which social, political, technological and economic forces are implicated in the MCS diagnosis and how those involved in the diagnostic process become, to use Rapp's (1988) concept, 'moral pioneers' undertaking significant emotional and bureaucratic labour. Our data show how boundaries between VS and MCS are constructed in relation to their implications for treatment withdrawal (permissible for 'vegetative' but not for MCS patients, *W v M* 2011), access to rehabilitation therapies (recommended only for MCS patients), and also in relation to personal values and broader cultural beliefs about the nature of personhood, risk, consciousness and 'quality of life'.

**Wednesday 11 September 2013**

**13:20 - 13:50**

Experiences of Health and Illness

Derwent Room 003

*Kokanovic, R., Philip, B.*

*Monash University*

**Questioning notions of 'recovery' from 'depression'**

Emotional distress has been conceptualised across the entire lay/medical spectrum, from the normal highs and lows of the human condition to a mental illness called depression. Much of the sociological literature questions what is seen as the medicalisation of emotional distress, and illustrates the increasing biologisation of emotions via the dominant view that depression is caused by a chemical imbalance in brain chemistry. Most research on recovery from depression has been conducted within a clinical framework, with an emphasis on notions of 'clinical recovery' defined in terms of an absence of symptoms. Recently, interdisciplinary studies have highlighted the need to explore subjective experiences of 'personal recovery' from mental illness, with particular attention to how social networks, workplaces and the broader community can support self-generated personal recovery practices. While an emphasis on 'personal recovery' is a welcome counterpoint to dominant clinical approaches, the very notion of recovery tends to uncritically accept and reproduce the contested depression label. In this context, a better understanding of how people conceptualise the possibility of getting better or 'recovering' from emotional distress and depression is needed. This paper draws on narrative interviews with men in Australia conducted in 2010 and 2011, which was part of a larger project on emotional experiences of depression. We explore how men narrate a continuous process of construction, deconstruction and reconstruction of selfhood, while negotiating their emotional distress in everyday life. We discuss our empirical findings in light of debates about bio-medicalisation, personal recovery and depression as a contested illness.

**Thursday 12 September 2013****15:45 - 16:15**

Inequalities

Derwent Room 036

*Kovandzic, M., Gaynor, E., Thompson, S., Cloke J., Gabbay, M.**University of Liverpool***Addressing Health Inequalities Through the Work of a Clinical Commissioning Group: Early Findings of Policy Ethnography Within an Action Research Project**

England's NHS Clinical Commissioning Groups (CCGs) are GP-led organisations that are, from the 1st of April 2013, in charge of the major part of local health service budgets. Addressing health inequalities is one of the stated responsibilities of these new organisations. However, development of policies regarding this responsibility has not been contemporaneously matched with a clear guidance on how to meet the expectation. Furthermore, it was recognised that clinical commissioning expertise didn't necessarily include the specialist public health knowledge and skills required to tackle the problem.

This was the context in which we designed a one-year action research project (the HiCCG Project) in order to support, observe and evaluate the process of addressing health inequalities by a newly established CCG in a deprived urban area. The project is composed of three complementary work streams using methodologies of action learning, policy ethnography and systematic literature review.

This presentation will outline emerging findings from the policy ethnography stream, based on data generated during eight months of the fieldwork. While seeking to understand the processes of creating and integrating 'health inequalities agenda' in the work of the CCG, we will explore the ways in which stakeholders think, act and interact in relation to health inequalities, in the given socio-techno-political context. We will also discuss identified artefacts of the policy-making processes, as well as avenues of possible theoretical articulations of the overall findings.

**Thursday 12 September 2013****09:40 - 10:10**

Health Policy

Derwent Room 104

*Kriznik, N.**University of Durham***What's the Problem of 'Health Inequality' Represented to be?**

It has been known since the 19th century that differences in health exist between different groups of the British population. However, it was not until the late 1970s, and in particular with the publication of the Black Report in 1980, that these differences came to be defined as 'health inequality' and therefore became recognised as a problem requiring social policy intervention. Traditional approaches to policy analysis tend to focus on evaluating solutions to the given problem. The emerging field of Interpretive Policy Analysis, however, seeks to question the 'given' nature of policy documents, particularly questioning the way in which problems are constructed. Using the framework developed by Bacchi (1999, 2009, 2012) this paper will examine how the problem of 'health inequality' has been defined and understood as a policy problem in English social policy documents from 1980 onwards. Attention will be paid to the political contexts in which these documents were published in order to show how ideas about the problem of 'health inequality' fit within wider political ideologies. This analysis will highlight the political nature of policy production and also discuss the ontological status of 'policy problems' and how they can be analysed, as well as examining the benefits of an interpretive approach to health policy analysis.

**Friday 13 September 2013****09:00 - 09:30**

Experiences of Health and Illness

Derwent Room 056

*Lally, J., Exley, C.**Newcastle University***Living with Waiting: Patients' Accounts of Waiting for a Transplantation**

Respiratory diseases account for one in five UK deaths. Lung transplantation offers the only realistic therapeutic option for some patients with end-stage chronic lung disease; 20-30% of patients waiting for lung transplantation will die before an organ becomes available. Few research studies, to date have examined in detail people's experiences of such waiting. This paper draws on qualitative interviews, 17 pre-transplantation and 5 post-transplantation to examine people's experiences of waiting for transplantation. Data collection and analysis is on-going.

Waiting for lung transplantation, means living with tensions of hoping for the 'cure' of transplantation, but also the possibility of dying. People on the transplant register experience waiting in many ways: 'waiting'

until they are 'sick enough' to go on the list; 'waiting' to be called when an organ becomes available; and, 'waiting' in hospital to see if the lungs are suitable. Respondents' accounts suggest 'waiting' significantly impacts on their everyday life, relationships and their own identity. Many respondents talked about waiting for a transplant, but mindful that for them to receive lungs meant someone else had to die, and they were 'waiting' for this to happen. This paper examines personal accounts of waiting, and provides new insights into this hidden area of healthcare experiences.

This project is funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme (ref:10/82/01). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HTA, NIHR, NHS or the Department of Health

**Friday 13 September 2013**

**11:55 - 12:25**

Open

Derwent Room 049

*Lamont-Robinson, C., Thompson, T., Williams, V. University of Bristol School of Medicine*

**Going to Sea Together: The Experiences of Medical Students and Disabled Crew Members**

The Jubilee Sailing Trust (JST) has invited disabled and non-disabled sailors to voyage together for the past thirty years. Inspired by the opportunity for students to engage in the lived experience of disability, Bristol medical school has developed a short Student Selected Component in collaboration with the JST titled At Sea With Disability, this elective is now in its fourth year. The crew living with impairments and students are 'buddied' in pairs, and support each other throughout the voyages.

We found that notions around 'the healthy body' and 'disability' are brought to the fore during shared experiences such as sea-sickness, challenging weather conditions and living in close proximity with 'no place to hide'. In many instances the crew with disability are now 'expert' sailors, experienced in passing on their nautical skills and insights.

This paper draws on a qualitative analysis of diverse data sources from the perspective of disabled and non-disabled crew-members including on board audio-diaries, post-voyage interviews and focus groups.

In this presentation we outline the JST ethos and structures which may contribute to drawing the disabled crew to return time and again to these voyages. Current findings indicate the crucial role of the bounded environment, emphasis on teamwork and provision of diverse participatory roles. The desire to be challenged and to contribute authentically is a core theme in the data analysis. The presentation will include artworks and 'live' audio-data narratives contributing further perspectives around the experiences of health and illness offered by this unique maritime experience.

**Thursday 12 September 2013**

**09:05 - 09:35**

Mental Health

Derwent Room 037

*Lavis, A., Lester, H., Everard, L., Birchwood, M.*

*University of Birmingham*

**'A Worthwhile Gamble', Not-Yetness and Anti-Psychotics: Listening to Service Users' Views of the Physical Healthcare of Individuals with Severe Mental Illness**

It is recognised that life expectancy is lower and physical health poorer in individuals with psychosis than in 'the general population'. These disparities result from many inter-related factors, such as inequalities, stigma, smoking, inadequate healthcare and long-term effects of anti-psychotic medications. Although addressing the physical health and healthcare of this population is crucial, in making the leap from poorer health outcomes to service delivery mechanisms, recent research and policy have rarely engaged with service users' views.

Drawing on in-depth interviews with over 80 individuals with first episode psychosis in English Early Intervention Services who are enrolled in the SUPEREDEN study, this paper asks what service users themselves think about physical health and healthcare.

Interview narratives elucidate multifaceted relationships with anti-psychotics as ambivalently valued mediators of personhood and illness. When taking them, service users make daily complex transactions between - 'gambles' with - present and future, mental and physical, health. Just as such processes cannot be dislocated from individuals' social contexts or personhood, they also actively shape service users' desire or reluctance to engage with interventions into, or even knowledge about, future physical health; not knowing or acting can be a way of maintaining agency against both illness and medication.

## PAPER ABSTRACTS

By highlighting service users' multiple priorities and needs as they navigate psychosis, its vulnerabilities and aftermath, we offer insights into how services can focus on and care for the physical health of individuals with psychosis, but do so in ways that fit with wider contexts of their lives and selves.

**Thursday 12 September 2013**

**15:45 - 16:15**

Lifecourse

Derwent Room 037

*Law, C., Culley, L., Hudson, N., Denny, E., Mitchell, H.*

*De Montfort University*

### **Endometriosis, Biographical Appraisals and the Couple Unit**

Endometriosis is a chronic condition affecting between 2-17% of women of reproductive age. Common symptoms are chronic pelvic pain, fatigue, severe pain during menstruation, heavy menstrual bleeding, and pain during sex. The ESRC-funded Endopart study ([www.endopart.co.uk](http://www.endopart.co.uk)) aimed to explore the impact of endometriosis on women and their male partners. This paper reports findings relating to the biographical disruption which couples experience when living with endometriosis.

In-depth, face-to-face interviews with 22 heterosexual couples were conducted. Women and their partners were interviewed separately (n=44). Interviews were fully transcribed and entered into NVivo for analysis. Data were analysed using a systematic, thematic method, informed by an interpretivist relational approach.

Biographical disruptions (Bury, 1982) are not only experienced by chronically ill individuals but also by those around them. Findings suggest that endometriosis creates disruptions, appraisals and revisions across several life domains, including sexual relations, planning for and having children, working lives and social lives outside the home, both for women and for male partners. Using Williams' (2000) qualification of the concept of biographical disruption, the paper discusses how timings and context mediate the impact of endometriosis on biographical disruption. Drawing on the idea that the fashioning of selves and of relationships is reflexive and contingent, it discusses how biographical appraisals in light of endometriosis are recurrent and have to be continually negotiated between partners. Finally it explores how couples strategically mobilise resources to maximise favourable outcomes and maintain a sense of hope.

**Thursday 12 September 2013**

**14:35 - 15:05**

Patient - Professional Interaction

Derwent Room 047

*Leader, C.*

*Newcastle University*

### **The Impact of Gender on Women's Relationships with Health Care Professionals Throughout Pregnancy and Childbirth: A Qualitative Analysis.**

**Aims** - This study aims to provide an insight into the relationship between a pregnant woman and her health care professional (HCP) using Foucault's 'technologies of power'. Focusing on interactions between women and HCPs, an investigation is presented into the impact that gendered technologies of power have on this relationship and decision making processes in the context of childbirth.

**Methodology** - A secondary analysis of data extracts taken from qualitative interviews with women who had a previous caesarean and were faced with a choice regarding mode of delivery in a subsequent pregnancy. The thematic analysis identified two themes: 1. where gendered technologies of power are present within interactions; and 2. the impact these have on the care giver/receiver relationship.

**Summary of findings** - This study highlights how gendered technologies of power have impacted on micro-level interactions between women and HCPs. In this context there was an evident shift from acquiescence to resistance following the women's first experience of childbirth. The technologies that the women used in order to resist were the same technologies that had been instrumental in their subjugation during their first experience.

**Conclusions** - The implications of this for first time mothers are greatest and it seems they are clearly at a disadvantage. It is imperative that a mechanism is sought to close the gap between first time and subsequent mothers to provide first time mothers with greater agency over their choices throughout childbirth.

**Friday 13 September 2013****09:00 - 09:30**

Ethnicity

Derwent Room 002

*Lee, S.**Brunel University***The Impact of Food Habits on the Health of Older Chinese Migrants in England**

This paper presents ethnographic data to show the link between diet and health concerns of some older Chinese migrants living in sheltered accommodation in the north of England. It documents how while these Chinese elders continued to take medication (eg for diabetes) dispensed by NHS doctors, they also sought to maintain good health through alternative 'diet therapies'. More significantly it shows how others took steps to avoid such diseases through the manipulation of their diet as culturally, diet and health – or food and medicine – always went together. I will argue that the availability of these 'ethnic' foods contributed to the well-being of these individuals. Even if there was no scientific evidence to show any effect of food habits on their health, this practice gave them the confidence to remain on the 'western' medication regime. However this was only possible because this sample of older Chinese lived in the middle of a Chinatown where they had easy access to Chinese food. The paper ends with a short discussion on the lessons we could draw from this case in the management of health of other migrant groups now ageing in Britain.

**Thursday 12 September 2013****16:55 - 17:25**

Methods

Derwent Room 049

*Lee, R. P., Thompson, B., Coady, D., Foster, E., Kay, L.,  
Watts, R., Rapley, T.**Newcastle University***Talking about Looking: Interviewing Carers of People with Rheumatoid Arthritis About Information Seeking**

Given the profusion of illness-related information, we consider how talking about information seeking – and in particular internet use – is difficult; not because it is necessarily a highly sensitive topic (though it may be), but rather due to the unusual and unfamiliar situation of talking about (rather than simply doing) information seeking. Difficulties exist for the interviewer and the interviewee when talking about looking, often resulting in generalised accounts which lack details of the specific practices employed.

In this paper we consider the relationship between the production of qualitative data from on-going interviews, analysis of this data, and understanding how carers of people with rheumatoid arthritis (RA) look for information. We do this to make sense of the way people talk about their information practices as part of an interaction and to advance our understanding of what and how carers learn about RA. Using serial interviews with newly-diagnosed dyads [n=25] and single interviews with longer-term review dyads [n=8], our aim was to understand these processes as they occur over time.

We then detail how changing interview questions and the form of interaction can help to produce more meaningful insights. Specifically we analyse how orienting some aspects of the interview around a computer enables discussion of practice. Additionally, talking about internet-based information can give rise to new and relevant interview topics. Despite this a number of practical issues remain and we conclude by considering the contribution of other approaches and the implications for understanding information seeking.

**Wednesday 11 September 2013****15:05 - 15:35**

Experiences of Health and Illness

Derwent Room 056

*Lerum, S. V.**University of Oslo***Exploring Health Professionals' and Carers' Categorizations of Motor Neuron Disease: A Qualitative Study**

The study explores chronic and terminal categorizations of motor neuron disease (MND), outside Britain often known as amyotrophic lateral sclerosis (ALS). For this diagnosis expected survival is 2-5 years, but a small proportion may live considerably longer. There is no known cause or cure, but several interventions are available to improve and prolong life. In the study, taking place in Norway, three groups were interviewed; health professionals in hospitals and primary care, and family carers living in MND homes, totaling 54 interviews. The analysis show how actors involved in MND care are emphasizing chronic and terminal aspects in subtly different ways, making for a complex and dynamic understanding of the challenge at hand. Frail terminality is a preliminary concept to describe this. MND

## PAPER ABSTRACTS

is a fatal diagnosis. However, the terminality is frail; it may be challenged and negotiated, as contingencies, choices, and interventions may make it less terminal. The indefinite time-scope may create an ongoing tension between enduring the situation in an unsustainable manner, appropriate for a terminal condition; simultaneously as the situation prolongs there is a need for more sustainable routines. The unsettledness complicates issues such as access to health services (hospice being one example), legal status (for instance regarding resuscitation), and attitudes among health professionals and carers. As health services and medical interventions develop, this study illustrates the need for concepts to frame new choices and dilemmas in illness trajectories.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Mental Health

Derwent Room 003

*Lewis, S.*

*Loughborough University*

### **Challenging and non-judgemental support: The role of unmet needs in creating specific support environments in online anorexia forums.**

This paper explores the different cultures of support present on two online anorexia forums. Using grounded theory this study combines non-participant observation and interviewing to gain insight into a pro-recovery community and a pro-anorexia community. While the focus of the two communities appears to be different, similarities are present, especially in the form of members expressing a need to access the community due to unmet needs in their offline life. Members frequently comment on the lack of understanding that they experience when with friends, family and medical professionals, which impacts on how members offer support on the two forums.

Both communities' have developed normative elements that offer members support inaccessible in their offline lives. These normative elements serve to regulate what behaviour is considered supportive, create a sense of responsibility on the sites and also marks behaviour as unacceptable. For the pro-recovery community support centres around 'challenging', meaning members are encouraged to challenge one another's eating disordered thoughts and behaviour. Challenging was described as 'harsh but kind' and does not conform to forms of support traditionally seen in self-help groups. While for members of the pro-anorexia community support functions under the guise of being non-judgemental. Focus is given to offering support in all circumstances, and the role of empathy is essential for this community. However this non-judgemental support does not extend to members who require support to exacerbate their anorexic condition.

**Thursday 12 September 2013**

**09:40 - 10:10**

Experiences of Health and Illness

Derwent Room 056

*Lian, O. S., Nettleton, S.*

*University of Tromsø*

### **Negotiating ME in Norwegian Virtual Symbolic Communities**

It is well recognised that socio-cultural and technological changes have transformed the role of the doctor, the role of the patient, and relations between them. These cultural and technological shifts have created windows of opportunity for empowering patients, by providing them with virtual arenas for challenging medical constructions of disease and illness. People living with chronic illness are afforded opportunities to negotiate the naming and framing of their conditions, both with fellow sufferers and with the medical profession. These negotiations are played out in an arena that is separated from the one-to-one relations that take place within the four walls of the consultation office, with all the trappings of asymmetric power. Instead, these discussions are played out in virtual locations and so are less formally regulated, more democratic and spatially flexible environments. In this paper, we explore text and images found on Norwegian websites that have been posted by women who report living with long-lasting exhaustion. Our main aim is to explore the content and the functions of these sites, and to highlight the ways in which the authors' make use of virtual symbolic communities to negotiate the medically contested diagnosis myalgic encephalomyelitis.



**Friday 13 September 2013****09:00 - 09:30**

Methods

Derwent Room 047

*Lie, M.**Newcastle University***Content Analysis: Two 'Simple' Examples of its Use in Health Services Research**

Content analysis has a long history in the social sciences and a well-known adaptation of this method is the constant comparative method and development of 'grounded theory' by Glaser and Strauss. Content analysis has popular connotations of being more quantitative (involving numerical word counts) than qualitative (being interpretive of meaning) in its method. At the same time, it has also been criticised for not being 'quantitative' enough or 'qualitative' enough (or too simplistic a method for either approaches).

This paper reports on two contrasting uses of content analysis in qualitative research, and leaves the discussion open as to whether the method applied in each case was too simplistic to be of any research value. The first study aimed to determine the experiences, beliefs and actions of participants in a qualitative study of gestational diabetes in order to develop a list of propositions to improve health services for this patient group. It utilised a 'deductive' or 'directed form of content analysis. The second study involved a textual analysis of qualitative studies of stroke experiences identified through a literature review. The narrative text in the published articles was coded and counts made to identify health state descriptors for stroke. The results raised questions about existing utility values for stroke based on health state descriptions that were clinically derived and neglected the patient perspective.

Much qualitative content analysis in health services research has employed grounded theory methods, thematic or framework approaches. This paper presents alternative applications of this flexible method.

**Wednesday 11 September 2013****13:55 - 14:25**

Ethics

Derwent Room 006

*Locock, L., Boylan, A.**University of Oxford***Biosamples and the 'Gift Relationship': How Participants in Biobanking Projects Talk About Donation**

**Objective** - To explore how people donating biosamples talk about this, and how they regard the notion of samples as 'gift'

**Methods** - Qualitative semi-structured interview study with a purposive sample of 21 participants, including healthy volunteers and people with a health condition/concern (cancer; motor neurone disease; hepatitis C virus; high-risk pregnancy) who had been asked to give biosamples for research. Transcripts were coded using NVIVO coding software; coded sections on motivation for taking part and attitudes to the term 'gift' were analysed thematically, combined with discourse analysis to explore language use.

**Results** - People reported taking part for various reasons, commonly foregrounding 'altruistic' motivations (e.g. helping medical science and future generations) but also including potential personal benefit (e.g. obtaining a free health check/information about one's health; obtaining better care; getting a possible cure for one's condition). The term 'gift' was seen as appropriate in some cases (especially regarding blood samples for research), but also evoked puzzlement, especially in relation to 'waste' material such as urine or tumour samples. Whilst 'giving' or 'donating' were commonly used terms, for many respondents 'gift' signified something more special and deliberate. The following themes emerged: unreserved gift; reciprocal gift; collective gift; unwanted or low value gift; gift as exaggeration.

**Conclusion** - While participants are motivated by altruism, the language of 'gift' does not always resonate well and should be used with caution. People also perceive personal and reciprocal benefit, and the use of 'waste' products evokes little concern. This has implications for communication with people about research biosamples.

**Thursday 12 September 2013****16:20 - 16:50**

Inequalities

Derwent Room 036

*Lorimer, K., McDaid, L.**Glasgow Caledonian University***Young Men's Digital Tastes: Implications for Internet-based Chlamydia Screening Inequalities**

Young men commonly remain at the periphery of chlamydia screening approaches. There is emerging, albeit variable, evidence that interactive technologies, such as the Internet, could serve men better than 'traditional', settings-based screening approaches. To assist with the development of an Internet-based screening intervention, we recruited young men aged 16-24 years from various community settings (e.g., community groups, further education), across areas of high and low deprivation, to 15 focus group discussions (n=60). Men were asked about their knowledge of chlamydia, their technology use and for their attitudes towards smartphones and Internet, so that we could build a picture of the barriers and facilitators of Internet screening. The paper focuses on key findings around men's 'digital tastes', including the levels of disconnect from technology, such as the Internet, particularly among the younger men and to a certain extent among men from deprived areas; men from more deprived areas expressed different views towards technology use and Internet-based Chlamydia screening than men from more affluent areas. Men's concerns about confidentiality and privacy were not always assuaged by the use of technologies for screening. The paper concludes by drawing on evidence of young people's digital tastes, shaped by cultural capital and habitus, to explore the potential for Internet-based chlamydia screening to produce a socially entrenched 'digital inequality', and thus screening inequality

**Thursday 12 September 2013****15:10 - 15:40**

Experiences of Health and Illness

Derwent Room 056

*Lowton, K., Hiley, C., Higgs, P.**King's College London***Moral Obligations and Expectations of Adult Survivors of Childhood Liver Transplant: Deserving or Undeserving Recipients?**

The implicit relationship in organ transplantation assumes that recipients should behave in ways that take care of the donor organ as a way of acknowledging the benefactor's act. This normative assumption renders recipients deserving or undeserving after they have had a transplant. In particular these issues are often the focus for moral controversy regarding who should be deemed suitable for liver transplantation; alcohol abusers with liver disease often being viewed as unsuitable recipients, illustrated in the UK by the case of George Best, who died following heavy drinking after receiving a donor liver. However, discussions regarding notions of moral obligations and expectations have to date focused on adult transplant recipients. 'New' ageing populations - adults growing older with diseases conventionally associated with childhood - create a new terrain for discourses of moral desert as well as moral expectations. All of this is contextualised by the fact that those who had childhood liver transplant were not parties to consenting to the procedure and have no preformed narrative or guidance on the 'best' ways to live their lives. The first global cohort of childhood liver transplant recipients undertook surgery 30 years ago and recipients, professionals and families are still negotiating what is both individually and socially appropriate in terms of behaviour. We explore these normative issues through 27 in-depth interviews with members of this first global cohort, now in their 20s and 30s. We find that conventional discourses of deserving and undeserving recipients remain resonant, with no counter-discourse as yet available to them.

**Thursday 12 September 2013****16:55 - 17:25**

Teaching Medical Sociology

Derwent Room 006

*MacBride-Stewart, S., Stone, A., Hawthorne, K.**Cardiff School of Social Sciences***Tricking Medical Students or Taming Sociology? A Critical Assessment of the 'Integration' of Sociology into Medical Education via 'Innovative' Methods**

In medicine, a debate has taken place between medical doctors and sociologists about how medical sociology should be taught, learnt and assessed in UK medical schools. In this debate sociological learning in medical school is suggested to be 'failing' or 'unpopular' because sociological theory lacks a meaningful relationship to everyday clinical practice, and students believe they are being tricked into using the language and concepts of sociology and express discomfort with this. Students also see barriers to embracing sociological knowledge in the attitudes of their peer groups and their medical

tutors. For the purposes of this paper, the authors are using a sociological perspective to reflect on a recent opportunity that we had to discuss with 3rd year medical students (in interviews and online questionnaire) about how sociology should be taught, learnt and assessed. Students had previously participated in sociological teaching that had followed a well established and conventional pedagogic approach for teaching in medical schools ie lecture and seminar based learning. More recently, the students participated in clinician-supported, self directed learning via sociology workbooks that were constructed around specific themes ie stigma. As the presentation will show, medical students overwhelmingly supported the self-directed learning of sociology. They believed that having the opportunity to peer review their own and others reflective critical writing was an effective means by which to overcome the historical prejudices of engaging with sociological concepts. Scambler (2009) has argued elsewhere that such innovation represents the taming of sociology and a dwindling of its critical focus, which inevitably stems from the rationalisation and corporatization of medical education in the UK. This paper does not question whether medical sociology has a role in medical school training. The place of medical sociology as a core aspect of the medical knowledge has been assured through its inclusion in the General Medical Council document (Tomorrows Doctors 2009). What this paper does is determine what sociological knowledge is valued by students in the 'pedagogical encounter' ie when meeting patients in general practice, in the different learning modes. Particular attention is paid to collaboration, power and authority, the construction of scientific and clinical knowledge, critical thinking, uncertainty, professional identity and individualism. The paper concludes by assessing how the method of delivery in the medical curriculum reflects and naturalises how the sociological world ought to be seen.

<b>Friday 13 September 2013</b>	<b>10:10 - 10:40</b>
Health Service Delivery	Derwent Room 104

*Mackintosh, N., Sandall, J., Humphrey, C.*

*King's College London*

**The Hidden Nature of 'Rescue Work'; Widening the Policy and Practice Focus Regarding Care of Acutely Ill Patients**

International concerns over 'failure to rescue' acutely ill patients on hospital wards have led to the widespread implementation of rapid response systems. Despite these system level changes, management of deterioration in patients' conditions remains problematic. Rescue is a complex process and only partially understood.

We explored the nature of 'rescue work', drawing on theoretical insights from medical sociology to illuminate relationships between organisational systems, department and individual level processes. Data collection involved ethnographic fieldwork over 12 months in two UK NHS Trusts, including observations (180 hours), interviews (35) with health care assistants, nurses, doctors and managers, and documentary analysis.

Our findings expand understandings of rescue beyond reified, linear trajectories to include overlapping structural, technological and diagnostic influences. We draw attention to the adaptability and intelligence displayed by frontline staff to handle clinical uncertainty. Caring for acutely ill patients is underpinned by much hidden diagnostic work which embodies the nature and status of different types of rescue work. Rapid response systems open up aspects of rescue work for scrutiny, facilitating the development of a shared management approach for caring for acutely ill patients. However, they also reinforce hierarchies and occupational boundaries. Structural processes such as access to critical care, and transfer of responsibility between medical firms influence patient pathways. Our analysis suggests that priorities and solutions for the acutely ill should include greater recognition of the significance of the mundane routine of rescue work, structural and professional influences and inequalities, and diagnostic categorisation regarding escalation of care.

<b>Thursday 12 September 2013</b>	<b>08:30 - 09:00</b>
Gender	Derwent Room 006

*MacLean, A., Hunt, K., Gray, C.,  
Smillie, S., Wyke, S*

*MRC/CSO SPHSU, University of Glasgow*

**'The Only Thing I Dinnae Have Any Control Over is Tea, Cos She Makes It': How Do Family Members Feature in Men's Accounts of Taking Part in the Football Fans in Training Weight-management and Healthy-Living Program?**

Obesity is a growing public health problem and prevalence in UK men is among the highest in Europe. Facilitating men's weight loss is challenging as most existing weight-loss programs are seen as

## PAPER ABSTRACTS

women's spaces. Football Fans in Training (FFIT), a weight-management and healthy-living program delivered to groups of overweight and obese men at Scottish Premier League football clubs, is designed to be gender-sensitized in content, context and style of delivery, building on sociological understandings of gender. The effectiveness of FFIT is being evaluated in a randomised controlled trial. We have conducted 20 observations of delivery and 10 focus groups on men's experiences of FFIT. This paper investigates men's accounts of how their decisions around dietary and lifestyle change have impacted on or been affected by family circumstances.

Support from family and friends is important in facilitating weight loss, but little is known about how family members feature in men's efforts to lose weight. Investigating how changes in family practices are negotiated when men are trying to lose weight is of interest, especially as practices involving food and eating have traditionally been considered the responsibility of women, even though they may defer to men's preferences in more traditional households. We will explore the ways in which men talked about the changes they were making both impacting upon and being influenced by family circumstances. Paying attention to themes of control and responsibility, we will reflect on the implications of our findings for understandings of gender roles and relationships within families.

**Friday 13 September 2013**

**09:35 - 10:05**

Citizenship and Health

Derwent Room 036

*Madden, M.*

*University of York*

### **Holding the Research Community to Account: Reflections on the Role of Public Involvement in Health Research from a Sociologist in the James Lind Alliance Pressure Ulcer Priority Setting Partnership (JLAPUP)**

In a speech on avoiding waste in research at the 2012 INVOLVE conference, Iain Chalmers (2012) made a case for more public involvement: 'the public needs to hold the research community to account, and be critically involved in health research, from agenda setting to dissemination of results.' This paper will use this speech and the experience of the author, a sociologist leading the James Lind Alliance Pressure Ulcer Priority Setting Partnership (JLAPUP), to reflect on the struggle over meaning and methods in healthcare PPI (Patient and Public Involvement), including avoidable waste in the production and reporting of PPI research evidence. The paper will consider JLA methods as experiments in deliberative democracy within the current neoliberal social and historical context. It will question how categories of the public (and the researcher) are produced for purposes of participation and discuss the role of PPI in the reconciliation of citizen healthcare needs, wants, rights and resources.

Chalmers, I. (2012) Avoiding waste in research: the role of public involvement. 'Putting people first in research' INVOLVE Conference Nottingham, 13 November 2012.

<http://www.jlapressureulcerpartnership.co.uk/>.

**Thursday 12 September 2013**

**08:30 - 09:00**

Health Care Organisations

Derwent Room 003

*Magnusson, C.*

*University of Surrey*

### **Patient Safety: Currencies of Accountability**

Accountability has been a driving force for NHS modernisation and in exploring more efficient ways to deliver high quality care. Recent healthcare scandals, such as Maidstone & Tunbridge Wells and Bristol (Sorell, 2007), have driven developments for greater transparency and accountability. However, there has been little research concerning implications of accountability in healthcare practice.

This study aimed to investigate how accountability for patient safety was manifested in NHS acute care. It aimed to analyse different systems of accountability at an organisational level. The study used an in-depth case study of systems of accountability for the control of Healthcare Associated Infections within one NHS Hospital in England. The methods used were ethnographic in nature: observations of meetings (N=14), documentary analysis (meeting minutes, guidelines, policies), and semi-structured interviews (N=37). Data was collected between 2008 - 2011.

Day and Klein (1987) claim that currencies of accountability is a crucial component within accountability systems. Currencies are the performance indicators and objectives of services or programmes. The findings from this study demonstrated that the currencies of accountability for patient safety provided a useful lens through which to analyse the data. Three key findings will be explored during this presentation. The first demonstrates that the powerful impact of targets and regulation made them an effective currency of accountability. The second finding concerns the lack of currency to evaluate clinical

performance and in particular individuals' non-conformance with Trust policy. The third finding describes how the complexities of working in multi-professional teams made evaluation of performance challenging.

**Friday 13 September 2013**

**09:35 - 10:05**

Lifecourse – Death and Dying

Derwent Room 003

*Mallon, S., Galway, K., Hughes, L.,  
Gonzalez, G., Rondon, J., Leavey, G.*

*Northern Ireland Association for Mental Health*

**Precarious Relationships: An Exploration of the Role of Relationship Breakdown in Suicide and the Impact on those Left Behind**

The importance of interpersonal relationships in providing individuals with a sense of resilience is well established. Conversely, it is also recognised that relationship difficulties, in particular the breakdown of an intimate relationship, may result in negative mental health outcomes. Separation and divorce are important risk factors for suicide. Considering the high proportion of suicides that occur in the context of relationship breakdown, we have limited understanding of these matters. In addition, few studies consider how suicides which occur within this context, impact upon the bereaved.

We draw on data collected from GP and Coroner records on 403 individuals who died by suicide. By applying the recently developed Sociological Autopsy Approach, we identified 129 deaths (32%) for whom relationship breakdown was cited as a key factor. We present a typology of the relationship issues reported to have contributed to the suicide. We combine this data with qualitative interviews from a range of bereaved family members, including siblings and children, to explore and critique how changes in intimate relationships are presented as explanatory factors for death by suicide. Finally, we present qualitative data from the ex-partners of the deceased in relation to the relationship and report on the complex nature of bereavement for those who often considered to be held partly responsible for the death.

We use our findings, in combination with theoretical insights, to explore how we can promote resilience both in the aftermath of a relationship breakdown and in those affected by those bereaved by suicides which occur at these times.

**Thursday 12 September 2013**

**14:00 - 14:30**

Inequalities

Derwent Room 036

*Marinho, M. L.*

*University of Warwick*

**Health Inequalities in Chile: Individual Choice vs. Structural Influence**

This paper examines how health inequality is produced in a highly unequal society analyzing the ways in which social relations, institutional arrangements and biography facilitate or hinder people from different socioeconomic groups and genders in engaging with a range of health related practices. It uses a mixed methods approach based on secondary quantitative analysis, semi-structured interviews and participant observation of middle and lower class men and women in Santiago de Chile. Preliminary results show that health related practices are associated with differences in social normative, macro level and individual level factors, which are related to particular social groups and gender. While people believe that health is mainly a product one's own actions, their narratives and experiences reveal the socially differential importance that factors such as socialization, social image, employment conditions, and economic situation have. These differences between social groups produce health inequalities by increasing or decreasing their risks of developing a non-communicable disease, including diabetes and high blood pressure. Hence, it is not only individuals' decisions that determine health practices, but also structural influences on the 'habitus' in a Bourdieusian sense. These results reveal the inappropriate character of a behavioural approach to causation and intervention in which individuals are taken fully responsible for their actions, and points to the need to understand the complexity of causal phenomena when formulating social policies aimed at reducing health inequalities.

**Thursday 12 September 2013****14:00 - 15:40**

MedSoc Committee Symposium

Derwent Room 028

*Martin, D.**University of York***The Choreography of the Kitchen Table: The Agency of Everyday Spaces in the Experience of Care**

This paper reports on the early stages of a research project that seeks to understand the social meanings of buildings and spaces designed to have therapeutic effects for those who use them. Based on research with a charity whose services have been designed to support those with cancer, their families and carers through periods of diagnosis and treatment, the paper will explore the affective qualities of their buildings, and in particular the design and use of everyday spaces to distinguish the services offered by this charity and those provided by other healthcare organisations. This is most effectively explored in the importance of the kitchen area within the charity's architectural brief, and the prominence given to such a domestic type of space within the buildings themselves. This paper explores the various and complex ways in which both visitors and staff members understand the value and functioning of the kitchen within their use of the building. The kitchen is, at the same time, an informal space for users and a workplace whose role is central to the services offered; as such, it exerts an agency in the experience of place that is instructive in understanding the wider therapeutic aims.

**Wednesday 11 September 2013****15:05 - 15:35**

Experiences of Health and Illness

Derwent Room 003

*Maskill, V., Whitehead, L., Crowe, M., Inder, M.**University of Otago***The Impact of Type 2 Diabetes and Comorbid Conditions on Sense of Self and Identity and Self-management Practices**

A diagnosis of a chronic condition, including Type 2 diabetes, can significantly impact an individual's sense of self and identity, which in turn can have considerable implications on how they adapt to, and self-manage their condition. This paper reports on the preliminary findings from a qualitative PhD study of forty participants diagnosed with Type 2 diabetes mellitus and comorbid conditions. The study focuses on the impact of the conditions on sense of self and identity and self-management practices.

Methods: Participants were recruited from a larger study which explored the effectiveness of a therapeutic intervention on glycaemic control. Interviews were audio-recorded, transcribed verbatim and analysed using a General Inductive Approach.

Results: The majority of participants experienced a loss of their normal self and struggled to integrate diabetes and comorbid conditions into their sense of self and identity. Acceptance, knowledge, and integration of conditions directly influenced self-management practices.

Conclusion: Living with diabetes and comorbid conditions can significantly impact individuals' sense of self and identity and, in turn, self-management practices.

**Thursday 12 September 2013****17:30 - 18:00**

Experiences of Health and Illness

Derwent Room 056

*Mathieson, A., Morris, R., Jefferies, M., Rogers, A.**University of Manchester***'It's Delightful Banter': Community Group Friendships and Self-management Support for Vascular Ill Health**

Friendships and friend-like relations have received less attention in medical sociology than research on 'the family'. Social enquiry has focused on 'intimacy' and 'individualization' in late modernity, ignoring other forms of connectedness such as acquaintanceship. With an increase in divorce, single person households and life expectancy, there is now a need for research to de-centre the family and explore other sources of support for long-term condition management. This study explores the role of third-sector groups in the self-management of long-term vascular conditions. Twenty participants, self-diagnosed as having Diabetes, heart disease or Chronic Kidney Disease, were recruited from a range of voluntary groups. Semi-structured interviews and an adapted version of the Hierarchical Mapping technique explored reasons for participation, and key people who helped with the day-to-day management of their chronic illness. Analysis highlighted the complex nature of friendships and how friend-like relations were formed within the context of community groups. There was a distinction

between friends inside and outside of the group; friends formed in the group played a specific role in the respondents' illness management. Respondents often disliked burdening their family and friends outside of the group by discussing their health. The group therefore offered 'a space to moan', where the participants could share their experiences without feeling guilty. Friends inside the group were seen as comforters, 'cheering people up', and offered advice. This support was not restricted to health specific groups. Medical Sociology could benefit from exploring how relationships, formed in different settings, influence engagement with long-term condition management.

**Wednesday 11 September 2013**

**15:05 - 16:45**

Symposium

Derwent Room 006

*Mazanderani, F.*

*Durham University*

**Illness Narratives, Experiential Knowledge and Contemporary Regimes of 'Living With' Disease**

Illness narratives – stories about personal experiences of health and illness – are frequently used in medical sociology as a method for analysing the subjective and socially contingent dimensions of living with different conditions. These narratives are often framed as enabling the articulation of 'authentic', 'lived' experience in contrast to supposedly 'reductionist', 'disciplinary' biomedical accounts. This paper analyses the tension between, on the one hand, illness narratives as articulations of supposedly unique personal experiences and, on the other, the ways in which they are transferred and transformed, generalized and applied in relation to other people and contexts. Drawing on interviews with women living with HIV and people affected by Multiple Sclerosis, I suggest that rather than seeing this tension as something to be resolved, it is in large part due to it that illness narratives, as simultaneously ethical and disciplinary, individual and communal, personal and biomedical enactments, have come to play such a key role in the construction of contemporary regimes of 'living with' disease. Through an exploration of how illness narratives are used in sociological research, patient groups, and the media, I argue that new methodological approaches need to be developed that place this tension at the heart of how we engage with illness narratives and the notion of 'experience' in our research practices.

**Thursday 12 September 2013**

**14:00 - 14:30**

Lifecourse

Derwent Room 002

*Mazanderani, F.*

*Durham University*

**When Bodies Fall Apart: Internet Use, Patient Activism and the Mediation of Medical Knowledge**

Multiple Sclerosis (MS) - the most common neurological condition to affect young adults - is widely believed to be an auto-immune condition. In 2006, Italian vascular surgeon Paolo Zamboni proposed that it is linked to abnormal cerebrospinal venous drainage - what he termed CCSVI (Chronic Cerebrospinal Venous Insufficiency). Since then, there has been a surge of transnational patient activism lobbying for CCSVI research and treatment. One of the most commented on features of this activism has been its online nature, with patients sharing their thoughts and experiences on websites, blogs, forums, Facebook pages, and YouTube. While this has been criticised as a dangerous source of misinformation that challenges evidence-based medical practice, drawing on on-going research on patient activism in relation to CCSVI, I argue that people affected by MS are not trying to undermine evidence-based medicine, but rather intervene in and reconfigure what counts as 'evidence' in contemporary neurological policy and practice. In particular, I focus on how the generation of different forms of knowledge online intersects with, problematizes and mediates the ways in which patients' bodies and diseases become 'known', and consequently treated, in three medical disciplines: neurology, vascular surgery and radiology. Thus, the debate on internet use, evidence and activism in relation to CCSVI becomes less about 'lay' versus 'expert' understandings, and instead, highlights the differences between what counts as evidence in different medical specialisms.

**Wednesday 11 September 2013****16:15 - 16:45**

Screening and Diagnosis

Derwent Room 047

*McNaughton, R., Shucksmith, J., Steven, A.**Teesside University***Diagnosing Uncertainty: Experiences of Engaging with a CVD Screening Programme**

Work on the sociology of diagnosis has highlighted how the receipt of a clinical verdict from the medical professions acts as an event that provides identification of ill health or disease, sanctions and legitimises certain behaviours, and provides a catalyst for the patient to either adopt or resist an illness identity.

This paper explores these frameworks within the context of the Department of Health's NHS Health Check (NHSCH) programme – a national screening programme for 40-74 year olds in England and Wales that aims to identify individuals at an increased risk of experiencing a cardiovascular event (such as a heart attack or stroke) in the next 10 years and offers both lifestyle advice and medical intervention in the form of lipid lowering medications.

The NHSCH programme has been constructed to mirror an accepted model of illness diagnosis. However individuals have not had a clinically diagnosable condition identified. Rather they are informed they have the potential to experience an adverse event – in essence they have been afforded a diagnosis of uncertainty. These individuals are expected to make changes to their lifestyles, and in some cases embark on medical treatment and sustain these behaviours over the long-term.

This paper will draw on evidence collected through qualitative interviews with individuals that have been identified as high risk through the NHSCH programme in the Tees Valley. It will explore the views and experiences of individuals grappling with a diagnosis of risk and how this, in turn, leads to decisions of (non)compliance with medical advice.

**Thursday 12 September 2013****09:40 - 10:10**

Lifecourse

Derwent Room 049

*McDaid, L., Martin, S., Hilton, S.,**MRC/CSO SPHSU, University of Glasgow***UK Newsprint Media Reporting on Sexual Health and Blood Borne Viruses in 2010**

Improving sexual health and blood borne virus (BBV) outcomes continue to be of high priority within the UK. It is evident that the media can and do impact on the public health agenda and in shaping the public's understanding and awareness of sexual health and illness. This paper presents the first large-scale exploration of UK national newsprint media representation of sexual health and BBVs and provides valuable insights that could help identify potential avenues for future prevention, education and awareness initiatives. Using keyword searches in electronic databases, 677 articles published during 2010 were identified from 12 national newspapers. Content analysis was used to identify manifest content and to examine the tone of articles. Whilst there was a mixed picture overall in terms of tone, negatively toned articles, focusing on failures or blame, were common, particularly within HIV/AIDS and other STI coverage (41% were assessed as containing negative content, 45% had negative headlines). Differences were found by newspaper genre, with 'serious' newspaper articles appearing more positive and informative than 'mid-market' newspapers or 'tabloids'. Across the sample, particular individuals, behaviours, and risk groups were focused on, not always accurately, and there was little mention of deprivation and inequalities (9%). A gender imbalance was evident, particularly within reproductive health articles (71% focused on women, 23% on men), raising questions concerning gender stereotyping. We suggest that this needs further investigation to explore these discourses and challenge patterns of 'blame' and 'responsibility' concerning risk behaviour, which may promote unhelpful messages about sexual health.

**Thursday 12 September 2013****09:05 - 09:35**

Health Care Organisations

Derwent Room 003

*McDonald, R.**University of Nottingham***Desert Island Doctors: Medical Work, Music and Social Class**

This paper shows how a focus on social class can help to provide a useful perspective from which to approach the study of professions and the profession of medicine in particular. It draws on Bourdieu who takes as his starting point Weber's view of class and status as being distinct ideal types. Bourdieu sees the two not as distinctly different, but as inextricably linked with status groups and related



differences being just class groups and class differences in disguise. A class is defined in part 'by a whole set of subsidiary characteristics which may function, in the form of tacit requirements, as real principles of selection or exclusion without ever being formally stated'. Social classification is simultaneously a social allocation of honour. According to Bourdieu, 'nothing more clearly affirms one's "class", nothing more infallibly classifies, than one's taste in music' (1984:18). The paper takes as its source material the accounts given by medical elites appearing on 'Desert Island Discs' a weekly radio show in which they discuss their lives and musical tastes. The paper highlights the importance for sociologists of professions of going beyond Weberian 'closure' to see status and class as linked. It demonstrates insights to be gained from examination of the social conditions underpinning the transmission and acquisition of cultural capital. As part of this process, it shows the importance of cultural capital and its mode of acquisition (in most cases, family and education) in explaining the elevated status of some professional groups relative to others.

**Thursday 12 September 2013**

**11:25 - 11:55**

Inequalities

Derwent Room 002

*Meadows, R., Arber, S.*

*University of Surrey*

**Marital Status and Health in a Society in Transition: A Conceptual and Empirical Investigation into the Possible Role that Sleep Plays**

Consistently, and across populations, evidence has shown that married people live longer and healthier lives than their unmarried counterparts. Marriage has been found to lead to better outcomes for health conditions such as heart disease and hypertension. Conceptual frameworks have been put forward which attempt to explain this enduring link between marital status and health. Umberson et al (2010), for example, see social ties influence health behaviour directly through symbolic meaning and indirectly through support/stress and social control.

We offer a fivefold criticism of existing conceptual models. Of particular import for the current paper, recent sociological work has yet to filter through and there remains a lack of consideration of the role that 'sleep' may play as a possible explanatory tool.

We draw on data from Understanding Society to examine whether sleep mediates the relationship between marital status and health. Wave 1 data were collected in 2009-2010 from a representative sample of households in Britain. In total, 30,169 households gave full or proxy interviews; resulting in 50,994 individual interviews.

Data are analysed using a series of mediation models. 'Simple mediation analysis' includes self-reported health as the dependent variable, marital status/quality as the independent variable and subjective sleep quality as the possible mediator. Age, education and ethnicity are included as controls. Gender is added to see if any mediating effects differ for men and women. Models suggest that sleep serves as a partial mediator of the effect of marital status on health and that these indirect effects are moderated by gender.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Experiences of Health and Illness

Derwent Room 056

*Mechlenborg Kristiansen, T., Antoft, R.,  
Primdahl, J., Hørslev-Petersen, K.*

*University of Southern Denmark*

**The Patient Education Community**

In Denmark, group-based patient education programmes targeting people with chronic illness have developed since the 1990's as a central tool within the field of health promotion. Aims and methods differ, but the different programmes have a common focus on strengthening the individual's self-management capabilities, emphasising active patient participation and in taking responsibility and seeking to integrate the chronic condition into self and everyday life. Within medical sociology and anthropology, studies of participation in such programmes have primarily focused on individuals' experiences of participation.

This paper explores another perspective, namely, that of the creation of a patient education community and its potential meaning for everyday life. By means of ethnographic fieldwork, the fieldworker followed a patient education programme targeting people with rheumatoid arthritis and followed key informants back to their everyday life settings.

Drawing on a social phenomenological perspective of the sociology of everyday life (Birte Bech-Jørgensen, 1994, 2002) and the sociology by of Zygmunt Bauman (Bauman, 2001), the paper analyses;

## PAPER ABSTRACTS

1). The different motivations and concepts of community the participants bring into the patient education programme, 2) How the community unfolds and develops during the educational sessions and 3) How the participant community develops after completing the programme. It will be discussed which models of community are likely to develop based on a common chronic condition and how these new communities might affect the way in which chronic illness is experienced and managed in everyday life by the participants.

**Thursday 12 September 2013**

**11:25 - 11:55**

Health Care Organisations

Derwent Room 003

*Melby, L.*

*Norwegian University of Science & Technology*

### **Sharing or Communicating Patient Information: Tensions Between Policymakers' Wish and Healthcare Workers' Needs?**

Health information technologies (HIT) are increasingly introduced in Norwegian healthcare. The last years it has been strongly argued for the need for developing HIT for sharing information between health care providers across the sector, e.g. developing a summary care record (SCR). Currently no such system exists in Norway, meaning that each different healthcare organization only has access to its own patient documentation. A SCR, it is argued, would make healthcare workers better informed, and thus able to provide more seamless care. However, research has shown that information sharing without mutual communication about the patient's problems, and information without context is not so useful as it might seem. In this paper I discuss the issue of information sharing vs. communication of patient information.

Empirically, the paper is based on a study of the introduction of electronic messaging (e-messaging) as a means for exchanging patient information in Norwegian healthcare. The data material comprises interviews of general practitioners, hospital staff, and homecare workers, and of observations of homecare nurses' work.

Exploring how e-messages are used among healthcare workers provided insight into both (1) how e-messages can function as relevant, common information for both parties in the information exchange, and how (2) the exchange of e-messages trigger the need for clarifications and further discussions around what the information actually means. The paper elaborates on when information sharing is sufficient and when the exchanged information triggers a need for further communication. It further aims to enhance our understanding of communication and collaboration in healthcare.

**Thursday 12 September 2013**

**14:00 - 14:30**

Experiences of Health and Illness

Derwent Room 056

*Monaghan, L., Gabe, J.*

*University of Limerick*

### **Chronic Illness as Biographical Contingency: Understandings from a Qualitative Study of Children with Asthma**

The seminal work of Mike Bury in the early 1980s on chronic illness as biographical disruption, defined as a critical situation following the diagnosis of an incurable disease, spurred a generation of medical sociologists to research, refine, critique and extend knowledge of the illness experience. While valuable empirical insights into a range of conditions (e.g. HIV/AIDS, stroke) are identifiable and a useful toolbox of concepts has emerged (e.g. chronic illness as biographical reinforcement and biographical anticipation), the literature is largely adult-centric. Accordingly relatively little is known about the social meanings and experiences of children with chronic illnesses. This deficit in sociological knowledge includes a paucity of research on children's understandings of asthma, especially those living with mild to moderate asthma. Drawing from 31 interviews conducted with children in Southwest Ireland in 2010, this paper offers qualitative insights into the culturally specific and socially embedded meanings of this condition. The sample includes both boys (N=15) and girls (N=16) aged between 5 and 17 (mean age 12.7 years) from the indigenous Irish Traveller community and the larger settled community. Conceptually, the study prompts us to explore the potential value of what we call biographical contingency. This concept refers to the 'now you see it, now you don't' nature of a chronic illness that varies in terms of symptomatology, meaning and consequence. Connecting with the sociology of childhood, interviewees are viewed as 'health actors' who actively engage with their condition and wider social world through talk about the management and accommodation of symptoms, normalisation, stigma and re-framing.

**Wednesday 11 September 2013****15:05 - 15:35**

Embodiment and Emotion

Derwent Room 049

*Montgomery, A.**Queen Mary University of London / University of Leicester***Disclosing Prostate Cancer: Juxtaposing the 'Good', the 'Bad', and the 'Unsaid'**

This study contributes to understanding disclosure issues around prostate cancer (PC) taking into account how men with prostate cancer (MWPC) orientate to interactional ease or difficulty in such disclosures. It also addresses the 'phoney war' between 'public' and 'private' approaches to the study of illness. NexisUK was used to retrieve all articles in UK national print media predominantly containing illness narratives of MWPC over two 10 year periods (n=39/1990-2000; n=101/2000-2010). Comparative keyword in context (CKWIC) analysis identified a collective voicing of PC as a "taboo" disease that "no one dares talk about" more explicitly and frequently articulated in 1990-2000 than 2000-2010. This suggested both the potential for interactional difficulties in how MWPC disclose illness and also how this may have lessened over time. Analysis of illness narratives of 20 MWPC interviewed in 2000 and 2010 evidences that disclosure to 'friends and others' and 'colleagues' is at least as interactionally difficult for men in 2010 as in 2000. Additionally, men in 2010 have more nuanced interactional difficulties in disclosing to these audiences than in 2000. Men's disclosures to 'partners' and 'children and wider family' are similar in each period and evidenced as less interactionally problematic. However, men in both periods show an awareness of how best such a disclosure is interactionally accomplished and anticipate their audience's response. Examining the disclosure talk of MWPC is beneficial to these men, and those who care/advocate for them, to understand the interactional expectations of them as they engage in conversations with others about their illness.

**Thursday 12 September 2013****16:20 - 16:50**

Experiences of Health and Illness

Derwent Room 056

*Moore, L., Britten, N., Paterson, C.**University of Exeter - Medical School***The Occupational Model of Self-Management: Characterizing the Life and Illness 'Work' of Older Patients with Heart Disease**

Self-management policy encourages patients with long-term conditions to improve their health. However, the 'work' of self-management for patients appears to need certain skills and attributes. The aim of this research was to characterize the self-management 'work' of older patients with heart disease in primary care and identify the skills and attributes required for participation. This qualitative study employed longitudinal diary-interviews with 21 patients, and interviews with 8 professionals, in three contrasting socio-economic general practice areas in South West England. A literature review and mind mapping analysis of policy literature produced a model identifying 4 concepts described as active, competent, efficacious and responsible that exemplified successful self-management.

The analysis for this study drew on concepts of governmentality and the reflexive self. An alternative 'occupational' model of self-management was developed including 5 dominant occupational roles and 3 levels of occupational status. This occupational model identified the breadth of self-management practices by older patients with heart disease. Some patients had the interest and understanding to align themselves with self-management policy and improve their outcome. Other patients, particularly in deprived areas, lacked the skills, attributes and personal circumstances for optimum self-management. They were either constrained physically and socially, fatalistic or anxious with a negated sense of self, disengaged from professionals or distracted by competing priorities in the form of co-morbidities or caring roles. This occupational model provides a contextually sensitive method for describing the older person's experience of living with heart disease and highlights the tensions for policy makers and health care professionals.

**Thursday 12 September 2013****15:10 - 15:40**

Inequalities

Derwent Room 036

*Morcillo, V., Exworthy, M.**University of London, Royal Holloway***Health Inequalities in General Practice**

Primary care has often been seen as an appropriate and effective setting in which to tackle health inequalities. However, relatively little is known about how such strategies should be devised or implemented. In particular, there is a gap in knowledge in what General Practitioners (GPs) understand about their own role in health inequalities and how they act to remedy health inequalities that they

## PAPER ABSTRACTS

encounter in their own practise. We conducted a qualitative study using in-depth interviews with a maximum variety sample of 20 GPs. Each interview lasted between 45 and 90 minutes; it was audio-recorded (with permission) and transcribed in full. The transcripts were read independently by both researchers who identified emergent themes. The commonalities and differences within and between GPs' practices and types of strategies were thereby identified. The preliminary results show that GPs' understanding of health inequalities reflects a wide range of perspectives and they employ a variety of different strategies in tackling them. These considerations are influenced significantly by the GP's gender, seniority and ethnicity as well as the characteristics of the practice and of the local population. This study allows a better understanding of what GPs think about their role in addressing inequalities. It also offers insights into ways of improving the development and implementation of interventions in primary care to tackle health inequalities.

**Thursday 12 September 2013**

**15:10 - 15:40**

Lifecourse - Reproductive Health

Derwent Room 037

*Nash, M.*

*University of Tasmania*

### **Picturing Mothers: Exploring Body Image in Pregnancy Through Digital Photographs**

Drawing on qualitative data from a sample of pregnant women in rural Australia, this paper presents an opportunity to contribute to and extend health scholarship by describing an emergent social research method, photovoice, and how participant-produced digital photographs can be used to think critically about embodiment in pregnancy. A key contention is that participant-produced photographs can reveal important information about how pregnant women negotiate a changed embodiment over time. The examples discussed will demonstrate that digital cameras were tools that allowed women to portray themselves and their experiences of pregnancy in ways that would otherwise be impossible. Their visual accounts of their bodies reflected the more varied 'realities' of pregnant embodiment compared to the limited range of popular images of pregnancy.

This study is valuable given the dearth of photovoice research in the areas of women's reproductive health and body image. In addition to theory building, this research can potentially further knowledge about core concepts of interest to maternal health professionals. Photovoice can illuminate strategies that practitioners can employ to help women maintain health and well-being in relation to pregnant body image. For example, photographs can be a means of accessing information from pregnant women that can be useful in understanding which women are more at risk for developing antenatal and/or postnatal depression. The use of photovoice also has the potential to equip policymakers with narrative-driven policy and program recommendations.

**Wednesday 11 September 2013**

**14:30 - 15:00**

Pharmaceuticals

Derwent Room 002

*Nixon, M.*

*Copenhagen University*

### **Challenges of Discontinuing Medication Among Elderly People: The Example of Discontinuing Statins in Primary Care**

Among elderly patients the usage of statins has increased exponentially over the last 10 years. There are several problems with this increased usage, including overprescription of statins, a weak evidence base for effectiveness of statins for those over 65 years of age, especially among women, in addition to the risks of increased polypharmacy and reduced adherence to existing medication. One potential strategy for addressing these problems is the discontinuation of the statins, especially in primary care where most medication is prescribed. However, little is known about the decision-making process of general practitioners (GPs) in decisions to discontinue or continue.

Therefore this study used a qualitative methodology to examine the decision-making process of GPs to identify how appropriate discontinuation could be encouraged. Data used in the study included interviews, document analysis and participant observation.

The results highlight that medication discontinuation is a social process, with many different actors influencing the general practitioner (e.g. patient, nurses, secretaries). They also show that it is a highly reflexive process, with GPs in a state of constant ambiguity. GPs need to distinguish between all kinds of potentially relevant information to make decisions on discontinuation without unambiguous knowledge that it is a safe outcome.

**Wednesday 11 September 2013****12:45 - 13:15**

Ethics

Derwent Room 006

*Norvoll, R., Hem, M.H., Pedersen, R.**University of Oslo***Ethical Challenges in Mental Health Care: Relatives' Views on Use of Coercion and Involvement**

Some of the most important ethical challenges in mental health care are tied to the use of coercion. The project 'Mental health care, ethics and coercion' aims at gathering more knowledge about these challenges and to strengthen ethical reflection in mental health care. This presentation will discuss some early results from a qualitative study exploring relatives' views on use of coercion and involvement.

Qualitative interviews were conducted with 20 relatives of adult patients from next of kin's -organizations and 16 relatives of young patients from hospitals in Norway.

Early analysis shows that relatives have complex and conflicting moral views on coercion. Coercion and ethical dilemmas are seen in a broad perspective, relating to age, everyday life, treatment quality and interactions with mental health services. Many relatives experience too little involvement, often as a result of staffs' views on patient confidentiality. However there is also reluctance towards getting involved. Ethical challenges also occur in relation to power dynamics; both powerlessness due to lack of knowledge or involvement and power due to the possibility of initiating coercion from the mental health system.

The stories confirm the multiple and ambiguous roles of relatives as seen through history. Ethical dilemmas and their solution are socially constituted and arise from interactional processes between patient, families and health services. This underlines the need for a social perspective in ethics research and in mental health services.

**Thursday 12 September 2013****09:05 - 09:35**

Health Policy

Derwent Room 104

*Nunn, S., Archer, J., Regan de Bere, S.**Plymouth University***'When the Old Fellows Drop Off their Perches': Exploring Perceptions of Generational Identity and Regulatory Change in Medical Practice**

Revalidation, the process by which doctors in the UK demonstrate that they are 'up to date and fit to practise' medicine, began on 3 December 2012. Initially a highly controversial policy, it took 12 years of negotiation before full implementation.

This paper draws on two empirical studies: Revalidation in policy, which examined revalidation from the perspective of key stakeholders involved in policy development, and Revalidation: in practice, which explores the early impact of revalidation on individual clinical practice.

Specifically we discuss one emergent theme of the research, common to both studies, that we are provisionally calling reactionary generationalism. By this we mean the apparent 'given' in medical discourse that older doctors are resistant to formal professional regulation, and to revalidation in particular. Key to this perception is the view that older doctors regard regulation as a bureaucratic procedure rather than an integral part of the development a new professional landscape.

Our participants' assumptions about older doctors draw on populist notions equating age with resistance to change rather than any empirically validated group identity. There is no sense of the complexity of 'generation' incorporating both the private sphere of the individual and the public sphere of complex structural relations: a simplification that we feel has implications for both policy and practice.

This paper argues for the need for a more nuanced understanding of generational identity in order to prevent it from becoming a proxy for reactionism, and to support the needs of individuals in the context of an emergent new professionalism.

**Thursday 12 September 2013****08:30 - 09:00**

Health Policy

Derwent Room 104

*Obstfelder, A., Lotherington, A.T., Halford, S., Nilsen, A.B.**University of Tromsø***Nurses as System Tailors: Making Healthcare Information Systems Function 'Like Magic'**

Digital information systems are thoroughly embedded in Western healthcare. Accordingly, where once public policy concentrated on getting new systems into use, attention is now shifting towards maximizing returns from the systems already in use. The paper explores what this shift may mean in practice. Drawing on information infrastructure theories from Science and Technology Studies we begin with the proposition that the returns from systems-in-use are on-going achievement, rather than a one-time result from initial implementation. In this context, our aim is to explore how healthcare information systems are maintained in-use and the consequences of this for delivery and organization of healthcare work.

We build our analysis on a longitudinal study (2004-13) tracing the implementation and subsequent usage of an Electronic Patient Record in a large Norwegian hospital. Our study reveals a new group of specialists in hospitals, performing a largely unanticipated and increasingly important form of work embedding the EPR with other technologies, routines, documents and people that comprise everyday life in the hospital. In doing so, existing practices are simultaneously connected, influenced, and changed.

The conclusion is that maximization of returns from mature ICT systems rests on iterative and long-term processes involving on-going socio-technical work. The system tailors sits between computer scientists and clinicians designing the procedures that turn generic information systems into information infrastructures. As information infrastructures shape the work practices of clinicians, administrators and managers the system tailors have become key change agents in modern hospitals. Yet, remarkably little attention has been paid to their work practices.

**Wednesday 11 September 2013****13:20 - 13:50**

Health Service Delivery

Derwent Room 104

*O'Donnell, C., Cooper, M., Conway, E., Mackenzie, M.**University of Glasgow***Using Candidacy to Understand Migrants' Use of Primary Healthcare**

The 2011 UK census reports that 13% of the population of England and Wales were born outside the UK. Reasons for migration are diverse and migrants are a heterogeneous group including workers from within and outside the EU; family dependents; students; asylum seekers; and undocumented migrants. Many will, at some point, need to access healthcare in the UK.

Studies have explored barriers and facilitators to healthcare access and use for migrants, but often from a descriptive, non-theoretical perspective. Accessing and using healthcare is, however, structurally, culturally, organisationally and professionally constructed with previous experience, current need, and recognition of need, informing such decisions. This dynamic view of access and utilization – candidacy – was originally articulated by Dixon-Woods and developed in relation to public services by Mackenzie et al.

The UK primary healthcare system is very different to systems previously experienced by many migrants. In many countries, healthcare is located in specialist centres and hospitals and out-of-pocket payments are common. Faced with a generalist system of primary care this may impact on how migrants first view themselves as candidates for care, then present and negotiate access to healthcare with primary care professionals. In this paper, we will explore what we can learn from a critical interpretive synthesis of literature published since Dixon-Woods original review in relation to healthcare access and utilization. Then, using empirical qualitative data generated from interviews and focus groups with asylum seekers, African migrants and health care professionals test out the notions and assumptions inherent in the candidacy model.

**Thursday 12 September 2013****12:00 - 12:30**

Inequalities

Derwent Room 002

*O'Donnell, S.**University College Dublin***The Social Determinants of Health and Type 2 Diabetes: What are the Challenges Towards a Wider Acceptance Among Key Stakeholders?**

In recent years, there has been an increasing body of evidence to suggest that significant reductions in diabetes related morbidity and mortality cannot be achieved without addressing income inequality and the social determinants of health (SDOH). Despite this, interventions have generally remained confined to targeting individual behaviour change through lifestyle education, while structural issues remain unaddressed. This study examines the factors which explain the continuing promotion of individualised solutions to prevention and treatment by key stakeholders (medical professionals, policy makers, charity organisations), at the expense of an SDOH approach. Semi-structured interviews were conducted with an internationally based sample of leading figures in diabetes medicine and the policy making arena (n=12). The findings showed that participants were aware that education was a necessary but insufficient condition of improving diabetes outcomes and there was general consensus that social conditions constrained individual agency. They outlined a number of barriers which preclude wider acceptance of SDOH among key stakeholders, including the continual equating of diabetes with poor personal choices and the persistence of prejudicial attitudes towards lower socioeconomic groups. However, while all participants sought to challenge such stigma, some also engaged in discourses which framed marginalized populations as irresponsible and viewed policies aimed at wealth redistribution as ultimately counterproductive. The study demonstrates the tensions and contradictions which accompany the emergence of SDOH as a legitimate explanation for the causes of diabetes within a field that has been largely dominated by the logic of neo-liberalism and atomistic conceptions of disease aetiology

**Thursday 12 September 2013****15:45 - 16:15**

Experiences of Health and Illness

Derwent Room 056

*Oktem, P.**University of East Anglia***The Social Construction and Management of HIV-Positive Identities in Turkey**

The paper is based on my recently completed PhD thesis exploring how HIV-related discourses are shaped and how people living with HIV (PLHIV) experience and manage the physical, emotional and social aspects of living with HIV in Turkey. This is the first sociological research to analyse the social construction of HIV/AIDS and the management of HIV-positive identity in Turkey, a country with low-prevalence, heterosexually-driven epidemic. The paper offers an empirically informed discussion of the management of the biological body and social identity in relation to the broader discursive power relations.

Primary data were generated through biographical narrative interviews with PLHIV. Semi-structured interviews with key informants, participant observation in PLHIV networks and documentary analysis provided additional data.

The paper overviews the findings in three sub-sections:

- 1) I identify the two conflicting discourses around HIV/AIDS in Turkey ('cultural immunity' and 'rights-based' discourses, at the state and civil society levels, respectively) linking these with the social perceptions about sexuality, 'modernisation' and religious discourses.
- 2) I focus on the family and healthcare as the main institutions where HIV-positive identities are formed. Here I highlight that although family support was high, the social expectations shaped around 'familial roles' acted as the primary drivers of internalised stigma. Discussing the management of physical health, I focus on the health-system-level constraints affecting the restorative effects of antiretroviral therapy, a problem frequently overlooked in contexts like Turkey where treatment access is secured.
- 3) I highlight the implications of the discursive formation of HIV/AIDS for PLHIV's agency at the subjective and collective levels. The participants' reconstructions of HIV through narratives of 'injustice' and 'neglect' are discussed within the conceptual framework of biological citizenship.

**Friday 13 September 2013****10:10 - 10:40**

Open

Derwent Room 049

*O'Neil, S., Baker, R., Shucksmith, J., Kaner, E.**Newcastle University***Autonomy, Special Offers and Routines: A Q Methodological Study of Industry-driven Influences on Young People's Drinking Practices**

Alcohol marketing is associated with initiation and progression of alcohol use amongst young people. However, less is known about how the entire marketing 'mix' influences drinking decisions and behaviour. This paper aimed to identify patterns of shared, subjective accounts from young people relating to the influence of price, promotion, product and place on drinking practices. Q methodology was used to generate 'factors', statistically significant clusters of opinion, based on the results of a card sorting procedure undertaken with 28 young people aged 14-17 in North East England. Using data from prior in-depth interviews, participants rank ordered 39 statements from 'most' to 'least' like their drinking choices, a process followed by short interviews to aid interpretation of factors. Q factor analysis generated three distinctive accounts: Factor One ('Autonomous, Sophisticated Consumers') articulated self-defined individuality in drinking practices; Factor Two ('Economically Driven Consumers') was price-led, choosing to drink what was most accessible or cheapest; and Factor Three ('Context Focused Consumers') described situated drinking practices, with products chosen to serve a particular purpose. Rather than passive consumers, young people articulated distinct choices underlying drinking practices and appeared to be active participants whose drinking behaviour could be specifically shaped by marketing activity. In all three groups, differing aspects of the marketing mix were relevant yet only partially recognised, illustrating the heterogeneity of young people's responses to alcohol marketing. Findings suggest interventions designed to raise young people's awareness of the socio-political landscape of alcohol consumption and industry, rather than a traditional health focus, should be considered.

**Thursday 12 September 2013****09:05 - 09:35**

Pharmaceuticals

Derwent Room 002

*Ozieranski, P., King, L.**University of Bath***Institutional Nomads, Elite Cliques and Pharmaceutical Policy-making: The Case of Deniability in Drug Reimbursement in Poland**

During postcommunist transition, patients in Poland have suffered from impeded access to drugs reimbursed by the state. On the other hand, the development of reimbursement policy has been associated with irregularities involving state officials, drug companies' representatives and medical experts. Nevertheless, very rarely have the key stakeholders in the policy process been made accountable based on democratic procedures, business codes of conduct or rules of scientific good practice. We attempt to solve this puzzle by applying the concept of 'deniability', proposed by anthropologist Janine Wedel, to describe the new global system of power and influence emerging after the fall of communism. To this end, we draw on 109 interviews with stakeholders in the reimbursement process, official documents and media coverage of key developments in Polish reimbursement policy in recent years. We found that deniability was created through four mechanisms, largely consistent with Wedel's theoretical position: (1) blurred boundaries and 'blame games' between different centres of state authority; (2) bridging different sectors by 'institutional nomads', who escape existing systems for monitoring conflicts of interests; (3) institutional nomads' 'flexible' methods of influence premised on managing roles and representations; (4) and coordination of resources and influence by elite cliques. On this basis, we conclude that the greatest power over drug reimbursement was often associated with lowest accountability. We also show potential for using Wedel's theory to explore pharmaceutical policy-making in Western democracies and indicate scope for its integration with existing theories in the political sociology of pharmaceuticals.

**Wednesday 11 September 2013****15:05 - 16:45**

Symposium

Derwent Room 006

*Paparini, S.**University of Bristol & the Terrence Higgins Trust***Culture/s in HIV Research in the UK**

This presentation will focus on the use of the concept of 'culture' in mainstream social research about HIV in the UK. It will introduce the ways in which culture has been operationalised to differentiate the



behaviours, beliefs and attitudes of ethnic minority people living with HIV from those of the rest of the HIV population. The presentation will then deconstruct some of the ideas about 'cultural competence' in the NHS and explore the ramifications of traditional views about culture (as bound to ethnicity) as they affect the ways in which the epidemic is currently understood in Britain. Drawing from a recently completed qualitative study of discrimination against people living with HIV, the presentation will juxtapose the current uses of culture with the interconnected personal, political and activism-related cultures that frame the experiences of participants in the study. These can be briefly referred to as liberalism, the culture of those 'back home', the culture of the 'gay community', and HIV support group culture. These four frameworks will be proposed as alternative ways to retain the concept of culture to address the broader dynamics that shape the daily lives of people living with HIV, whilst refraining from the potentially reductionist use of culture as a proxy for ethnicity.

**Friday 13 September 2013**

**11:55 - 12:25**

Citizenship and Health

Derwent Room 036

*Papoutsis, C., Lewis, R., Reed, J., Bell, D., Marston, C.*

*Imperial College London*

**Negotiating the Potential for Electronic Health Records in the NHS: Patient and Public Views and Understandings**

The 'Power of Information' strategy for the technological future of the NHS prioritises systems interoperability and wider information sharing through Electronic Health Records (EHRs). However, the potential of EHRs for improving healthcare is often debated in the literature, while patient preferences are usually presented either as dichotomous (yes/no) options that remain constant and static, or as a result of personal risk-benefit equations.

We explored how people with different health conditions draw on their biographies to articulate views on EHRs, using 18 focus groups and interviews with patients and carers, and 4 focus groups also involving health professionals and researchers – 116 participants in total. This qualitative work was preceded by a large-scale cross-sectional survey of 5331 patients and members of the public recruited from outpatient and general practice clinics in West London.

This paper analyses how people situate their own experiences to formulate and negotiate understandings of EHRs. Our participants drew on their individual and collective biographies to contextualise health technologies and attribute potential to EHRs, both in terms of possible benefits and risks. In articulating and negotiating this potential, participant narratives often brought to the fore the imagined, including utopian and dystopian expectations. As participants positioned themselves in relation to technological practices, they also engaged with shifting notions of patienthood. We show that patient preferences about health information sharing are not static or simply context-dependent, but emerge together with the situation at hand in an incremental, multifaceted process.

**Wednesday 11 September 2013**

**13:20 - 13:50**

Experiences of Health and Illness

Derwent Room 056

*Parsons, J.*

*Plymouth University*

**'I was a Fat B... I went from Almost 110 kg to 79 kg, but People Were asking how the Treatment was going?' An Exploration of Gendered Responses to Dietary and Weight Management Practices**

Approaches to dietary and weight management issues in my doctoral study were particularly gendered. The women's narratives tended to outline how they had become lipoliterate or learned to read their own and 'other' bodies. Women had also engaged in 'fat talk' (Ambjörnsson, 2005) as a form of heteronormative feminised practice in their adolescence and these experiences formed part of an affective sedimentation of their lipoliteracy (Graham, 2005) as adults. The men on the other hand articulated their weight issues within hegemonic discourses of masculinity; they distanced themselves from the highly feminised affective practices of dieting, by resorting to health discourses that focussed on a masculine value of control. The women in the study were equally concerned with a Westernised neoliberal value of control, but not being in control was also a means of 'doing' gender (West and Zimmerman, 1987) and an expression of an affective value of femininity. Hence, the women presented their life history narratives in terms of a series of highly emotive periods of equilibrium when they were either in or out of control. The men on the other hand, even when reporting weight gain did so without considering this a failure of control.

Ambjörnsson, F., (2005) 'Talk', in Kulick, D. & Meneley, A. (eds), *Fat, The Anthropology of an Obsession*, (pp.109-120) London: Tarcher/Penguin

## PAPER ABSTRACTS

Graham, M., (2005) 'Chaos', in Kulick, D. & Meneley, A. (eds), *Fat, The Anthropology of an Obsession*, (pp.169-184). London: Tarcher/ Penguin

West, C., & Zimmerman, J., (1987) 'Doing gender', *Gender & Society*: 1, pp.125 151.

**Wednesday 11 September 2013**

**14:30 - 15:00**

Ethics

Derwent Room 006

*Paton, A.*

*Newcastle University*

### **Oncofertility in the UK: A Socio-ethical Approach to Studying the Experiences of Adult Female Cancer Patients**

This paper examines the social and bioethical aspects of the emerging field of oncofertility in the United Kingdom. It highlights the need for empirical research into the experiences of female oncofertility patients, in order to address social, clinical and ethical concerns surrounding how the future fertility of cancer patients is managed and how patients make decisions about their future fertility. The medical impact of cancer treatment on female fertility has been well documented; however very little research has investigated the social, psychological, ethical and emotional consequences of this impact. While oncofertility and fertility preservation techniques for female patients are available in the United Kingdom, little is known about how female patients feel about being made infertile as a direct consequence of their cancer treatment. In particular few studies have examined this difficult time and how it influences patient decision-making and autonomy. This paper argues that these experiences should be accessed empirically, with interviews providing the necessary in-depth detail required in order for bioethical recommendations to be made and clinical practice improved for the benefit of future female cancer patients. In this paper I will also present preliminary analysis from interviews done with female cancer patients across England.

**Friday 13 September 2013**

**10:10 - 10:40**

Citizenship and Health

Derwent Room 036

*Penn, R.*

*University of Toronto*

### **Drug Use, Work and Citizenship: Claiming Legitimacy Through Peer Work**

Background: My research on a peer harm reduction project at a Toronto community health centre revealed that many peers, upon being recognized as experts by both colleagues and clients, gained pride and a strengthened commitment to their own recovery. Yet peers also describe an unaccustomed pressure to be a positive role model, while experiencing a deep fear of letting themselves, and others, down by relapsing. This illuminates the depth of the struggle that peer workers face in identifying themselves within the dichotomies of expert/client, and healthy/pathological.

Methods: This case study involves multiple in-depth interviews with two people who use drugs who are employed as peer harm reduction workers. Digitally recorded interviews were transcribed verbatim and analyzed employing a narrative technique and a Foucauldian perspective. My analysis draws upon Frank's (2010) narrative typologies (quest, chaos, and restitution narratives) and considers the 'work' that the stories do.

Results: The peers' narratives reflect their claims to be legitimate service providers and responsible citizens. Many of their stories also appear confessional in nature. Partly asking for absolution, partly asking for understanding and acceptance, these confessional tales provide a counterpoint to stories of their strengths and successes. The sum of the work suggested by these stories allows insight into the precariousness and complexity of their experiences. From a Foucauldian perspective, the work of these stories (both confessing and claiming) is central to the production of subjectivity, specifically that of a "good" (if addicted) citizen.

**Thursday 12 September 2013****15:45 - 16:15**

STS and Medicine

Derwent Room 003

*Pickersgill, M. D.**University of Edinburgh***Depharmaceuticalising Mental Health? Psychological Therapy Today and the Logics of Care**

Recent work in sociology and STS has been concerned with 'pharmaceuticalisation' – the increasing place, role and impact of prescription drugs in and on society. Compelling case studies have been produced - particularly in regards to mental health in the US - which demonstrate the importance of industry, healthcare systems, and consumerism in developing and expanding drug markets. In this paper, I draw on research funded by the Wellcome Trust around the sociology of psychology in order to suggest that in the UK, we can see a partial depharmaceuticalisation of mental health. Drawing on documentary analysis and interviews with clinicians and key policy actors, I elucidate the mutually constituting economic, ethical and clinical imperatives that are seeking to scale down the use of pharmaceuticals in mental health. In so doing, I underscore the ways in which discourses and debates associated with processes of pharmaceuticalisation also adhere to and develop depharmaceuticalisation. In this regard I discuss particularly calls to improve access to therapy, and taxonomies such as the Diagnostic and Statistical Manual of Mental Disorders (DSM). These figure (mental) illness as discrete and bounded, demanding in turn targeted approaches to treatment; such a logic of care, however, can be agnostic in regards to the modality of therapy employed. In sum, this paper shows first, that processes of depharmaceuticalisation are in place and actively driving policy and practice in the UK, and second, that, perhaps counter-intuitively, these are being supported by similar material and symbolic elements that have propelled pharmaceuticalisation in other contexts.

**Wednesday 11 September 2013****13:20 - 13:50**

Ethics

Derwent Room 006

*Pieczenko, S.**University Centre Grimsby***Autonomy, Capacity and Suicide: An Investigation Regarding the Current Assessment of Suicide Wishes from the Mentally as Opposed to the Physically Ill**

This paper investigates the current practice to order the values of the good of life as such versus an individual's autonomy when a patient desires a termination of her life. The apparent difference in the value ordering for the mentally ill as opposed to the physically ill is critically assessed, as the physically ill seem to be able to trump the value of the good of life with their autonomy, while this option is not available to the mentally ill.

Although a rule for this ordering of values, based upon the belonging to a diagnostic group of mentally or physically ill must not be logical inconsistent, the mentally ill appear to be disadvantaged nevertheless. The paper argues that these disadvantages are brought about by an inconsistent application of the rule, by systematic differences in assessment practices and by an assumed a priori lack of capacity on behalf of the mentally ill.

These identified difficulties seem to warrant further research and the instigation of a social discourse regarding the overall problem.

**Thursday 12 September 2013****14:00 - 14:30**

Patient - Professional Interaction

Derwent Room 047

*Pilnick, A., Zayts, O.**University of Nottingham***Advice and Autonomy in Shared Decision Making in Antenatal Screening: the Importance of Context**

Shared decision making (SDM) has been widely advocated across many branches of healthcare. The rationales used to support SDM are equally wide- ranging, extending from the ethical (based on the notion of bodily integrity), through the philosophical (the principle of individual autonomy) to the practical (an assumption that compliance is more likely with a shared treatment decision). However, is also considerable debate over the practical application of SDM, whether all settings are amenable to it, and whether decisions can be studied in isolation from the rest of the clinical encounter.

## PAPER ABSTRACTS

This paper arises from a study of antenatal screening provision in Hong Kong. We focus here on a subsample of 19 women who have received initial screening results indicating higher risk of fetal abnormality. These women are subsequently invited by clinicians to discuss their results and consider invasive diagnostic testing. Using conversation analysis, we examine these consultations to show how decisions are made in this context. We note a curious paradox; where women respond minimally to the delivery of test results and the outlining of options, clinicians are more likely to steer women towards a particular choice. However, where women seek to engage more actively in the discussion, and/or explicitly seek advice, they are frequently exhorted to make their own decision. We argue that this particular operationalization of SDM in practice is tied to a context in which non-directiveness has long been upheld as a principle, and that this highlights the importance of considering context in research into SDM.

**Friday 13 September 2013**

**10:45 - 11:15**

Lifecourse – Death and Dying

Derwent Room 003

*Pollock, K., Caswell, G., Harwood, R., Porock, D.*

*University of Nottingham*

### **Dying in Hospital: The Significance of Place**

Home is currently considered to be the preferred and most appropriate place of death for frail older people who constitute an increasing proportion of an increasingly aging population. Supporting individuals to die at home, and decreasing the number and costs of hospital deaths, is a policy and health care priority. Nevertheless, hospital is the most common place of death, and is likely to remain so in the foreseeable future. The preoccupation with enabling dying at home has distracted attention from the quality of end of life care provided in hospital and how this can be improved. The significance of where death is located within the hospital has also been overlooked. This paper presents findings from a qualitative study of care of dying older patients on acute hospital wards in the UK. It considers the impact on the delivery of care of where in the hospital death takes place, and how place contributes to the experience of death as 'good', or not, from the perspectives of relatives and staff. There are trade-offs to be made between the privacy and solitude of a side room and the more sociable but public location of a bay. The place of death in hospital has implications for how staff and families manage care of dying patients and makes a substantial impact on the sentimental order of the ward.

**Thursday 12 September 2013**

**16:55 - 18:00**

Symposium

Derwent Room 028

*Pollock, A., Carter, S., Scambler, G., Speed., E.*

*Queen Mary University of London*

### **MedSoc Committee Event**

Prof Allyson Pollock undertakes research and teaching intended to assist realisation of the principles of social justice and public health, with a particular emphasis on health systems research, trade, and pharmaceuticals. A strong emphasis is on developing critical analysis through education and research and through translating research findings into policy at the national and international level. The work is interdisciplinary, including epidemiology, law, statistics, economics, accounting, sociology, and anthropology.

Universal access to health care is the primary focus and in particular the means by which local and national systems redistribute resources across society by sharing the risks and costs of ill-health. The work includes the study of public private partnerships in health and long term care, pharmaceuticals, and medical research, and how public health interfaces with trade law and intellectual property agreements.

**Friday 13 September 2013**

**11:20 - 11:50**

Citizenship and Health

Derwent Room 036

*Porter, T., Ong, B.N., Sanders, T.*

*Keele University*

### **Social Resources and Health: A Gift Exchange Perspective**

The relationship between concepts of community and illness experience is complex, and attempts to employ the former in mediation of the latter have a long and somewhat chequered history. In recent years, community has again been identified as a component of health and social care policy. Programmes, such as 'asset-based' approaches to health, are premised upon the notion that people

experiencing illness have access to resources by virtue of their social relationships and wider social networks.

Sociology has contributed extensively in this arena, with social capital theory often cited as theoretical rationale for such policies. However, the widespread amalgamation of social capital theories in health literature – from thinkers as diverse as Bourdieu, Coleman, and Putnam – often results in a theoretical assemblage which fails to accommodate the complexities inherent in processes of social resource exchange. This paper, seeks to depart from previous conceptualisations of social capital and social resource exchange, and instead re-orientates the debate as informed by a sociology of the gift.

Gift exchange literature contributes concepts such as 'symbolic value' and 'moral economy' which are presented as heuristic devices. Data will be presented from the author's qualitative research which investigates the role of 'others' – friends, family, work colleagues – in shaping individuals' experiences of living with multiple chronic illnesses. Results will be considered in relation to their implication for policies involving social resources, and in particular, in relation to our understanding of what resources may be given, by whom, and how they are received.

**Friday 13 September 2013**

**09:35 - 10:05**

Critical Public Health

Derwent Room 006

*Powell, K.*

*University of Sheffield*

**Theorising Processes of Social Change in an Area-based Health Initiative: a Developmental and Relational Approach**

This paper examines processes of social change among residents in socio-economically deprived areas targeted by community-based health improvement initiatives. Such initiatives have been central to government efforts to address inequalities in health but, despite heavy investment in their evaluation, understanding about their impact on health, or the social conditions that shape health, is limited. Drawing on ethnographic case study data from a 3-year study, this paper presents a substantive theory of social change, which centres on shifting positions of power among residents within the complex set of networks in which they are embedded. The findings indicated that change could be more adequately understood with reference to the historical context of power relations between residents, and between residents and service providers, in the targeted area. Theorising initiative 'outcomes' in terms of consequences that emerged from interweaving long-term processes avoided the artificial separation of 'intervention' and 'social context' that has beset many ABI evaluations. Given that relations between groups of providers and residents are always in a constant state of flux, it was difficult to discern the 'order' of events that led to change, indicating that linear models of cause and effect in public health interventions need to be reconceptualised. The study was able to explain links between processes and consequences and suggests that seeking to identify propitious circumstances, or the preconditions that facilitate or constrain certain consequences, provides a more adequate explanation of social change.

**Thursday 12 September 2013**

**14:00 - 15:40**

MedSoc Committee Symposium

Derwent Room 028

*Prior, L.*

*Queens University - Belfast*

**The Architecture of the Hospital Ward: Some Reflections on Forms of Spatial Organization**

This presentation is based on a study of 'paper architecture' – buildings, and especially hospital wards, as planned rather than as used. In that vein, architectural drawings can be studied as inscriptions that make manifest ideas about disease, the patient, and the role of the hospital in the healing process; as artifacts assembled by identifiable individuals and groups; as inscription devices that inveigle a variety of human agents into the therapeutic mesh; and as 'actors' that function in systems of social organization. By exploring a variety of examples of hospital wards in Europe and the USA for 'children' and 'babies', I hope to explore the aforementioned dimensions of paper architecture for underpinning our notions of sickness and of childhood as they have emerged in the modern world.

**Thursday 12 September 2013****16:20 - 16:50**

Methods

Derwent Room 049

*Psaila, C., Watts, J.**University of Malta***Methodological Innovation in the Use of Focus Groups in Qualitative Health Related Research**

Focus groups are 'ideal for exploring people's talk, experiences, opinions, beliefs, wishes and concerns' (Kitzinger, 2005: 57) and are increasingly used in a wide range of qualitative research. The dynamics of the focus group method centre on participants providing an audience for each other that encourages a greater variety of communication. Focus groups are not a natural event (Kitzinger, 2004); they are social process involving issues of trust, meaning and interpretation as well as relations of power between group members and between the researcher/facilitator and the group. These concerns informed the design of a series of focus groups undertaken to explore the spiritual dimension of psychotherapy with a group of psychotherapists. The requirement for an evolutionary process rather than a single focus group resulted in the development of a FOST group method. This group method is a blend of a focus group and a study approach. This paper discusses the context and practice of this method that is a spiral and evolutionary process of personal reflection and group interaction over a period of time. Details of different techniques used to stimulate discussion and debate as opposed to consensus seen as one of the limitations of focus groups, will be outlined. Also discussed are ethical considerations relating to potential vulnerability of participants in sharing ideas about spirituality that is both a theoretically complex and deeply personal topic.

**Wednesday 11 September 2013****12:45 - 13:15**

Embodiment and Emotion

Derwent Room 049

*Purcell, C., McDaid, L.**University of Glasgow***Women Talking About Later Termination of Pregnancy in Scotland: A Qualitative Study**

The majority of terminations of pregnancy (abortions) in Scotland are carried out at early gestations (<12 weeks). However, a small number of women require terminations later in their pregnancy, and this paper presents findings from the first study of women's experiences of later terminations (=16 weeks gestation). Findings are based on in-depth interviews with 30 women (of which 11 had been interviewed by April 2013).

The ways that the women interviewed talked about their experiences of later termination tell us a number of key things. Foremost is that women may experience a double stigmatisation: not only for seeking/having a termination, but also for not knowing they were pregnant sooner. This left the women feeling foolish, angry and embarrassed. Implicit in their accounts is not only the expectation that women should recognise the signs of pregnancy at an early stage (and that there are 'universal' signs of pregnancy), but that they fear being judged for not doing so.

Moreover, while the physical process of later termination may be similar to childbirth, the different outcomes and discursive framings of each suggest that women having terminations may not feel permitted to draw on the narrative resources of childbirth. This leaves them at a loss for words to organise their experience, and the stigma attached to having a termination exacerbates this. The paper concludes with critical reflection on women's accounts of the embodied experience of the visceral, physically/emotionally challenging transition from pregnant to not-pregnant that termination of pregnancy constitutes.

**Thursday 12 September 2013****17:30 - 18:00**

Inequalities

Derwent Room 036

*Quinn, C., Porter, I., Pettit, S., Byng, R.**Peninsula Medical School***Offender Health and Society: The Need for an Understanding of the Role of Power and Agency Within Each, in Order to Understand the Other**

'When sociology and medicine are separated, medicine loses sight of the social causes of disease and the meaning of sickness for the individual'. (Bryan S. Turner, 1987).

Male offenders prioritised health promoting, and limiting health damaging, actions in response to direct, open, questions about what would make their health better. This finding is supported by masculinities

literature which asserts male concepts of health promotion consist of positive physical actions. Participants' wider ranging descriptions of the meaning of good health included the integration of physical and emotional wellness, normality and having energy. [Content analysis, 180 partially-structured interviews].

Talking about health and care needs, within the context of the offenders' wider lives, demonstrated that although the participants identified aspirations that they wished to achieve, and motivations that would encourage them to do things, they generally lacked a positive sense of agency allied to either of these, which were manifested in a lack of a sense of control and inabilities in coping. [22 interviews purposively selected from the above, transcribed verbatim, thematic analysis followed by pictorial within case analysis to examine interactions between themes].

This presentation will use the analyses described above, to explore how this socially marginalised group, who have frequently tried to digress from what Foucault describes as societal processes of 'surveillance and control' and 'normalization', are still subject to the social and economic processes, and inequalities, of that society which have contributed to both their health, particularly their mental health, deficiencies and their ability to address these.

**Thursday 12 September 2013**

**11:25 - 11:55**

Theory

Derwent Room 047

*Reid, B.*

*Newcastle University*

**Forms of Dialogue in Discourses of Evidence-Based Healthcare**

Being interested in the relationality of social elements, sociologists have found dialogue a useful principle for theorising the mechanics of discourse. A discourse of evidence-based healthcare (EBHC) has, in recent years, existed in various forms across different institutional healthcare contexts. In this presentation I address the discourse of EBHC by reference to its terms of dialogue. I use examples from earlier and later periods of the discourse in medicine; from allied professions (especially physiotherapy); and from sociological and health-policy literature. I use ideas from Bakhtin to describe these various dialogical forms in relation to their institutional context. I observe that sociology has played an important role in sustaining and developing the dialogical terms of the discourse; from relatively confrontational pseudo-dialogues in early-clinical literature, into forms which are technically sophisticated and subtly dialogical. Rather than creating critical space sociology has, on the whole, acted as a guarantor for the legitimacy of a discourse which is basically conservative and concerned with the preservation of healthcare institutions. I finally consider some ways in which sociologists could have accessed more suspicious and critical spaces by disrupting the dialogical mechanisms of EBHC discourse. I suggest that, in appreciation of the tradition of critical sociologies of medicine, sociologists can use ideas of dialogue to re-discover their capacity for critical analysis.

**Friday 13 September 2013**

**11:55 - 12:25**

Risk

Derwent Room 037

*Richards, J., Graham, R.*

*Newcastle University*

**Reproductive Loss from a Multiple Pregnancy: Bereaved Parents Perceptions of Risk in Relation to Surviving Babies**

The rates of multiple pregnancies continue to rise as a result of increasing maternal age and the use of assisted reproductive techniques. Multiple pregnancies carry increased risks and yet there is little in-depth research into the views and experiences of parents who have suffered a loss. This presentation draws upon a qualitative study in which semi-structured interviews were conducted with 14 parents who have lost a baby from a multiple pregnancy and the health professionals who cared for them.

Parents who lose a baby from a multiple pregnancy are often in hospital for many weeks after their bereavement whilst surviving multiples are cared for. During this time, the health of survivors can fluctuate dramatically, making the long-term risk assessment of a sick baby's health or chances of survival untenable. Health professionals, however, had developed strategies for managing and explaining daily risk which balanced the need to keep parents fully informed on the one hand and avoiding unnecessary alarm on the other. Parents suggested however, that whilst they received regular and clear information concerning their baby's health status, they felt that the trauma of their loss impacted upon the ways in which they interpreted the risk assessments given to them by health professionals. They articulated a range of responses ranging from denial to over-sensitivity to risk, whilst parents who had received assisted reproductive technology in order to conceive, suggested that this

## PAPER ABSTRACTS

factor further impacted upon their perceptions of risk and subsequent decision-making in respect of the care of survivors.

**Friday 13 September 2013**

**10:10 - 10:40**

Lifecourse - Death and Dying

Derwent Room 003

*Richards, N.*

*University of Sheffield*

### **The Desire for a 'Civilised and Certain' Death: The Beliefs and Motivations of Individuals who Plan to Travel to Switzerland for an Assisted Suicide**

This paper presents findings from interviews with seven people who all made plans to travel to Switzerland for help to end their lives. It is also based on knowledge gained through long-term immersion in the euthanasia debate in the U.K. The paper examines the decision-making processes which led up to these individuals' final determination to foreshorten their lives. How did they arrive at that decision? What role did their relatives and friends play, if any, in their decision? Right-to-die campaigners often cite the desire for control as the common factor among people requesting help to die. While this was a common theme in the interviews, other significant themes also emerged. One woman said she wanted her death to be 'civilised and certain'. But what is meant by 'civilised' in this context? A lethal dose of barbiturates offers certainty of outcome, whereas in many cases, further medical interventions or diagnostics does not. All seven interviewees wanted to bring an end to their suffering. They spoke about the difficulties they had finding people who would listen to them, including medical professionals. The paper also offers some reflections on the meaning which is given to suffering, and how the interpretation of suffering influences the euthanasia debate more generally.

**Thursday 12 September 2013**

**09:05 - 09:35**

Gender

Derwent Room 006

*Robertson, S., Zwolinsky, S., Pringle, A., Daly-Smith, A., McKenna, J., White, A.*

*Leeds Metropolitan University*

### **'It's Fun, Fitness and Football Really': A Process Evaluation of a Football Based Health Intervention for Men**

Concerns about gender inequalities in longevity, particularly premature male mortality, have prompted a range of innovative approaches to health promotion work with men dating back to the 1980s. In developing such work, sport, and football in particular, has emerged as a gendered cultural field that has utility for engaging men in health initiatives. Evaluations of such work, whilst few in number, have shown that health initiatives using football settings, football based interventions, or even football club branding, can have positive impact on various health measures in the short and the longer term. However, little work to date has looked at the underlying mechanisms that generate success in such projects. This paper presents secondary analysis of data collected during the evaluation of the Premier League Health (PLH) programme specifically focusing on these underlying mechanisms and how/where gender (masculinity) appears in these processes. We draw on interview data with sixteen staff who had been involved in the delivery of the PLH initiative and fifty-eight men who took part. Thematic analysis highlighted two overarching (and underpinning) themes: 'Trust', what processes it was key to and how it was developed and sustained; 'Change', including what it was facilitated by and what impact it had. Active listening, flexibility and sustained engagement were all key to projects generating success. For the men themselves, the physicality and sociability of involvement, rather than any direct focus on 'health' was important acting as a spring-board for facilitating reflection and aiding lifestyle changes in line with PLH programme desired outcomes.

**Wednesday 11 September 2013**

**13:55 - 14:25**

Experiences of Health and Illness

Derwent Room 003

*Ryan, S.*

*University of Oxford*

### **'I thought if I Haven't Got Asperger Syndrome, then there Really is Something Wrong with me': Capturing the Diagnostic Journey of an Autism Spectrum Condition**

Autism spectrum conditions (ASC) trouble conventional understandings of the concept of diagnosis. As Singer, drawing on her personal experiences as a person with ASC suggests; 'whereas the traditional image of 'diagnosis' is of something reluctantly sought, dreaded, resisted and imposed from outside,



people with 'marginal' neurological differences clamor at the gates, self-diagnosed and demanding to be let in (Singer 1999, 65). Singer seeks to capture the peculiarity of the medicalization of autism in that, for her, ASC is ontologically linked to personal identity; it is not a condition that people have, but rather an identity that people are. Yet, for many, including Singer, there is significant delay in accessing this identity and diagnosis may not happen until adulthood.

The experiences of those diagnosed with ASC in adulthood have received little attention in existing research and yet these experiences can challenge narrowly drawn, stereotypical understandings of autism. In this paper, I explore notions of self, identity and aspects of the life course, through an analysis of narrative interviews describing the diagnostic journeys undertaken by 19 people diagnosed with ASC as adults in the UK. Some of these narratives capture the development of a reflexive autistic self. A 'self' challenged by those who argue that autistic people are unable to 'share understandings' and lack co-mindedness. I further explore how participants made sense of their diagnosis and conclude with a discussion of the power an 'official' diagnosis holds for participants.

**Wednesday 11 September 2013**

**13:55 - 14:25**

Screening and Diagnosis

Derwent Room 047

*Salter, C., Howe, A.*

UEA

**Managing and Empowering the Ageing Body Through Physical Activity and Self Care: Older Women's Embodied Responses to the Risk of Fracture and Osteoporosis**

Women's bodies are often viewed by medical society as inherently problematic and deficient. Declining oestrogen at menopause has long been viewed as a threat to health leading to enfeeblement and disruption with loss of bone strength a growing biomedical concern (Salter et al, 2011). With reference to findings from a study of older women's experience of being screened for their risk of fracture and osteoporosis, this paper will consider embodiment as an ongoing process of 'becoming', involving what Merleau-Ponty highlights as a complex shifting back and forth between mind and body. Although overtime our participants adjusted to their new diagnosis they illustrated the instability of the mind-body relationship that can threaten identity and turn bodies into external objects highlighting the capacity for the field of biomedical science to disrupt or spoil this embodied identity.

Tulle suggests that the body be understood in terms of physical capital – a site of accumulated strength, experience and activity (Tulle, 2008:151). The older women in this study present their active bodies as sites of capital accumulation. Activity was revealed as a form of agency. Physical occupation represented metaphors for productivity, control and self management helping to resist threats to health and self. Even those women no longer describing themselves as active talked of their past activity levels, perhaps linking to notions of an ideal/idealised state of physical embodiment and suggesting that bodily experience and accumulated capital is not lost entirely from value of the self and body just because frailty or ill health forbids.

References

Tulle, E. 2008. *Ageing, the Body and Social Change*. Palgrave Macmillan.

Salter, C, Howe, A, et al. Risk, significance and biomedicalisation of a new population: Older women's experience of osteoporosis screening. *Social Science & Medicine*. 73 (2011) 808-815. <http://dx.doi.org/10.1016/j.socscimed.2011.06.030>

This paper is linked to recently completed empirical research.

This research has implications for screening programmes and the biomedicalisation of older women.

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**Thursday 12 September 2013****12:00 - 12:30**

Theory

Derwent Room 047

*Scambler, G.**University College London***Getting the Hang of Class: SECs, The BBC and Doing Sociology**

Maybe class is 'dead', a cremated by-product of modernity. Certainly the classical sociological tradition of class theory no longer seems to excite or to pay career dividends. Or is the explanation of this shift itself the issue of class? In this paper I challenge our community by sketching - via Kuhn and Lakatos - a new research programme.

The argument takes off from the recent furore surrounding the 'Great British Class Survey' of 2013, a blend of academic investigation and BBC populism. Does the academic investigation withstand scrutiny, theoretical and substantive? Is the BBC's promotion of the research an example of public or pop sociology? More significantly, what pieces might be salvaged from the detritus of debate the 'class calculator' has stirred up?

I review the debate that has taken off in both academic circles and in social media like blogging and twitter. I argue that a reappraisal of the classical sociological tradition of class theory is timely, and that such a reappraisal must acknowledge: (a) 150 years of change within capitalism, and (b) the need for a sociology of agency and culture as well as of structure. In anticipation of this rethink I offer a frame for a new research programme and pose specific research questions vital for the sociology of health and illness.

**Thursday 12 September 2013****16:55 - 18:00**

Symposium

Derwent Rom 028

*Scambler, G., Carter, S., Speed., E., Pollock., A.**University College London***MedSoc Committee Event**

Prof Graham Scambler has researched and written about social and critical theory and a wide range of issues in the domain of health and healthcare. He retains an interest in the sociology of chronic and disabling conditions, as well as in theories of social stigma. More recently, however, his writings have focused in health inequalities and the various ways in which macro-social structures contribute to their production, reproduction and durability.

When the Health and Social Care Bill was first mooted, Graham became involved in the campaign of resistance, strongly believing that this was a Bill that needed to be strangled at birth. Now that the Act has been passed, and the rearguard action against 'section 75' has also failed, another question arises: what is the appropriate response of the academic community when evidence-based policy yields to policy-based evidence? Graham has suggested that Burawoy's four sociologies be joined by a fifth, action sociology. As this implies, the academic engagement should not simply fold when the going gets tough.

**Wednesday 11 September 2013****13:55 - 14:25**

Health Service Delivery

Derwent Room 104

*Scambler, S., Asimakopoulou, K., Gupta, A.**King's College London***Is there Such a Thing as Patient-centred Dentistry?**

Patient-centredness has been advocated as an approach within healthcare for over 40 years and many models have been developed in an attempt to explain and define the concept. Whilst there is no universally accepted definition, patient-centred care models have been developed within medicine that offer some common ground and discuss a way of practicing that is fairly well-defined. Recent publications by the Department of Health within dentistry focus on the need to practice patient-centred dentistry. There is, however, little evidence available on what the concept of patient-centred care means to dental professionals. This paper presents the results from a qualitative study seeking to fill this gap and exploring the concept of patient centred care within dentistry, what it means and how it is practiced. In total 20 semi-structured interviews were conducted with practicing dentists who also hold clinical teaching positions and teach undergraduate dental students. All interviews were recorded and transcribed verbatim and were analysed using a thematic framework derived from the literature and developed through the analysis process. The results of the study suggest that, whilst all participants felt

that they were practicing patient centred dentistry, there was no shared understanding of what this involved and no formal training on how to be patient centred. Patients with unhelpful attitudes and unreasonable expectations were identified as the biggest barrier to patient centred dentistry. Examples of practice were predominantly paternalistic and patients were expected to acquiesce to the dentist's recommendations, albeit in an informed and positive way.

**Wednesday 11 September 2013**

**16:15 - 16:45**

Health Service Delivery

Derwent Room 104

*Segar, J., McDermott, I., Checkland, K., Coleman, A., Harrison, S. University of Manchester*

**Multiple Leadership Identities: the Case of Women GPs on the New Clinical Commissioning Groups in the English NHS**

The NHS in England has just undergone one of the most comprehensive reorganisations ever seen. The Coalition Government initially promised that there would be no more top-down reorganisation of the NHS however, one of their first actions has been described as reorganisation so large it is 'visible from space' (Timmins, 2012). The key aims underpinning the development of the new system are to establish clinical leadership at all levels. The responsibility for commissioning the majority of care for populations has been removed from (managerially-led) Primary Care Trusts (PCTs) and given to (clinically-led) Clinical Commissioning Groups (CCGs). CCGs, through their governing bodies, represent GP members and have powerful new roles in commissioning services for patients in their local health economies. However, women are underrepresented in clinical leadership roles. Although 60% of medical school entrants and 60% of GP Registrars in England are women, there are few women GPs in leadership positions (Future Forum, 2011). This underrepresentation of women GPs was also evidenced in our Pathfinder study (Checkland et al., 2012). Drawing from qualitative case studies this paper focuses on the women GPs who have taken up only 20% of leadership roles on CCG Governing Bodies. We consider some of the structural factors that may explain this underrepresentation and then use Systemic Functional Linguistics (Halliday & Matthiessen, 2004) to focus on the language of women GP leaders. We show how this approach is useful for understanding gendered leadership identities.

**Thursday 12 September 2013**

**10:50 - 11:20**

Health Care Organisations

Derwent Room 003

*Seymour, T.*

*University of Edinburgh*

**Community-building around Genetic Conditions in Scotland: Exploring the Role of the Third Sector in Partnership Activities**

This paper will discuss the emerging findings of a multi-methods qualitative research project that is exploring processes of partnership between different professional groups within the Scottish healthcare arena. In particular, the study examines the intersection between third sector organisations that support individuals with complex genetic conditions such as Huntington's Disease, and the other professionals with whom these third sector workers engage. The need for additional empirical research on this particular professional interface has been highlighted in the sociology of health and illness literature throughout the last decade. However, to date, there has been little work focusing on these processes within the devolved Scottish context.

In this paper, it will be argued that recent shifts in how health care is organised in the UK make research on the networking of professional relationships within healthcare particularly timely. Changes include the increasing divergence of the English NHS from its counterpart in Scotland, and pending Scottish proposals to integrate adult health and social care services. These have considerable implications for the role of the interested parties in the public, private and third sector, and how they relate to each other. Such shifts connect also with long-standing sociological debates about 'patient choice', 'professionalism' and 'expertise' in health. Discussion of the current findings of the research will highlight the continued relevance of such debates, and the potential identity implications of multi-organisation partnerships for both the professionals and patients involved.

**Friday 13 September 2013****10:10 - 10:40**

Critical Public Health

Derwent Room 006

*Shucksmith, J., Hamilton, S., Jones, S.**Teeside University***Pregnancy: a 'Teachable Moment'?**

Public health routinely characterises pregnancy as an important 'teachable moment' in a woman's life, when she may be uniquely susceptible to health improvement messages about smoking, alcohol consumption or obesity, for example. This susceptibility is linked both to the intensity of women's engagement with health services at this point, but also to an assumption - rarely explored in any depth - that women in this condition are psychologically ready for change for the sake of their own and their baby's health. Pregnant women have thus become the subject of some extraordinarily strong examples of surveillance, control and coercion, which would be considered unethical if pressed on other fractions of the population. Lupton (2013) has recently pointed out that this amounts to a 'fetishisation of the foetus', where the mother's physical embodiment is seen as a threat, and the wellbeing of the unborn child is used to lever behaviour change in ways that may deny the rights and needs of women themselves. Such characterisation of women as dangers to their own infant's health is not universally applauded within the midwifery community.

This paper explores early findings from two studies in the North East of England examining women's reactions to involvement in public health interventions at the time of pregnancy, one offering so-called lifestyle advice to control women's obesity and a second looking at promoting smoking cessation in pregnancy and beyond. It examines the views of health service providers and of women themselves as they negotiate pregnancy or reflect back on their experience.

**Friday 13 September 2013****10:10 - 10:40**

Ethnicity

Derwent Room 002

*Sidhu, M., Jolly, K., Gill, P., Marshall, T., Gale, N.**University of Birmingham***Chronic Disease, Self-management and Systems of Support: An Exploration of Health Beliefs and Practices Within the Sikh Community, Birmingham, UK**

The ability to self-manage chronic health conditions, such as diabetes mellitus and cardiovascular disease, has been attracting considerable attention from researchers and policy makers. Drawing on an interactional sociology perspective, focusing on social networks and support, we document the 'systems of support' (Rogers et al. 2011) that men and women, both migrant and British-born, from the Indian Sikh community use to manage their health in relation to the prevention of vascular disease.

We selected a community-based, qualitative interview approach (n=17) because: (i) accounts of lay knowledge and experience that privilege subjective meaning (Popay, Rogers & Williams, 1998); and (ii) talk-based methods (using community languages) were most suitable where there were low levels of literacy in the older generation.

Our findings suggest members of the Sikh community access self-management resources from four broad systems of support: health services for disease management, alternative sources of care and traditional practices for symptom management, community and identity group membership for lifestyle management, and spiritually-centred families for emotional management and physical care. Much of the support provided in the Sikh community was the product of dyadic relationships or ascribed membership

**Wednesday 11 September 2013****15:40 - 16:10**

Screening and Diagnosis

Derwent Room 047

*Skolbekken, J. A.**Norwegian University of Science & Technology***What Can we Learn About the Social Construction of Health and Illness Through the Medical Discourse About Overtreatment and Overdiagnosis?**

Concerns are currently being voiced on both sides of the Atlantic about the negative consequences for both individuals and society from medical overtreatment and overdiagnosis. This is not necessarily a new concern, as these concepts have been part of the medical literature for several decades, if not longer. They are furthermore strongly connected to notions of medicalization, represented in particular by the concept of overmedicalization, indicating a division between legitimate and illegitimate medicalization. These conceptualizations thus often carry moral connotations, as illustrated by the

classification of certain medical practices as unnecessary, carrying implicit characterizations of good and bad medicine, good and bad doctors. Indirectly, such terms can also be expected to carry epistemological connotations, as the characterization of what is to be considered as too much treatment also could be expected to tell us what the right treatment is, just as notions of overdiagnosis could be expected to tell us what a correct diagnosis is. Whether this is the case or not, and how the notions of overtreatment and overdiagnosis have developed over time, are among the aims of this study. More specifically, the aim of this paper is to present an analysis of the implicit social constructions of health of illness that are to be found in the medical discourse about overtreatment and overdiagnosis. Among the research questions asked are how these notions of health and illness are negotiated, by whom and with what implications. Answers are sought through analysis of relevant discourses within medical literature.

**Wednesday 11 September 2013**

**15:05 - 15:35**

Politics of Health

Derwent Room 037

*Skountridaki, L.*

*University of Strathclyde*

**Internationalisation of Health Care in Greece: A Story of Medical Entrepreneurship and Professional Dominance**

Interest in international patient travel and trade in health care has grown considerably over the past decade. Popularly known as medical tourism, the phenomenon signals inefficiencies in health care systems (of western countries) and is connected to advanced commercialisation of health care. While the role of Medical Doctors (MDs) is significant, albeit unexplored, the business interest in cross-border care is profound, and the emergence of a new key actor notable. The latter, known as 'medical tourism facilitators', account for a considerable portion of patient movement across countries. Therefore, along with the phenomenon of patient travel in itself, they may bring along dynamic changes in the politics and power balance in health care provision. Through the lens of the sociology of the professions, this paper examines the ongoing initiatives of MDs in Greece to strengthen the position of their private practices by becoming involved in the emerging phenomenon. Findings derived from qualitative interviews indicate that MDs, infiltrated by an entrepreneurial spirit, reflect on their dual identity as medics and businessmen as they explore ways to increase their international clientele. In their endeavour to do so, they carefully undermine, albeit in a remarkably uncoordinated way, the role of the medical tourism facilitators. Simultaneously, they see a minimal role for large private hospitals and largely envision the growth of the sector in Greece as a continuation of the current model where medical dominance remains unchallenged by other actors.

**Thursday 12 September 2013**

**17:30 - 18:00**

Lifecourse

Derwent Room 002

*Small, L. F.*

*Wright State University*

**Stress Reduction Interventions for older Adult Kinship Care Providers**

The United States Census Bureau (2010) estimates that 5.8 million grandparents maintain households that include grandchildren younger than the age of 18. Approximately, 2.6 million of these grandparents are custodial care givers and are primarily responsible for their grandchildren (2010). Studies on intergenerational care-giving (kinship care) highlight substance abuse, child abuse and neglect, psychiatric disorders, incarceration, death of adult child, HIV/AIDS, divorce, and economic hardship as primary factors for children being raised by their grandparents. As the number of aging grandparents, who assume primary parental roles, increases research regarding appropriate treatment of mental health stress experienced by these care givers is explored. Poor physical health, poverty, and social isolation are highly correlated with negative psychological effects (depression & psychological stress) experienced by caregivers. In response to the mental health needs of older adult kinship care providers several service interventions were developed as support systems designed to mitigate second time parenthood and ease psychological distress. This research is a metanalysis of care-giving intervention literature and provides evaluation of three most commonly implemented interventions. These service interventions; (1) individual and family psychotherapy; (2) support groups ; (3) and community educational programs are evaluated for treatment impact on psychosocial adjustment, appropriateness of intervention modality, and for long term impact on mental health and kinship care.

**Thursday 12 September 2013****08:30 - 09:00**

Pharmaceuticals

Derwent Room 002

*Smart, A.**Bath Spa University***Racialised Prescribing: in Search of Clinical Perspectives**

In a 2002 New York Times magazine article, US psychiatrist Dr Sally Satel argued that racial differences could be medically relevant, and supported her case for 'racialised prescribing' by citing numerous other physicians. When the issue was discussed on a BBC radio current affairs programme in 2005, Dr Jim Kennedy, then Chair of Prescribing Committee of Royal College of General Practitioners concurred that he would take race into account 'in certain circumstances'. Indeed, in at least one case, NICE guidance mandates differential prescribing on the basis of a judgment about racial and/or ethnic 'decent'. There are now a number of well-rehearsed arguments about the social and medical benefits and risks of racialised prescribing. However, notwithstanding the aforementioned viewpoints, there remains little evidence about what actually happens in everyday clinical practice. What are the circumstances in which race plays a part in prescribing? What roles are played by knowledge about pharmacological evidence, tacit clinical experience and underlying assumptions about difference? How are racial categories ascribed and how is uncertainty, especially about 'mixedness' and 'hybridity', addressed? This paper presents a preliminary analysis of clinical guidance and discussions of this area in the UK. The work addresses medical sociology by examining a process that may potentially contribute to or ameliorate health inequalities, drawing on concepts from science and technology studies concerning the biological construction of race, and considering the relationship between EBM and clinical practice

**Thursday 12 September 2013****16:20 - 16:50**

Lifecourse - Reproductive Health

Derwent Room 037

*Smidova, I.**Masaryk University***Medical Childbirth Made in the Czech Republic: Required and Desired Practices**

There is a polarisation in the debate on the quality of Czech reproductive medicine in the area of childbirth: Is medicalized or 'natural' childbirth the desired and/or required practice? In the Czech context, in contrast to many other European countries, medical doctors are the professionals legally and normatively responsible for and present at every childbirth. And they are advocating for the status quo. The goal of the presentation is to understand and explain their standpoints, frame them in broader social contexts, and facilitate relevant arguments for the public as well as expert discussions on changes in Czech obstetrics from a sociological point of view.

Czech practice is biomedicalised, reaching top ranks in international indicators of mortality and morbidity figures. Basically all births take place in hospitals (no legal alternatives). At the same time, strong voices confronting this favourable evaluation and medicalized practice are heard from the civic society initiatives representing a significant segment of birthing women and independent midwives, pointing out the limits of wellbeing of women and their dissatisfaction with the birthing process following hospital routine procedures. The ideological clash is strongly polarized; few attempts for a moderated cooperation have resulted in a failure, so far. The powerful party is, based on significant structural context, the biomedical one.

Based on interviews with medical doctors (gynaecologists and obstetricians), I analyse their opinions on desired changes in the area of 'childbirth' – 'delivery'. Concepts of authoritative knowledge, biopolitics, and governmentality as well gender hegemonies have been incorporated in the analysis to help sociologically grasp the phenomenon of 'desired and required childbirth'.

**Wednesday 11 September 2013****14:30 - 15:00**

Politics of Health

Derwent Room 037

*Smith, K., Stewart, E.**University of Edinburgh***Physicians as 'the Natural Attorneys of the Poor': Perceptions of 'Public Health Advocacy' and the Role of Public Health Research**

The Prussian physician Rudolph Virchow famously declared physicians to be 'the natural attorneys of the poor'. Reflecting this, public health has a long tradition of advocating for policy change. Indeed, one popular academic response to the failure of recent policy efforts to reduce health inequalities in the UK

has been to call for public health researchers to become more actively involved in 'public health advocacy'. Yet, there is currently no clear agreement on the nature of this role or how public health researchers might combine politically-engaged work with their 'scientific' credibility. This paper draws on a systematic literature review plus interviews and focus groups with members of the UK public health research, policy and advocacy communities to explore: (i) how different actors understand 'public health advocacy'; (ii) how public health research is employed (or not) by organisations and individuals involved in 'public health advocacy'; and (iii) the extent to which public health researchers working in different areas consider themselves to be 'public health advocates' and how those that do balance this role with their more traditional, academic work.

**Thursday 12 September 2013**

**17:30 - 18:00**

Methods

Derwent Room 049

*Smith, M., McDaid, L., Wight, D.*

*MRC/CSO SPHSU, University of Glasgow*

**The Effects of Ethnographic Engagement on Recruitment, Interviews and the Researcher: Participant Relationships in a Study Concerning Sensitivities to HIV/AIDS Among African Migrants in Scotland**

This PhD research project seeks to explore the heterogeneity of the African migrant Diaspora in Scotland and what effects various dimensions of this heterogeneity might have on sensitivities to HIV/AIDS-related testing and research. The project is qualitative, involving ethnographic research and interviews, with participants from five case study sites across Scotland (including a faith group, a church, an integration network and two advocacy groups). This paper discusses the effects that the ethnographic engagement has had on various methodological aspects of the research, including: Form of recruitment; the data collected through interviews; and the relationship between researcher and participant. Ethnographic engagement has facilitated recruitment through an adjustment of the researcher-participant relationship, building of trust between the two, and through a lessened dependence on gatekeepers. Format and content of interviews have been affected, with perceived higher levels of disclosure (due to an adjustment of the insider/outsider position held in relation to participants) and in smoother negotiation of sensitive topics (in comparison with interviews with participants not first engaged with ethnographically). Ethnographic engagement has also had a profound effect on the researcher, in both positive and negative ways. The paper will conclude with a discussion of the place of the researcher within the research process, and the impact of this on the neutrality and objectivity of the researcher relationship with participants.

**Friday 13 September 2013**

**09:35 - 10:05**

Experiences of Health and Illness

Derwent Room 056

*Snow, R., Sandall, J., Humphrey, C.*

*King's College London*

**The Changing Role of Patient Expertise**

Increasing emphasis is being put on making patients more responsible for their own health, with formal courses teaching people with long-term conditions how to be self-managing 'Expert Patients'. This study explored the impact of education interventions on patients' lives, including their relationships with healthcare professionals. Focusing on DAFNE (Dose Adjustment for Normal Eating), an international programme for Type 1 diabetes, it is one of the first studies in the field to be entirely service-user led.

A qualitative approach was taken, using narrative analysis and informed by disability theory. Participants were recruited from three English NHS hospitals. Eleven new students were interviewed pre-course, observed during education, then re-interviewed. Retrospective narratives were collected from ten former students. Data was gathered from 32 interviews and 146 hours of observations, including five days of complete participation in DAFNE by a diabetic user-researcher.

Most students spoke of the intervention as life-changingly positive. However, post-education health interactions could be fraught. Students emerged from the course with greater condition-specific knowledge than many of the healthcare professionals they encountered. When these professionals did not understand what the patients were trying to do and were uncomfortable trusting patient expertise, there could be serious consequences for students' ability to self-manage effectively.

Patient expertise can be seen as inappropriate in standard healthcare interactions, and information taught to patients in one branch of medicine can be considered non-compliant by those who are not specialists in that field. Support for healthcare professionals to recognise and value patient knowledge might mitigate these problems.

**Thursday 12 September 2013****09:40 - 10:10**

Mental Health

Derwent Room 037

*Spencer, I. H., Wood, V., Curtis, S., Gesler, W., Close, H.,  
Mason, J., Reilly, J.**Durham University***Private Finance Initiative in Practice: The Impact of PFI on In-patient Psychiatric Care**

The Private Finance Initiative (PFI) was used by successive governments to fund capital building programmes in the NHS. This paper examines the practical impact of PFI from the perspective of the staff and service users of a new, PFI funded, psychiatric in-patient facility in the North of England. Drawing on focus groups, participant observation, as well as a habitation experiment where non-service users spent 24 hours in the facility, this paper draws attention to the benefits and limitations of PFI as a way of developing psychiatric services. In particular, we examine the ways in which PFI shaped the physical, therapeutic landscape of the hospital. There were some surprising findings in terms of PFI supporting the effective re-nationalisation of forensic psychiatry. We also draw on quantitative data to show that the new hospital 'at least did the sick no harm'. Aside from the cost, the new hospital was an advance over the old asylum it replaced but PFI did place some new constraints on therapeutic spaces.

**Thursday 12 September 2013****09:40 - 10:10**

Complimentary and Alternative Medicines

Derwent Room 047

*Spooner, S.**University of Liverpool***Developing data: Making Sense of It All With Situational Analysis**

In a drive to describe and understand the social world, researchers may seek to incorporate information from multiple sources and from opposing perspectives. Interactions occurring in the delivery of health care are often complex and currents generated within organisations may appear incongruous with performances enacted by individuals. Faced with historically ill-defined theoretical distinctions between micro and macro aspects of the social world, this wealth of empirically derived and diverse data presents an analytical challenge.

The tasks of exploring meaning and action, proposing cause and effect and describing relationships and processes, demand that data is thoroughly assimilated, reflectively considered and contextually grounded. As an adjunct to interpretive exploration, Situational Analysis offers a visual, versatile and practical means of opening data, layer by layer.

This paper presents examples of how adaptation of the analytic exercises described by Clarke enhanced my understanding of a series of professional narrative accounts. By unfolding stratified stories of lived experience of doctors in the NHS, the mapping process facilitated formation of links between meaning-making, actions, structures and phenomena across the micro, meso and macro worlds of their lived experience. This contributed to greater clarity when examining relationships between individuals and collective bodies, understanding their relative power and influence and constructing theoretical ideas behind contrasting views based on factors such as motivation and a sense of a professional self.

**Wednesday 11 September 2013****13:55 - 14:25**

Experiences of Health and Illness

Derwent Room 056

*Standing, H., Exley, C., MacGowan, G., Rapley, T.**Newcastle University***Me, My Bag and I: Patients' Accounts of Living with Ventricular Assist devices**

Heart disease is one of the leading causes of death in the western world. Until recently heart transplants were often the only treatment available to patients with advanced heart failure. However, technological advances coupled with a decline in the number of donor hearts available for transplantation has resulted in increased use of ventricular assist devices (VADs). VADs are mechanical circulatory devices which support or replace the function of a failing heart. Currently, VADs are only offered to patients waiting for a heart transplant; however the use of these devices is likely to increase in the near future. Presently, there is a dearth of literature exploring the day-to-day realities of living with a VAD which will become increasingly important as the role of VADs is increased.

This on-going study uses qualitative interviews (n=12) with a range of patients on VAD support to highlight the key features of everyday life for VAD patients. Whilst the pump aspect of the VAD is



internal patients must also manage external components of the VAD, including batteries and a controller which are permanently connected to them via a driveline. These external peripherals are carried in a 'VAD bag'. Respondents' accounts of their day-to-day life with the VAD suggest the continual presence of this VAD bag has far reaching impacts, shaping their sense of self and identity and their daily life and routines. This paper will explore VAD patients' relationship with the external components of the device to offer new insight into the experience of these patients.

**Friday 13 September 2013**

**09:00 - 09:30**

Citizenship and Health

Derwent Room 036

*Stevenson, F. A.*

*University College London Medical School*

**The Use of Electronic Patient Records for Medical Research: Conflicts and Contradictions**

The use of electronic patient records for medical research is extremely topical. The Clinical Practice Research Datalink (CPRD), the English NHS observational data and interventional research service, was launched in April 2012. The CPRD has access to, and permission to link, many healthcare related datasets. The CPRD is ideologically driven but questions around the feasibility and acceptability of implementing and integrating the necessary processes to enable electronic patient records to be used for the purposes of research remains. This paper considers the contradictions evident in the fact the CPRD is presented as a benign and bureaucratic imperative which will produce benefits at both individual and societal levels, yet the processes involved in the collection of electronic patient records contradict with other centrally held values of information governance and consent

The analysis is based on focus group and interview data collected from patients and staff from two GP practices involved in piloting the technical and practical aspects of downloading electronic patient records for research. The paper considers the ways in which sense was made of the work of implementing and integrating the service. In particular how key aspects of the service; namely issues of patient consent for the use of the data and information governance, were dealt with.

The ideology that drives the CPRD is considered alongside the realities of sourcing the data and the probable success or areas of difficulty likely to be faced in the future by the CPRD.

**Thursday 12 September 2013**

**15:45 - 16:15**

Health Policy

Derwent Room 104

*Stewart, E.*

*University of Edinburgh*

**'That Would Seem a Really Strange Thing for Me to do': Engaging with Outsider Perspectives on Public Involvement Policy in the Scottish NHS.**

The Scottish NHS has been the site of significant policy shifts since devolution in 1999, most recently with patients and the public enlisted (at least rhetorically) into the project of creating a 'mutual' NHS. In common with experience in other countries, concerns have been expressed that the transformative appeal of these policies has not been met by the engagement of new publics. Given the apparent failure of public involvement policies to forge new relationships between healthcare organisations and their publics, this paper asks how, as researchers, we can meaningfully incorporate 'outsider' perspectives on policies for public involvement in health. Drawing on interviews with 'unengaged' young adults (aged 18-25) within one Community Health Partnership in Scotland this paper explores the ways in which these young adults exert agency in informal ways removed from the structures of public involvement. The resulting 'gap' between the questions of researchers and the answers of young adults is both a challenge and an opportunity. This paper proposes that interpretive approaches to policy analysis, which start from the standpoint of citizens' lived experiences, can provide a critical space from which to understand the assumptive worlds of public involvement policy

**Friday 13 September 2013****10:45 - 11:15**

Health Service Delivery

Derwent Room 104

*Stobbart, L.**Newcastle University***Living apart, together: Conducting Clinical Research in an Acute Care Setting - an Ethnographic Study.**

Stroke is a major cause of death and disability in the UK. The few treatments that exist e.g. thrombolysis, must be given urgently and are not risk-free. Large scale randomised controlled trials are crucial to develop safe, effective acute interventions, but progress is limited, ostensibly due to ethical and regulatory difficulties. Theoretical work has focussed upon capacity and consent, potential conflicts of interests inherent in the dual role of clinician-researchers, and the notion that research and clinical practice are, can be, and should be conducted separately. Empirical evidence is lacking. This study empirically examines claims made in the literature regarding difficulties in conducting emergency research. It also explores whether, how and to what effect, the distinction between research and clinical activity advocated in the literature is maintained.

Ethnographic methods were employed, including participant observation, semi-structured interviews, and audio-recording of research consent interactions in an acute stroke unit. Data analysis drew upon constant comparative and framework methods.

The data support some of the theoretical and conceptual literature, but also furnish a detailed account of pragmatic issues encountered and managed by healthcare professionals in the acute stroke environment. Attempts to separate clinical and research activity at the study site demonstrated that absolute separation is neither attainable, sustainable, nor desirable. Deploying research nurses within the clinical environment may promote transparency and greater understanding of their role, whilst demystifying research concepts. Ultimately this may enhance working relationships, contributing to improved recruitment, retention and management of research participants.

**Thursday 12 September 2013****15:10 - 15:40**

Lifecourse

Derwent Room 002

*Stocker, R., Close, H., Hungin, P.**Durham University***Experiences of Prognostication and the Transition Point from Active to Palliative and End of Life Care in Heart Failure: A Grounded Theory Study**

Background: Heart failure (HF) is a progressive, life-limiting illness with a mortality rate of 50% within four years. It is difficult to accurately predict the end-of-life phase due to the unpredictable disease trajectory, co-morbid conditions, and non-specific signs and symptoms. These challenges mean that many patients and carers report little/no prior communication about the terminal nature of HF. Investment has been made in multi-disciplinary palliative care (PC) teams, combining pathway and communication skills development. However, little is known about their impact on end-of-life care in non-cancerous illnesses, particularly HF.

Aim(s): To explore the perceptions and experiences of communicating prognostic and palliative/end-of-life care information from the perspective of clinicians, HF patients, and carers.

Methods: A qualitative, longitudinal, grounded theory methodology combining observations of clinic appointments and interview data from 14 clinicians, 14 HF patients, and 9 HF carers.

Findings: Analysis revealed strong clinician ambivalence surrounding prognostication and resulting PC needs. Many clinicians found it 'cruel' to disclose prognostic information, preferring instead to maintain hope throughout, delaying PC discussions until very near the end-of-life. Most patients and carers felt PC/end-of-life considerations did not apply to them, focussing more on negotiating everyday restrictions. The vast majority of patients reported that they had never been spoken to about their prognosis, including end-stage patients.

Discussion: The topic of palliative and end-of-life care remains the elephant in the consultant room. Societal knowledge of HF is poor and this reflects in the way in which patients think and feel about their prognosis, especially the taboo of death.

**Wednesday 11 September 2013****14:30 - 15:00**

Screening and Diagnosis

Derwent Room 047

*Thomas, G.**Cardiff University***Picture Perfect: '4D' Scans and Consumer Practices in the Antenatal Clinic**

This paper considers how emerging medical technologies have transformed the antenatal clinic into a site of consumption. The commercial availability of non-medical '4D' ultrasound scans, providing detailed real-time images of an unborn baby, is an evolving industry in the UK. The scans are advertised as promoting maternal 'bonding,' as offering reassurance, and as tendering an entertaining experience for parents-to-be during a pregnancy. Drawing on an ethnography of a private antenatal clinic, I pay attention to the discursive exchanges which occur during 4D ultrasound scans in conjunction with the performative materiality of the clinical space. The ultrasound scans create a setting in which participating actors can distinguish the unborn baby as a consumable entity, together with providing opportunities for gendered and (good) parental performances, for constructing familial relations, and for gazing at the 'perfect' child. The materiality of the clinic upholds the cultural ideal of perfection by adorning walls with pictures of photogenic babies, by supplying DVDs of the ultrasound imaging, and by offering parents other purchasable keepsakes to memorialise the unborn. I consider how this construction of perfection in the clinic simultaneously reproduces a non-perfect imaginary, namely, the born or unborn baby with a physical defect. In a society fostering a climate of extensive marked-oriented consumption, the presence of disability can be viewed as disrupting expectations of predestined perfection/normality in foetal outcome. I conclude by briefly reflecting on how the reconciliation of prenatal care with prenatal entertainment points towards the increasing commoditisation of the pregnancy experience.

**Thursday 12 September 2013****15:10 - 15:40**

Health Policy

Derwent Room 104

*Tierney, E., MacFarlane, A.**University of Limerick***Service User Involvement in Primary Care: A Critical Interpretive Synthesis (CIS) of Contemporary Practice**

**Background:** Public and patient involvement is enshrined in health policies across international settings. Recently there have been important advances in conceptualising and operationalizing involvement. However, problems persist in relation to its normalisation as a routine way of working. In this review, we focus on current practice to critically interrogate factors known to be relevant for normalisation – definition, enrolment, enactment and appraisal.

**Method:** Our team consisted of a multi-disciplinary and inter-agency team which included community representatives. We searched EBSCO host for papers between 2007-2011 and engaged in an iterative, reflexive approach to sampling, appraising and analysing the literature following a critical interpretive synthesis approach (Dixon-Woods, Cavers et al. 2006).

**Findings:** From an initial sample of 289 papers, 26 were chosen as a purposeful sample using five emergent sampling parameters. Few papers provide a clear working definition for service user involvement. The dominant rationale for involving service users in projects was linked with policy imperatives for co-governance and emancipatory ideals. In practice, the nature of the reported work did not meet these ideals. The methodologies employed generally reflected medium-low level service user involvement. Most studies only report positive outcomes raising questions about the balance or completeness of the published accounts.

**Conclusion:** The field of service user involvement is dominated by a rhetoric that is not being realised in practice. It is necessary to augment the evidence base about involvement, encourage more methodological innovation to enable co-governance and the achievement of emancipatory ideals and to disseminate research processes as well as findings to religious and caste communities. For descendants, adhering to cultural and caste values remains important but were location and context dependent.

We argue that understanding health practices as a product of embedded and emergent social practices as well as 'cultural difference' is vital for the development of effective and responsive policies and interventions.

**Thursday 12 September 2013****15:10 - 15:40**

STS and Medicine

Derwent Room 003

*Timmons, S.**University of Nottingham***A Technological Solution to a Sociological Problem? Predicting Mortality Post-cardiac Arrest.**

Even for patients who are successfully resuscitated and admitted to hospital, outcomes post-cardiac arrest are typically poor. This is problematic for the physicians who care for these patients on both ethical and resource management grounds. Because of these problems there have been numerous attempts to establish scientific methods of predicting which patients will have a poor outcome i.e. are likely to die, and which patients are more likely to survive. These methods are typically based on physiological measurements such as the presence of biochemical markers, evoked potentials or neurological signs.

The 2010 Resuscitation Guidelines devote a whole section to these methods of prediction and conclude that none of them are adequate for the tasks that physicians ask of them. What is particularly problematic is that unlike most tests used in medicine it is essential that they have a zero false positive rate. It is clear that predicting imminent death for someone who subsequently lives, or vice versa, would be a deeply undesirable occurrence.

In this paper I will argue that physicians are seeking a technological solution to what is actually a much wider sociological and ethical problem in health care. Drawing on a science and technology studies approach I will show that it is unlikely that any 100% reliable technology of prediction could be found, but that by delegating to technology, physicians are seeking to personally avoid making a painful and uncertain prediction of death.

**Friday 13 September 2013****11:20 - 11:50**

Methods

Derwent Room 047

*Tjora, A.**Norwegian University of Science and Technology***Offline Health**

Studies in health-related use of the Internet has become significant within sociology, providing insight both in issues related to health, to online communication, and to broader societal issues. Taking a different, experimental approach to the study of how the Internet is part of people's lives, I invited daily Internet-users to stay offline in 3 weeks during Oct/Nov 2012. Fourteen participants volunteered and 13 of them were able to stay offline during the whole period, and were interviewed regularly. In this paper I am concerned with health aspects of staying offline. On basis on an analysis of the more than 100 depth interviews conducted during the project, an elaboration and discussion of 'offline health-experiences' is inductively developed in this paper. The experimental design provokes participants' accounts that challenge the idea of the Internet as just another medium of social connectivity (in addition to everything else). Applying, among others, the concept of 'familiarity bonds' (Scambler & Tjora 2012), a typology of offline health experiences is developed.

**Friday 13 September 2013****11:55 - 12:25**

Experiences of Health and Illness

Derwent Room 056

*Tompkins, C., Armes, J., Harding, S., Ream, E., Scanlon, K.**Breast Cancer Care***The Influence of Culture, Faith, Family and Cancer Beliefs on Breast Cancer Survivors' Experiences and Identities: A Multi-ethnic Sample in England**

Little is known about the experiences of non-white breast cancer patients after treatment despite increasing women from these ethnicities being diagnosed and treated. We qualitatively explored the lived health and wellbeing experiences of 59 women from varying ethnicities during early recovery from breast cancer. Framework analysis identified that all women had a changed sense of self after treatment and diminished feelings of wellbeing. Cultural beliefs about cancer compounded recovery and contributed to non-white women feeling particularly changed and 'different'. The stigmatised beliefs about cancer held by older South Asian and Black Caribbean generations and the need to conceal the diagnosis in order to protect the family's name and reputation played a key role in women's new sense of self. The perceived association between cancer and death amongst these communities, the prior experience of family bereavements to cancer and the importance of maintaining outward appearances

also contributed to difficult recoveries and altered identities. Faith helped South Asian and Black Caribbean women manage their new identities through prayer, attending places of worship and supportive religious friends. Whilst the role of the family was generally supportive during recovery, this was complicated by maintaining traditional mothering roles and protecting family from the true extent of their feelings for South Asian women and needing to maintain a 'strong' identity for Black Caribbean single mothers. These findings will be discussed in relation to current cancer survivorship care, considering how understanding shifting cultural and generational beliefs may help to alleviate negative identity issues amongst non-white cancer survivors.

**Wednesday 11 September 2013**

**15:40 - 16:10**

Health Service Delivery

Derwent Room 104

*Trondsen, M.*

*Norwegian Centre for Integrated Care and Telemedic*

**Managing Everyday Life: Exploring an Online Self-help Group for Adolescents with a Mentally Ill Parent**

A considerable body of research has described the implications of parental mental illness. However, most children and adolescents with mentally ill parents are left to manage their family situation with limited information and support, and their perspectives have rarely been addressed. In this action-oriented study, I explore the role of a Norwegian online self-help group for adolescents (aged 15 to 18) with a mentally ill parent. The analysis was conducted through participant observation of the group for 2 years and in-depth interviews with 13 participants. The adolescents experienced a variety of difficult challenges related to their parent's mental illness: lack of information and openness; unpredictability and instability; fear; loneliness; and loss and sorrow. They also discussed several strategies to manage their family situation. I found that the online self-help group affords 'communal normalisation' by which participants, through communication in the forum, make sense of everyday experiences and emotions arising from having a mentally ill parent. Three main aspects of this process were identified: 'recognisability'; openness; and agency, all of which are important for the adolescents' efforts to get support, to be supportive and to handle everyday life situations better. Communal normalisation in the online self-help group might provide resources for significantly improving the participants' everyday lives, and could demonstrate similar potential for users in other life situations characterised by stigma, loneliness, silence, or health worries. I emphasise the importance of including perspectives of children and adolescents in further research to improve health care for families with parental mental illness.

**Thursday 12 September 2013**

**12:00 - 12:30**

Experiences of Health and Illness

Derwent Room 056

*Trusson, D.*

*University of Nottingham*

**Biographical Disruption and Liminality: The Case of Early-Stage Breast Cancer/DCIS**

This paper discusses the way that Bury's (1982) theory of illness as a biographical disruption and Turner's (1969) theory of liminality can be applied to the experiences of women who have been treated for early-stage breast cancer/DCIS. Not only can a diagnosis of a life-threatening disease represent a biographical disruption, but the end of treatment can also be disruptive. With an ongoing fear of recurrence, the simultaneous loss of medical and social support can engender feelings of isolation and vulnerability. In addition, permanent bodily changes resulting from breast surgery can prevent women returning to how they were pre-diagnosis; instead entering a state of liminality 'betwixt and between' states of health and illness (Turner, 1969:95).

Biographical disruption and liminality have previously been combined to study men's experiences of prostate cancer (Navon & Morag, 2004, Cayless et al, 2010). However, studying an illness that mainly affects a female population offers a unique insight into gendered aspects of the experience. Data will be presented from the narratives of 24 women who had completed intensive treatment between 6 months and 29 years previously. These suggest that the nature of ESBC/DCIS and its treatments have profound and long-lasting effects. As well as possible disruption to women's traditional roles, I argue that surgery leaves embodied reminders which can affect femininity and identity with possible repercussions for current and potential intimate relationships. I also discuss how familial and wider relationships are managed during and after treatment and how some women report positive outcomes from their experiences.

**Wednesday 11 September 2013****15:40 - 16:10**

Pharmaceuticals

Derwent Room 002

*Tutton, R.**Lancaster University***Post-Personalized Medicine? Contested Futures of Pharmaceutical Research**

Nik Brown (2005) observes that the life sciences are populated with innovation concepts whose associated promise has changed over the last decade, from revolutionary potential to despairing disappointment. This can be vividly illustrated by the case of personalized medicine. In the 1990s, personalized medicine emerged – reinvented for the speculative world of late 20th century biotechnology – to convey the economic and health benefits that would flow from drugs developed using pharmacogenomic technologies. Yet, after what has been called the 'irrational exuberance' of the late 1990s, those who were once hopeful or excited by the prospects offered by pharmacogenomics now appear disappointed by what has been achieved to date. Against this background, my paper examines what is happening to the vision of personalized medicine at this particular juncture in its 'hype-disappointment' cycle. Following the work of scholars such as Brown, I investigate the extent to which we can see 'communities of promise' migrating to alternative ways of imagining the future of pharmaceutical research, such as 'stratified medicine' and 'precision medicine'. Drawing on both primary and secondary sources, I discuss which groups are promoting these alternatives and consider the potential practical significance of this change in language.

**Thursday 12 September 2013****14:00 - 14:30**

Lifecourse - Reproductive Health

Derwent Room 037

*Ullrich, C.**Hochschule Osnabrueck***From Informed Choice to Paternalism: the Flexible Doctor-patient Relationship in Assisted Reproduction**

Since Parson's definition of the sick role, several models describing the doctor-patient relationship have been developed (e.g.. Emanuel and Emanuel 1992). In my paper, I employ these rather static models to describe the treatment trajectory in assisted reproduction, namely in-vitro fertilization (IVF), as a process. My findings draw on an ethnographic study including participant observation, recorded consultations and semi-structured interviews with ten patients and four physicians that I conducted in an infertility clinic in Germany.

IVF treatment is a process that involves consecutive steps, taking place in different places and involving different technologies. Each of these steps corresponds with different qualities of the doctor-patient relationship: While choosing a clinic, the patients appear as customers, and in the initial consultation the doctor-patient interaction is rather informative and interpretative. During hormonal controlling of the ovulatory process, the doctors tend to be more paternalistic, and in the surgery for retrieving the ova the patients are passive. Stating those differences, the underlying premise is that doctors and patients both agree on the assumption that a problem should be solved medically – the physicians professionally trained to do so, the patients while searching for help.

What can be observed throughout the treatment is that the success of the treatment is the responsibility of a complying, yet cautious patient.

**Thursday 12 September 2013****09:05 - 09:35**

Experiences of Health and Illness

Derwent Room 056

*Walker, L., Price, E.**University of Hull***Chronic Illness and Relationships: The Impact of Lupus on the Family.**

This paper explores the impact of illness and disease on relationships and the family. It focuses on the effects of Lupus (and other auto-immune disease) and the resulting changing roles and responsibilities within families and intimate relationships. Intimacy, sexuality and desire are significantly shaped by the onset of long term, chronic, conditions and, in this paper, we explore how people living with Lupus have negotiated and alternatively expressed and reconstituted their relationships in this context. In addition, Lupus disproportionately affects women and we therefore focus on the gendered dimensions of living with an auto-immune disease. For example, we explore the ways in which the roles of mother and partner are implicated and renegotiated in the context of shifting gender power relations. Drawing on in-depth interviews with people living with Lupus, we analyse the impact of the unpredictability of

symptoms on relationships and the particular challenges this poses for partners and children. We argue that the long term limitations imposed by Lupus can alter people's perceptions, aspirations and expectations of families and relationships: these intimate shifts and finely balanced negotiations are the subject of this paper. Their implications for the long term management of Lupus are highlighted.

**Thursday 12 September 2013**

**09:05 - 09:35**

Professions

Derwent Room 036

*Wall, S., Kunyk, D.*

*University of Alberta*

**'Safe, Competent, and Ethical Care': Governmentality and Professional Nursing Regulation**

In Canada, professional nursing regulation is legislatively delegated by provincial governments to nursing organizations. These regulators enforce licensing and disciplinary processes to ensure their members provide safe, competent, and ethical nursing care. Most are also professional associations, although they deliberately place more emphasis on public protection than professional advancement. The regulator in our province tends to operate from an especially conservative perspective, adhering to restrictive licensing and punitive disciplinary policies while attaching a moral element to non-standard conduct. Drawing on the findings of two separate studies, this presentation examines some regulatory requirements imposed upon nurses, using the concept of 'governmentality' to frame the analysis. Governmentality, as conceptualized by Foucault, involves the 'conduct of conduct,' the shaping and evaluation of behaviour, identity, and choices through definitions of knowledge and techniques of control, brought to bear in apparently mundane day-to-day practices. In the first study, self-employed nurses, working in non-traditional roles, encountered difficulties in obtaining licenses to practice. In the second, nurses accused of professional misconduct were dealt with punitively. These empirical examples illustrate how power and control are currently exercised in nursing regulation and allow us to examine particular contexts in which governing is called into question. These studies also enable an exploration of how governmentality, with its dependable processes and structures, fits with contemporary discourses of risk, individualism, enterprise, and health. The study findings provide insightful suggestions for balancing risk and change with compassion while adhering to necessary standards for public protection, which are both practically flexible and theoretically significant.

**Thursday 12 September 2013**

**10:50 - 11:20**

Inequalities

Derwent Room 002

*Warr, D., McVernon, J., Geard, N., McGraw, J., Mouat, C., Patterson, P., Robbins, G*

*University of Melbourne*

**Exploring Associations Between Neighbourhood Environments, Network Structures and Health in Contrasting Socioeconomic Regions**

There is growing evidence that place-based disadvantage is associated with characteristic social network patterning among residents. In particular, evidence suggests that residents of socioeconomically disadvantaged neighbourhoods are likely to have more local networks and fewer extra-local networks, than residents living in other kinds of neighbourhoods. This patterning may be linked to processes of 'socio-spatial polarisation' that are producing effects in which the poor and non-poor increasingly live apart from each other. For populations living in settings of locational disadvantage, sociological insights suggest that characteristic network patterning across socio-spatial contexts has diverging implications for the processes through which social network involvement is associated with positive health (and other social) outcomes. In this presentation, we explore these issues by drawing on findings from research currently underway in two socioeconomically contrasting local government areas in Melbourne, Australia. Research data is being collected using contact diary methods and telephone surveys data and describes the usual social network involvement of participants over a two-day period, participants' assessments of local social contact and available local resources. Participant samples include: general population; parents with young babies and Turkish migrant background parents with young babies (a predominant ethnic group in the low SES research site). Data analyses are generating insights into relationships between patterns of network involvement and socio-ethnic-spatial contexts. Analyses are also examining the implications of network patterning and key mechanisms through which social connectedness is thought to influence health-related processes across spatial settings, population groups and life-stages.

**Thursday 12 September 2013****14:35 - 15:05**

Experiences of Health and Illness

Derwent Room 056

*Webster, M.**University of London, Royal Holloway***Experiences of Epilepsy: Children with Epilepsy, their Parents and their Siblings**

This paper focuses on the impact that having a child with epilepsy can have on family relationships and family life. Existing sociological literature details the experiences of adults with epilepsy, and their recollections of their childhoods. There is, however, no current literature exploring children's experiences of epilepsy, their siblings' experiences or the impact epilepsy can have on family relationships. Drawing on individual interviews with parents and individual autodriven photo-elicitation interviews with children with epilepsy and their siblings in 15 families, this paper will present preliminary findings from an on-going piece of PhD research. Particular attention will be given to individuals' interpretations of varying seizure types and the impact this can have on family life and family interactions. Additionally, the various meanings different family members attributed to the condition and its treatment will be discussed. It is intended that this research will contribute to the literature on uncertainty by detailing how families, and particularly children, manage and make sense of such an unpredictable condition.

**Friday 13 September 2013****09:00 - 09:30**

Critical Public Health

Derwent Room 006

*Whelan, E.**Dalhousie University***'We Stand On Guard For Thee': The Problematization of Hand Washing in Canada**

Detailed instructions about hand washing are now posted routinely in washrooms in restaurants, universities, government offices, and many other public venues and work settings throughout Canada. This is a development of the early twenty-first century; in the recent past, little direction has been given to adults about the proper way to wash their hands. Furthermore, some indicators suggest that concern about proper hand washing is particularly intense and ubiquitous in Canada compared to other industrialized countries. Why Canada, and why now? This paper reports on preliminary results from a larger historical-sociological analysis of hand washing as an object of waxing and waning concern in Canada and internationally, and particularly of its connection to models of responsible (and irresponsible) citizenship in the context of epidemic diseases and periods of global migration. The paper will focus upon municipal and public health interest in and newspaper coverage of hand washing as a social problem in Canadian cities.

**Friday 13 September 2013****11:20 - 11:50**

Critical Public Health

Derwent Room 006

*White, K., Moss, J., McGann, M.**Australian National University***The Material and Psychosocial Impact of Insecure Work in Rural Australia**

In this paper we present results of a qualitative study of 72 rural workers in Victoria, Australia. Against the background of the growing casualisation of the workforce we demonstrate the impact on the health and well-being of these workers. The interviews demonstrate the material pathways casualisation produces which results in sickness and disease: coming to work sick; putting health on hold; and concealing injuries at work. We also demonstrate the psychosocial pathways (1) which impacts on workers through reduced autonomy and control of their place in the labour market; showing the debilitating effects of intermittent and uncertain work; and (2) the psychosocial impact of their precarious labour market and lower social status in the workforce on their self-esteem and social participation both inside and outside the labour market. The paper concludes that it is only with reforms to labour market regulation that workers health and well-being will be enhanced.



**Thursday 12 September 2013****15:45 - 16:15**

Patient - Professional Interaction

Derwent Room 047

*Williams, A., Twycross, A., Gabe, J., Nicolson, P.**St. George's University of London***Managing Acute Pain in Children: The Ceremonial Order of the Hospital Ward**

This paper explores the work that nurses do in managing children's pain, and how this work sustains the ceremonial order of the hospital ward. The hospital ward is seen here as a place with its own social and moral order, or what Strong (1988/2006) calls a 'distinctive micro-social world...with its own special forms, rules, processes and problems' (2006; 37). Their aim here, therefore, is to examine the ceremonial order of this micro-social world, specifically as it involves nurses, parents, and children, and to show how different forms of work, done by nurses, serve to construct and sustain it.

It is argued that in the course of caring for children nurses do many different forms of work including identity work and emotion work, and they do so within a specific social context. Using Fagerhaugh and Strauss' (1977) concept of 'pain work', it is also argued that this pain work is cross-cut with identity work and emotion work as well as the moral work which underlies all three.

The findings presented here demonstrate the importance of considering the complexity of the work that nurses do managing children's pain, and how this sustains the ceremonial order of the ward. Importantly, it also highlights the dynamic nature of parent-nurse-child relationships and interactions during periods of hospitalisation. There are therefore important temporal dimensions to both the ascription of identities and the rules of interaction which are central to the ceremonial order. This paper contributes to an understanding of lay-professional relationships, extending Strong's work on the ceremonial order paediatric clinics (1979) to new setting, and involving nurses, children, and their parents.

**Friday 13 September 2013****10:45 - 11:15**

Citizenship and Health

Derwent Room 036

*Williams, O.**University of Leicester***'Risky' Resistance: The Paradoxical Effects of Dominant Neo-liberal Discourse on Obesity**

Dominant neo-liberal ideas of individual moral responsibility frame obesity as a health 'risk' and failure of civic duty, meaning everybody can now be considered under moral scrutiny. In this context, the impact of socio-economic inequality appears crucial as there are radical differences in citizens' capacity to engage with lifestyle advice and adopt 'healthy' behaviours.

This paper draws on eight months of participant observations and interviews with three NHS-subsidised, single-sex weight-loss groups (one male, two female) at a Leisure Centre in a deprived area of England. The data reveal a novel interpretation of the individualised obesity discourse by the 'at risk' people attending these groups.

People influenced by dominant public health messages might be expected to feel a personal responsibility to avoid becoming/being obese. Indeed, this research demonstrates that people who, due to their relative disadvantage, might otherwise question the logic of individualism usually understood their health in this way. However, many questioned the validity of bodyweight guidelines and the need to comply with them. This scepticism, and a desire to avoid stigma, meant many group-members refused to accept they were obese and would 'reclassify' themselves with the less scorn-inducing/shameful, but also less 'risky', label of 'overweight'. Therefore, although neo-liberalism has been influential in positioning health as an individual responsibility it has also facilitated 'at risk' people questioning health guidelines and justifying non-compliance using this reasoning. Therefore, the neo-liberal interpretation of obesity seems of questionable value to the NHS as it facilitates 'risky' resistance alongside fostering a sense of civic duty.

**Thursday 12 September 2013****10:50 - 11:20**

Health Policy

Derwent Room 104

*Wilson, J., Prior, L., Donnelly, M.**Queens University Belfast***A Review of Published Definitions on the Concept of 'Well-being' and Its Implications for Health Policy**

The measurement and advancement of 'well-being' have emerged as important objectives for governments and NGOs across the globe. However, this desire has outpaced willingness to understand the concept; we have yet to agree a universal definition of well-being. We believe that exploring how the term is understood in academic discourse might shed some light on the concept and help devise policies for lasting improvement. To this end, we reviewed a random sample of 600 academic papers across six academic disciplines (i.e. economics, medicine, philosophy, psychology, social sciences and politics) for explicit definitions of 'well-being' between January 1990 and September 2012. We retrieved 300 definitions which we analysed using grounded theory. Our findings show some degree of consensus that 'well-being' is an individual, psychological phenomenon of betterment over the life course. However, they also show that the substantive content of this entity varies across databases. For example, economic papers focus on positive affect, life satisfaction and low negative affect, perceptions which are shaped by objective conditions. Conversely, although medicine talks of this trinity, it places greater emphasis on the development of human potential, shaped by internal and inter-subjective processes. Thus, although the term is a useful mechanism for facilitating its expression, there are functional differences in its usage. Such differences have important implications for health policy. For example, prioritising subjective perceptions suggests that health policy ought to concern itself with individual feelings without having to detail the nature and level of social infrastructure needed to achieve a sense of 'well-being'.

**Thursday 12 September 2013****08:30 - 09:00**

Lifecourse

Derwent Room 049

*Young, I., Flowers, P., McDaid, L.**MRC/CSO SPHSU, University of Glasgow***'It Makes Me Feel Like I'm Less Toxic': Responses to Treatment as Prevention (TasP) by People Living With HIV**

Recent, clinical research with anti-retrovirals (ARVS), the treatment currently used to treat HIV, has demonstrated their radical potential in the prevention of HIV transmission. Findings from randomised controlled trials have resulted in changes to clinical treatment guidelines in the UK and elsewhere, which now include the option to start treatment for preventative – and not clinical – reasons. Although 'Treatment as Prevention' (TasP) has been hailed as a public health breakthrough, there has been little discussion with people living with HIV about how TASP is understood, how they feel about TasP and how it might be incorporated into 'positive HIV prevention' strategies. Drawing on four focus group discussions and twenty individual in-depth interviews with gay and bisexual men, and men and women from African communities, this presentation will explore responses to TasP by people living with HIV in Scotland. Findings highlight how the use of ARVs to prevent HIV transmission complicate embodied understanding of HIV, HIV prevention, and the management of HIV as an 'identity.' While some participants described a significant gap between managing their health (and HIV identities) with ARVs and using ARVs for prevention, others were excited about the potential of TasP to make them feel 'less toxic.' This paper argues that embodied and social understandings of HIV, HIV technologies and HIV identities, will play a critical role in considering if TasP should be adopted, in what circumstances it might be most appropriate, and how this prevention option should be supported in practice.

**Thursday 12 September 2013****14:35 - 15:05**

STS and Medicine

Derwent Room 003

*Ziebland, S.**University of Oxford***How the Internet is Transforming Health Experiences: Reflections from a Decade of Qualitative Research on Experiences of Cancer, Chronic Illness, Infertility and Bereavement**

This study explores how people talk about the internet and how attitudes and cautions about different types of websites have changed over the last decade, drawing on comparative qualitative analysis of narrative interview studies, conducted during the years 2002- 2012.

In the early 2000s patients' narratives suggested that only particularly engaged, expert and activated patients sought health information online. By 2010 the web had become an almost unremarked, routine part of people's experience (eg 'of course we all looked it up straight away'). The internet has transformed how people make sense of and respond to symptoms, decide whether to consult, make treatment choices, cope with their illness and connect to others.

Increasingly doctors are aware of this and recommend useful sites to their patients yet, even in 2012, respondents express reluctance to talk to their doctors about what they find online, fearing that such revelations might damage the relationship.

Overwhelmingly people describe benefits from using the internet. A possible exception is those experiencing issues that may isolate people from their immediate social world (such as infertility or bereavement): in such cases connecting with others online can be greatly valued, but also reinforce isolation.

People want more than information online, they also want to find reflections, insights and practical advice from other patients. UK doctors may want more evidence about the health effects of using the internet but patients and the public are routinely online, even if they do not mention it in the consultation.