Paper Abstracts

Listed in alphabetical order by first named author

Thursday 11 September 2014 at 10:50 - 11:20
Patient-Professional Interaction
B. Kendrick, Main Building

Raising Work-related Concerns in Primary Care Consultations for Musculoskeletal Conditions: A Qualitative Study

Alcock, E., Sanders, T., Wynne-Jones, G., Chew-Graham, C., Ong, B. N., Paskins, Z.  
(Keele University)

Musculoskeletal (MSK) conditions of a chronic nature affect work significantly often resulting in presenteeism, reduced productivity, sickness absence and long-term work incapacity. Good primary care management of such conditions can result in a positive impact on occupational health outcomes. However, despite a number of studies concerned with this area, research exploring primary care management in such cases is scarce. Moreover, insufficient research exists exploring the individually differing and complex work issues of older adults (50 +) living with MSK conditions.

This study aimed to explore musculoskeletal and work-related discussions within the primary care consultation and the patient experiences of the process and surrounding issues. 100 video recorded consultations of patients aged 45 years plus were observed and analysed utilizing constructivist grounded theory to develop a coding frame. A purposive sample of 20 patients aged 50 years plus, having indicated experiences of both MSK and work related issues, were identified from a cohort study and interviewed. A comparative analysis of the two data sets is underway. Preliminary analysis has highlighted key themes including: 1) the normalisation or dismissal of work-related concerns as a barrier to support, 2) the patient struggle to negotiate legitimacy and deservedness as a barrier to both consulting and discussing work concerns and 3) the socio-cultural co-construction of credibility and deservedness to consult and raise work.

The theoretical framework of ‘Candidacy’ is being utilized to explore and expand on the difficulties faced by patients in negotiating access to the consultation and work-related discussions.

Thursday 11 September 2014 at 16:55 - 17:25
Complementary and Alternative Medicines
White Hall 2, CAMS, Main Building

The Differential Response of Medical Doctors towards CAM in Portugal

Almeida, J.  
(Royal Holloway, University of London)

In Portugal the interest in CAM has persisted within a faction of orthodox medical doctors. Furthermore, acupuncture has been regulated by the Medical Council while homeopathy has acquired more institutional acceptance. Given the unprecedented ‘countervailing power’ (Light, 2010) of CAM in Portugal since the 1990s, it is of interest to explore the responses of the medical profession to CAM, having acupuncture and homeopathy as two cases in point. Drawing on a social closure framework, where professional relationships are seen as relationships of conflict over power, status and interests, this paper attempts to answer the following research question: How have orthodox medical doctors responded to CAM practitioners’ attempts to encroach upon healthcare provision in Portugal?

The data analysis compares the interview accounts of two groups of medical doctors: those uncommitted to CAM and those committed to acupuncture and/or homeopathy. The findings suggest that medical doctors have responded differently to CAM – with the models of subordination and differential incorporation of CAM being the ones with more expression. This can be a signal of increasing fragmentation of the medical profession, which can reflect a postmodernist view of healthcare. Nonetheless, the aim of both models remains the same: to protect their profession from potential competitors and to attain jurisdictional control over CAM, which can reflect a modernist view of healthcare. Thus, it can be argued that contradictory signs, some moving towards, other moving away from, a postmodern disposition towards healthcare have been inherent in the discourse of medical doctors in Portugal.
Paper Abstracts

Friday 12 September 2014 at 09:35 - 10:05
Inequalities
White Hall 3, CAMS, Main Building

Silencing Stereotypes about Weight: Bias, the Female African Caribbean Body and the Clinical Encounter
Andrews, N., Redwood, S., Drever, W., Greenfield, S.
(University of Birmingham)

Stereotyping in the clinic can threaten social interaction between patients and professionals and may contribute to health inequalities. We highlight how the societal construction of Black femininity is linked to notions of physical and emotional strength which are often depicted through images of the larger Black female body. This representation of excess weight contradicts mainstream negative views of large bodies that view excess weight as a form of weakness. We suggest that this notion of strength influences the health behaviours of African Caribbean women and contributes to shaping interaction with healthcare professionals in the clinic. This paper will examine the intersection of race, ethnicity and gender in relation to discourses about the ‘fat body’ and Black femininity.

We will explore the historical origins of stereotypical imagery of Black femininity, drawing on Black feminist and cultural studies literature. We will illustrate how these depictions continue to manifest in contemporary mainstream societal discourse. Such stereotypes are not benign or neutral because they have the power to shape the behaviour of both Black women and healthcare professionals in the clinic. Bringing these to the surface and exploring the mechanisms in which they may actively silence Black women and professionals during consultations is the aim of this paper. This issue has particular significance in relation to how weight and weight management are/are not talked about and what support Black women are/are not offered. We argue that unintentional bias can have tangible impacts and health outcomes for Black women and other minority ethnic groups.

Friday 12 September 2014 at 09:00 - 09:30
Open
B. Kendrick, Main Building

Studying Doctor-Patients Interaction through Narrative Inquiry: Advantages and Concerns
Arieli, D., Tamir, B.
(Emek Yezreel Academic College)

There is clearly greater recognition of the advantages of the study of narratives in the field of health care. Nevertheless, most of the narrative interviews are focused on the study of illness experiences, while there are relatively scarce attempts to understand doctor-patient interaction through narrative study. This paper examines stories which people tell about interactions they had with their doctors. The study draws on data from qualitative in-depth interviews with 22 middle-aged middle-class Jewish Israeli men and women, generally healthy, who were asked to describe interactions they recently had with doctors. The stories they told us were classified according to their performative characteristics and self and other positioning. The data point to a large gap between the narrators' expectations of the interaction with their doctors and the actual experiences. The paper discusses the advantages of narrative inquiry for the study of patient-doctor interaction, and in particular the fact that it allows for expressions of deep notions of vulnerability which usually stay un-voiced. The study also raises questions and concerns regarding the ‘tellability’ of stories about ‘good care’ vs. the tellability of stories about ‘bad care’.

Friday 12 September 2014 at 11:20 - 11:50
Screening and Diagnosis
Stafford 1, CAMS, Main Building

“If it's your Own Kids you are Always Going to Think that they are Great at Everything aren't you?” Parent-report Tools for Developmental Assessment of Babies Born Late and Moderate Preterm
Armstrong, N., Johnson, S., Boyle, E.
(University of Leicester)

Evidence currently accumulating shows late and moderate preterm (32-36 weeks’ gestation) babies to be at increased risk of developmental problems, compared with those born at term. Historically regarded as low risk, they are not currently followed up but there are now calls for routine surveillance in order to allow early identification of developmental problems and appropriate intervention. Babies born before 32 weeks receive routine follow-up including formal developmental assessment at two years but, due to the high numbers involved, replicating this model is not feasible and other options need to be considered.
This paper draws on interviews with parents of 41 babies born at 32-36 weeks’ gestation which took place alongside an assessment of the clinical utility of a parent-report questionnaire as a screening tool to identify those babies with developmental delay at two years.

Most parents reported completing the questionnaire to be acceptable, and even enjoyable. However, this was in the context of a research study in which a follow-up assessment by a member of the research team would be taking place. Parents were less comfortable with a non-research context in which this ‘safety net’ assessment would not be routinely available. There were several points of uncertainty about how to score their child and concerns about potential consequences if they ‘got it wrong’. Parents were also concerned about whether they lacked the degree of detachment needed to produce an objective and valid assessment of their child or may unwittingly give them the ‘benefit of the doubt’. How parent-report tools can position parents as quasi-health professionals will be discussed.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 2, CAMS, Main Building

Experiences of Alzheimer’s Disease: Stigma and Future Planning
Ashworth, R.
(University of Stirling)

This PhD aims to understand whether people with Alzheimer’s disease and their supporters (often referred to as carers) experience stigma (negative attitudes of others) and how this may affect future planning. People with early onset Alzheimer’s disease (under 65 years old), late onset Alzheimer’s disease (over 65 years old), and their supporters will be recruited. This study aims to explore whether there are differences in attitudes towards dementia based on age, as this has currently only been alluded to in previous research. Future planning has currently only been researched in terms of end of life care for people with dementia, this study aims to focus on future planning across the journey of dementia. A mixed methods approach will be used, which involves questionnaires for all participants, followed by interviews for a group of participants selected based on questionnaire scores. Participants will be recruited from the Scottish Dementia Clinical Research Network (SDCRN) research register, which holds information about people with dementia and their supporters across Scotland who would like to be involved in research. People with early onset and late onset Alzheimer’s disease, and their supporters, will be compared in terms of levels of perceived stigma, as well as quality of life and insight. Interviews will then be looked at using thematic analysis, to explore how the experience of Alzheimer’s disease affects future planning. The findings are important to improve future policy and understandings surrounding dementia care and ageism, from the perspective of people affected by dementia.

Friday 12 September 2014 at 11:20 - 11:50
Embodiment and Emotion
White Hall 1, CAMS, Main Building

Emotional Care and Non-disclosure when Caring for the Dying in Ethiopia
Ayers, N., Vydelingum, V., Arber, A.
(University of Surrey)

Ethiopia, one of the poorest countries of the developing world has limited resources for those with advanced cancer requiring end of life care. A focused ethnographic study was carried out exploring the culture of care of the dying in Addis Ababa, where fieldwork was carried out for 6 months at a hospice home care service.

The findings reveal the pivotal importance of community and family in providing end of life care in this setting. However, the awareness of a terminal diagnosis in many cases is kept from the patient by the family and health professionals, in order to protect patients from the emotional distress that awareness of a life threatening condition can bring. The importance of emotional support by the family was found to be the essence of care provision. This was demonstrated by the way family members and hospice staff sacrifice other relationships in order ‘to be with’, the person who is ill, by offering ‘Accompanied Dying’ to ensure that the patient is physically, spiritually and emotionally supported.

This study offers a unique insight into non-disclosure of terminal diagnosis and how the family protects the person who is ill to sustain them during this period. The findings extend Glaser and Strauss’s (2005) theory on awareness contexts. Furthermore, it highlights emotional care and how this is expressed through physical actions, such as cleaning, handling body fluids and touch, thus adding to our knowledge of emotional labour theory (Hochschild 2012).
Health for Mortals: Rethinking Health to Fulfill on the Promise of Critical Medical Sociology
Banerjee, A.
(York University)

Conventional approaches to sustainability in the health sector, which advocate for the more efficient use of scarce health care resources, take for granted the limitless ambition to fight death and disease that lies at the heart of the modern medical project. In this paper, I argue that sustainability requires a rethink of the meaning of health such that it can be oriented by values other than the management of mortality. I argue that an existential and ecological approach to health – which understands health as a state of congruence between intention and capacity – creates a space for a range of values and ambitions to guide health practice (e.g. wholeness, love, connection, appreciation, peace, etcetera). Such an approach suggests strategies for the production of health that take us beyond medicalization and control. Specifically, this conception draws attention to the ways in which healing can be achieved through the reconfiguration of intentions, desires and expectations so that they are inline with available social and vital capacities. I argue that fulfilling on the critical medical sociology’s promise to contribute to the development of a sustainable and compassionate health practice will require developing non-medicalized definitions of health that can guide sociological research. I conclude by considering how such an approach to health may guide critical sociological research within the context of aging and long-term care.

Shark bites, The Simpsons & Vilification: Experiences of Illness Disclosure in Young People Living with Liver Disease
Bashir, S., Lowe, P., Peel, E.
(Aston University)

In young people, liver disease includes a range of different conditions of which some are congenital, others can have an onset during adolescence, and they can vary as to the extent they are visible or a hidden disability. Currently young people with liver disease are an under-researched population in the UK. This paper arises from a wider PhD research project funded by The Children’s Liver Disease Foundation. This paper will draw upon the experiences of young people living with liver disease in relation to their decision on whether or not they disclose their illness status to others. It draws from semi-structured interviews conducted with young people aged 14-25 living with different liver diseases. Participants were recruited through four NHS hospitals and via online condition-specific arenas. Interviews were audio-recorded, transcribed verbatim and analysed qualitatively. Preliminary findings suggest that young people’s experiences of disclosure vary with some young people choosing to conceal their illness from others. Using the concept of stigma, this paper will illustrate the contexts in which decisions to disclose are taken, the reactions of others, and any implications for young people’s agency. Attention will be paid to the young people’s accounts of managing accidental disclosure and any challenges they may face in maintaining their illness disclosure decisions in wider social contexts.

Socio-economic Status (SES) and Health in Middle Income Countries
Baumann, P. M.
(University of Graz)

Middle income countries are a curious case with regard to health and health inequality. While they are on the rise economically (in varying degrees), they may lag behind (also, in varying degrees) in other domains, such as the social. Therefore, much may be learned about the dynamics of SES and health in different settings in general. Additionally, to facilitate these countries’ further development, it is crucial to identify the respective determinants of health and the interplay between individual characteristics and national conditions.
In order to account for the complex data structure necessary to answer such a question of the interaction between the individual and the country level, multilevel modeling is required. For this presentation, self-reported health will be explored as the indicator of individual health. On the individual level a multifaceted model of the relationship between SES and health will be tested. This model does not only include indicators of SES, such as education and wealth, but also health care needs and satisfaction as well as risk factors (tobacco, alcohol, nutrition, exercise). On the country level, GDP, the Gini coefficient (in order to test the Wilkinson hypothesis), total health expenditures, and the Human Development Index will be included.

Results will express either the odds ratios or the probability of being healthy or ill given the individual SES in the light of the other explanatory variables. Moreover, the influence of interaction effects within and between the two different levels (for example, between SES and GDP) will be explored.

Wednesday 10 September 2014 at 13:20 - 13:50
Open
White Hall 1, CAMS, Main Building

‘When you have a Child with RS, you Want to Know you have a Lot of Areas Covered!’ The Role of Online Support Groups in Modern Caring Practices

Belcher, J.
(University of Surrey)

The role of online support groups is a neglected area in medical sociology. Research to date has tended to rely on visible interactions on forums and only a handful of studies have explored their embeddedness within wider health and caring practices. This presentation describes research exploring the role of online peer support groups for parents of people with Rett syndrome, a rare neurological condition associated with complex health problems and profound disability. 186 parents (recruited by letter through a national charity and via online support sites) completed a survey about their use of online support groups. 18 parents were also interviewed in-depth about the role of online support groups in their wider caring practices. The parents least likely to have ever used such groups were aged over 55, had children over sixteen or had received a diagnosis more than nine years ago. Existing access to peer and professional support networks and higher perceived caring expertise were linked to a lower reliance on groups. Among users there was a felt imperative to become or remain an ‘expert carer’. Parental expertise shared online was more valued than medical support in dealing with quotidian care dilemmas and was used as ‘ammunition’ when advocating for investigations, support and equipment from health professionals. However, parents censored their own posts to avoid sanctions and appearing ‘too negative’. This research demonstrates the importance of exploring the embeddedness of online support groups in modern caring practices, illness narratives, the transmission of lay health knowledge and interactions with professionals.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
Stafford 2, CAMS, Main Building

‘If There was Something Wrong I’d Want to Know’: Patients’ Experiences and expectations of Diagnostic Information for Early Stage Chronic Kidney Disease

Bennert, K., Evans, J., Locock, L., Feder, G., Blakeman, T., Simmonds, R., Murray, E., Horwood, J.
(University of Bristol)

Background -NICE guidelines (NICE 2008) incentivise GPs to record and monitor patients who show mild and asymptomatic kidney impairment (Chronic Kidney Disease Stage 1-3) to enable early identification of those at risk of further decline. Previous research has found unease amongst GPs about applying a diagnostic label of CKD to patients regardless of age and other clinical factors, and uncertainty about whether and how to communicate such diagnostic information to patients.

Methods -Patients with early stage CKD were invited from 15 different GP practices located across 8 NHS sites and via adverts on websites, support group publications and social media. Fifty face-to-face interviews were conducted, audio- or video-recorded, transcribed verbatim, imported into NVivo10 and analysed thematically using the constant comparative method.

Results -A majority of participants had no or only partial awareness of their CKD status. Most were concurrently monitored for other co-morbidities and many did not perceive their kidneys as a specific area of health concern.
Paper Abstracts

Analysis is presently ongoing. In this presentation, we focus on the language that patients report health professionals to be using when they share diagnostic information and the differential meanings patients attach to such explanations. We also examine patients’ views about the ‘threshold of seriousness’ at which they expect to be told about kidney impairment. We contextualise our findings in relation to the ‘sociology of diagnosis’ literature.

Conclusions - Our findings provide insights into existing gaps between what health professionals seek to explain and what patients may understand and provide some initial ideas on how kidney monitoring could be made more meaningful from patients’ perspectives.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 2, CAMS, Main Building


Bernstein, C.
(University of Warwick)

This multi-method, qualitative research study explores the experiences of patients living with a neurological disability known as dystonia and healthcare professionals, treating them. These heuristic insights are compared with the understandings of individuals attending dystonia support groups. The principal aim of the research is to explore how medical knowledge and practice co-construct the experiences of patients, healthcare professionals, support group members and representatives.

While dystonia is experienced and negotiated by individuals in the life world, very little research has explored how different kinds of experiential knowledge (Toombs 1993; Abel and Browner 1998) are utilised by lay and health experts to manage and understand dystonia. This is in contrast with previous sociological research which has investigated physical disabilities such as arthritis (Bury 1982; 1988), multiple sclerosis (Robinson 1988; 1990) and Parkinson’s disease (Pinder 1988). An attempt will be made to position the research within the nascent field of the sociology of disability (Thomas 2007) and explore individuals’ experiences and perceptions of dystonia in relation to medicalising processes and actions. This will serve to demonstrate how dystonia is socially constructed.

Utilising a grounded theory approach to analyse observations and interviews with patients, medical staff, local dystonia support group members and representatives, the research will employ a rigorous coding strategy by comparing emerging codes and categories to ‘make sense’ of the dataset (Charmaz 2006). Through a detailed exploration of participants’ accounts, the intention will be to generate a holistic and nuanced perspective of the emotional and social components underlying peoples’ experiences of dystonia.

Friday 12 September 2014 at 09:00 - 09:30
Embodiment and Emotion
White Hall 1, CAMS, Main Building

‘It’s Exactly Like you See on TV When People are Happy to be Having a Baby’: Women’s Experiences of Ultrasound in the Context of Abortion Care

Beynon-Jones, S. M.
(University of York)

An extensive body of feminist scholarship has explored the practice of obstetric ultrasound. This literature has focused on the visualizations of the fetus produced through ultrasound, and emphasizes the ways in which these images effectively ‘erase’ women, and their embodied knowledge, from representations of pregnancy. However, to date, empirical research concerning experiences of ultrasound has centred on the use of this technology during pregnancies that women plan to carry to term. In contrast, comparatively little is known about women’s experiences of ultrasound within the context of abortion care, where the technology is routinely employed as a clinical tool to manage the treatment of pregnant bodies. Drawing on semi-structured interviews (n=23) with women concerning their experiences of abortion in England, this paper begins to address this gap in the literature. It illustrates that, far from foregrounding the significance of fetal images per se, women’s descriptions of their encounters with ultrasound prior to abortion emphasize and expose hegemonic representations of the ‘feeling rules’ of pregnancy. In so doing, the paper suggests, they also offer new ways of narrating ultrasound as an embodied practice.
Disadvantage, Inequality and Narrative Accounts of Living with Obesity

Bissell, P., Peacock, M., Blackburn, J., Smith, C.
(University of Sheffield)

Despite the now well-documented social gradient in obesity, there are relatively few qualitative studies which locate the experiences of living with obesity in the context of social inequality. This paper addresses this omission, drawing on data from biographical interviews with obese adults living in socio-economically disadvantaged parts of northern England. We found that participants sought to position themselves as responsible, autonomous agents when accounting for their weight. We also highlight the often painful biographical work undertaken by participants where food practices and life histories were positioned in opposition to mainstream discourses of personal failure. We suggest these accounts can be viewed as weak forms of protective resistance, against ‘hostile’ anti-obesity discourses.

We also report on participants sometimes visceral but often muted and shaming accounts of the pleasures associated with consuming food. We suggest that whilst these practices can be understood as providing sources of comfort and to regulate mood, they also appeared to have another purpose which was to establish spaces for agency and control in lives shaped by disadvantage. In situating these findings, we refer back to Hilary Graham’s work on smoking and disadvantage and link her work with Lazarrato’s notion of the ‘entrepreneurial self’ under neo-liberalism. We argue that living with obesity in an unequal world not only constructs embodied identities but also shapes capacities for discursive resistance and protection.

Reflexivity and Practice in Home Energy Efficiency Installation: Implications for Health and Wellbeing

Bonnington, O., Green, J.
(London School of Hygiene and Tropical Medicine)

Home energy efficiency installations, such as insulation, double glazing and new heating systems, link to three main policy imperatives. First, the National Cold Weather Plan for England highlights them as key to reducing excess winter mortality/morbidity. Second, their installation is important to climate change mitigation. Third, they are significant in the fight against fuel poverty. But how do these items become domesticated and how can this be increased to achieve these broad policy aims?

Drawing upon qualitative research with households from a range of social backgrounds in three UK areas who have recently installed such items or are thinking about installing them, both reflexivity and social practice theory are used to understand why these items are brought into the home and what effect they have on pathways to health.

Critical comment is provided on the compatibility and utility of a critical realist notion of reflexivity and practice theory. Sociological public health research might currently be seeing a ‘practice turn’, where theoretical focus shifts from the interplay of structure and agency, to a focus on the interweaving of practices and analysis of individual practice assemblages. But where does this leave the role of reflexivity if somewhat de-personalised routine configurations take centre stage? Can practice theory adequately account for social change without affording reflexivity its say? And does it matter that practice elements are quintessential conflations of culture, structure, agency and objects? The paper will conclude with tentative explorations of these vital questions in the light of critical policy imperatives.
Exploring the Impact of Involving Patients and Members of the Public in Health Research

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

The Chief Medical Officer asserts that patient and public involvement (PPI) improves research processes, outputs and implications, but there is limited evidence demonstrating its impact (Brett, Stanizewska, Mockford, et al., 2012). This study aimed to explore the views of patients and members of the public regarding their involvement in research. Here we focus on their discussions about the value and impact of PPI and how this could be assessed.

Thirty-eight people involved in health and medical research participated in a semi-structured interview. They discussed their experiences and views of involvement in research, including how and why they became involved, and the value and impact of their involvement. The interviews were video or audio-recorded, transcribed verbatim and thematically analysed independently by two researchers. The findings were disseminated on the health information website, www.healthtalkonline.org.

Improving healthcare, policy and practice often motivated the participants’ involvement. They were convinced that PPI makes a difference and interested to know what researchers thought. Capturing impact was considered necessary, but participants expressed concern over how the specific effect of PPI could be isolated from its embedded position within the research process. They also questioned what is meant by impact and how it can be demonstrated, and whether any evaluative tools employed would be sufficiently sensitive to capture the often subtle impact of PPI.

In conclusion, it is necessary to evaluate PPI to establish a realistic understanding of its impact. Care should be taken to ensure its intangible, subtle contributions are captured during this process.

'Having a Fall' and Later Life Embodiment amongst Elderly Women in London, UK

Boyles, M.  
(Newcastle University)

Focusing on a small part of Southeast London, I describe how the everyday lives of local elderly women are reshaped by losses of mobility as a result of bodily change. In particular, I attend to their experiences of ‘having a fall’. Drawing from recent work on geographies of mobility and the theories of Tim Ingold, I expand upon the notion of life as movement to ask: what is life like for those whose capacity for easy everyday movement seems to be slipping away? Central to this experience of loss is the complexity of not knowing precisely what or how much is lost, due to the trajectory of one’s illness being unpredictable and unclear. These uncertain losses in mobility profoundly affect the feeling and experience of particular places: both the homes they live in and familiar local streets take on new meanings and implications. Cracked pavements, long distances, stairs, the clutter of furniture and carpets; all complicate the homeliness of everyday settings in the light of one’s changing, ageing body.

“Over Time you Know Who you can Trust to Make Sensible Recommendations and Those who are a Bit Fruit Batty”: Establishing Trust and Legitimacy Online

Brady, E., Sanders, C., Segar, J., Vassilev, I.  
(University of Manchester)

The Internet is increasingly being used a source of health advice and information by patients with long term conditions. In particular, online support groups allow individuals to easily gain access to relevant informational and emotional support from other patients. What is less clear, however, is how patients navigate the information that they encounter via Internet forums, and how they attribute legitimacy, credibility and trust to their peers online. In order to
explore this, semi-structured interviews were conducted with 20 patients with ME/CFS and 21 patients with type 1 and type 2 diabetes. Through thematic and narrative analysis, the strategies that patients use for evaluating and appraising information online have been examined. The findings indicate that discussion groups allow patients to build relationships and establish trust with other forum members, and to assess them as information providers. As a result, an individual’s background, views, opinions and perspectives were often seen as similarly important as the advice that they were presenting, and patients themselves were subjected to similar scrutiny and evaluation. This was particularly pertinent for patients with diabetes, as the nature of their condition meant that they often utilised the information and advice that they encountered online into their day-to-day lives. This ongoing verification afforded forum members the opportunity to establish credibility online. The findings indicate that patients engage in a dynamic process of evaluating information and advice online, drawing on the available evidence and assessing it in relation to their own health practices and chronic illness self-management.

**Thursday 11 September 2014 at 15:45 - 16:15**

**Health Service Delivery**

**White Hall 2, CAMS, Main Building**

**Why is Infection Control so Hard? A Qualitative Study**

*Brewster, L., Dixon-Woods, M., Ahmad, R., Holmes, A.*

*(University of Leicester)*

Healthcare associated infections remain a stubborn problem, despite efforts invested in infection prevention and control (IPC). Frontline healthcare staff remain responsible for IPC practice, but efforts to implement IPC interventions show inconsistent results. Little is understood about the factors that affect whether staff are able to implement good IPC practice and follow guidelines. Often individual staff are blamed and seen as deviant when they do not follow guidelines; we argue here that this explanation does not take into account organisational and cultural factors that affect compliance.

We conducted a qualitative study of two UK hospital trusts, interviewing 37 frontline and four executive staff about current IPC practice and perceptions of IPC. Analysis was conducted using the constant comparison method and informed by a recent systematic review of effective IPC strategies.

Staff described the problems encountered in implementing IPC interventions; they discussed a variety of competing priorities, which affected their ability to follow procedures. Local ward-level contexts were central to considering the ease of implementing an intervention. The wider context in which staff were trying to implement IPC interventions including organisational priorities and culture, resources, and professional boundaries all influenced their effectiveness. Staff also considered what an intervention needed to ensure its adoption in practice. The research has implications for current healthcare policy on IPC implementation, and will make a contribution to practice for healthcare professionals.

**Friday 12 September 2014 at 11:20 - 11:25**

**STS**

**G63, Main Building**

**Neurobiology, Health and Social Policy, and the Circulation of ‘Responsibility’**

*Broer, T., Pickersgill, M.*

*(University of Edinburgh)*

Concepts and findings ‘translated’ from neuroscientific research have begun to find their ways into UK health and social policy discourse. Neurobiological registers are employed to promote ‘active’ citizenship, with a concomitant responsibilisation of specific citizens. For example, parents are urged to create a good ‘home environment’ so that the still plastic brains of their offspring can develop in the best ways possible, and older adults are encouraged to stay physically and mentally fit as ‘what is good for your heart is good for your brain’. Especially in the former context, the ultimate optimisation of the social and economic contribution of (proto)citizens is framed as having neurobiological prerequisites. In this paper, we focus on an analysis of health and social policy documentation regarding older adults, adolescence, and (in particular) the early years, investigating if and how these policies draw on the neurosciences. We ask: what kinds of citizens are performed through policy documents, and what (self-)care practices are enabled and disabled? We conceive of responsibility as a discourse that ebbs and flows, rather than as a stable kind that moves linearly and uniformly from (for example) state to citizenry; hence, we consider the different kinds of ‘responsibility’ that are evident across policy domains. Our aim is to understand what the productive effects are of the political enrolment of neuroscience, whilst nevertheless remaining sensitive to the normative implications of this. We
thus contribute to medical sociology debates around the translation of biomedical knowledge and the production of care practices.

Thursday 11 September 2014 at 17:30 - 18:00
Professions
White Hall 3, CAMS, Main Building

Complementary and Alternative Medicine Degrees and the Limits of Professional Autonomy

Brosnan, C.
(University of Newcastle)

In 2012, debate erupted in the Australian media over the teaching of complementary and alternative medicine (CAM) in universities, echoing an earlier UK campaign led by biomedical lobbyists. In sociology, specialised knowledge and university qualifications have been identified as requirements of professional autonomy, and the emergence of CAM university degrees is taken as evidence of CAM's increased professional status and potential threat to medical dominance. However, the actual constitution of CAM within the university has received little analysis. This is significant, because what gets taught is likely to reveal more about CAM's professional autonomy than the fact that CAM degrees are available. Indeed, the recent debates suggest that university degrees have become central arenas in which struggles for autonomy play out. This paper conceptualises degree program curricula as a lens through which to evaluate the relative autonomy of university-based CAM modalities. The contents of chiropractic, osteopathy and traditional Chinese medicine degree curricula in Australia and the UK are analysed qualitatively and quantitatively, and interrogated for what they reveal about CAM's success at retaining specialised knowledge within the university, and the extent to which other institutions have been able to influence its knowledge base. Findings suggest that CAM's autonomy within the university is limited, and it is argued that this reflects not only relations between the health professions, but shifts taking place in higher education. In light of the findings, the need to reconsider longstanding theories of the relationship between higher education and professional status is discussed.

Friday 12 September 2014 at 09:35 - 10:05
Politics of Health
Stafford 2, CAMS, Main Building

Introducing the ‘Power Cube’ Conceptual Framework to Mental Health Service-user Involvement: Explicating the Inherent Tensions, Inequities and Power Dynamics

Brosnan, L.
(University of Limerick)

Service-user involvement (SUI) in mental-health services (MHS) is endorsed by top MHS management as a reform strategy. For service-users, however, SUI is linked to civil and human rights, originating from contestations of current practice in MHS, but is often confined to a consideration of improving implementation of existing services. My doctoral research utilised survivor standpoint epistemology in a case study of SUI occurring with one Irish multidisciplinary team and eight local involved service-users. The local participants were interviewed about their experience of SUI and this understanding was triangulated by the perspectives of twelve national user/survivor movement activists. The overarching theme for service-user participants is the inherent tension between contestation of the current MHS, collaboration in opportunities for reform and risks of co-option, given the power inequities in their positioning vis-à-vis the MHS. An additional tension for movement activists is the appropriateness of SUI as a movement strategy. The overarching theme among the service-provider participants is the tension between collaboration with service-users to reform service delivery, and various levels of awareness of real risks for service-users of co-option and tokenistic involvement.

These key findings are analysed using Gaventa’s (2006) power cube framework, based on the Rubik cube. The different planes of the cube represent forms (visible, hidden and invisible), spaces (closed, invited and created) and levels (strategic, operational and individual) of power. These different aspects of power constraining SUI are often tacitly known but difficult for participants to unpack without an explanatory model. Hence the potential of the Power-Cube as a useful social movement tool to conceptualise the politics of SUI.
Politics of Health
Stafford 2, CAMS, Main Building

Migrants, Media and Health: Moral Panics and the Impact of Immigration on Health and Health Resources

Brown, S., Warren, J.
(Durham University)

The Immigration Bill 2013 set out to “stop migrants using public services to which they are not entitled, reduce the pull factors which encourage people to come to the UK and make it easier to remove people who should not be here” according to Immigration Minister Mark Harper.

Prior to the Bill, debate had been driven by stories about the cost to the NHS of migrants, in particular those from newer EU states such as Romania and Bulgaria. However the issue of the impact upon the NHS of “health tourism” has also re-emerged.

This paper will explore how the concept of moral panic via analysis of media discourses can help us to better understand two key aspects of the debate about health migrants; firstly, regarding the true impact on health resources, what is the extent to which migrants cost and contribute to health care in the UK? Secondly is there an impact on disease incidence? Fears of disease being imported and public health concerns about controlling disease have long figured in debates about immigration.

We argue that there is a recurrent moral panic surrounding immigration which is linked with pervasive stereotypes of migrants and ideological arguments about entitlement. This is of concern as it has a direct impact on migrants and how they are perceived, a perception which appears currently to be both disproportionate and inaccurate. This perception is significant as it has potential consequences for the planning and delivery of health services to migrant groups.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 1, CAMS, Main Building

‘I Want to Dance at my Granddaughter’s Wedding’: Attitudes to Ageing in a Scottish Cohort Study

Carpentieri, J. D., Elliott, J.
(University of London)

The Scotland 6-Day Study follows a cohort of individuals born in Scotland in 1936. More than 1000 members of this cohort were interviewed and tested regularly between the ages of 11 and 27, primarily to understand the associations between cognitive ability, family background, and educational and employment outcomes in adolescence and early adulthood. The study then went into abeyance. Now in their late 70s, 174 surviving members of the cohort have been re-contacted and have re-joined the study, which has been re-launched as a multidisciplinary investigation.

The psychologists now working on the 6-Day Study are focusing on ageing and its impacts, in the form of physical and cognitive decline. As sociologists, however, our own focus is cohort members’ experiences of and attitudes to ageing. For example, what is important to them in their late 70s, and why? How have they adapted in order to maximise happiness and wellbeing as they have aged? What are their hopes for the future, and their worries? Within the context of the 6-Day-Study’s extensive past and current collections of quantitative data, we seek to elicit narratives on these and other questions, and to link our qualitative investigation to our colleagues’ quantitative work.

This presentation outlines the methodological challenges we have encountered in conducting narrative inquiries with this cohort, and the strategies we have utilised in order to overcome those challenges. In addition to reporting on these strategies, we provide preliminary analyses from the first wave of interviews.
Paper Abstracts

Friday 12 September 2014 at 09:35 - 10:05
STS
G63, Main Building

‘Saving Lives and Stopping Rashes’: Judging the Worth of Research in Relation to Secondary use of Medical Information

Carter, P., Parker, M., Brown, L., Dixon-Woods, M.
(University of Leicester)

Medical research is traditionally highly valued, with many people willing to participate in trials and /or allow access to their medical record.

We report findings from a qualitative interview study (n= 76) that explored the individual views of patients, health care professionals and researchers on the secondary use of medical records for research. Participants were given scenarios representing a range of studies and asked for their views on whether the benefits of the research warranted exemption from requirements for informed consent. Participants were also asked to reflect on opt-in and opt-out models of consent.

Participants highlighted the importance of confidentiality and discussed who is entitled to see what level of detailed information. Views on the degree of effort required to obtain consent varied. When evaluating studies, scientific merit, but also ethico-political views and personal experience informed responses. Cancer (‘The Big C’) was regarded as a worthwhile research topic; it was contrasted with ‘market research’, ‘poxy’ research and research on trivial conditions such as ‘stopping rashes’. The credentials of researchers were important to all participants. Some healthcare professionals described instances where they had acted as gatekeepers and prevented researchers from accessing medical records. Across all participants, a narrative of faith in the benefits of science contrasted with a critical narrative.

These findings indicate how judgements about research are weighed in relation to secondary use of medical records and are especially pertinent when the ‘health and wealth agenda’ promotes the benefits of data sharing for both medical advance and economic growth.

Thursday 11 September 2014 at 15:10 - 15:40
Health Care Organisation
Stafford 1, CAMS, Main Building

The Role of Professional Identity in Research Capacity Building

Carter, C., Moreira, T.
(Durham University)

Existing policy advocates the development of research capacity within the NHS to facilitate research and create the evidence on which to base best practice. Existing empirical work primarily focuses on the design and implementation of standalone research capacity building measures within institutions, and the quantitative evaluations of these endeavours. Subsequently, there is a lack of sociological research attempting to account for the impact of the construction and maintenance of professional identity on research involvement. Our study took place in a NHS Foundation Trust during a drive to substantially increase its research capacity. A period of ethnography with the Trust’s Research and Development team and interviews with clinical staff (N=25), focusing on experiences and perceptions of research involvement within the organisation, were conducted. Systematic coding of the data produced reveals that a clinician’s construction of their professional identity significantly shapes their understanding of what constitutes ‘research’, concurrently influencing their level of research involvement and structuring the type of research to which they will contribute. We explore this issue through the framework of Social Worlds/Arenas theory, and conclude that any attempts to develop research capacity need to take into consideration the cultural and symbolic meaning of research as mediated by health care practitioners. The work utilizes and develops ideas well established within the tradition of medical sociology to conceptualise and investigate this current issue in contemporary healthcare.
Obesity and Overweight in Japan

Castro-Vazquez, G.  
(Nanyang Technological University)

Grounded on symbolic interactionism, this paper aims to shed light on the culture and structural dimension underpinning public policies against overweight and obesity in Japan. Race, ethnicity and gender are suggested as three axes in the investigation. Policies draw on racial differences to contest the validity of BMI (Body Mass Index), which appears grounded on ‘Western’ standards. Instead, Metabolic Syndrome (Metabo) is used to diagnose obesity and overweight. Metabo’s ‘symptoms’ are having an abdominal circumference of 85 and 90 centimetres or longer, for men and women, respectively, and presenting at least two of the following three items: blood lipid, blood pressure and blood glucose. Available official data suggest that aged between 40 and 74, one out of two men and one out of five women suffer from Metabo. The ethnic component implies the idea that Japanesness and obesity are largely incompatible because Japanese food is a good example of ‘healthy’ food in the world. The construct of ‘Japanese food’ has been a critical component in the construction of a national identity. However, such identity is problematic as it tends to deny diversity and dynamism in current eating habits of Japanese people. Finally, the gender component entails the archetypal idea of the salaryman, which has been identified as a form of hegemonic masculinity in the country. A salaryman is most likely a white-collar worker who is prone to obesity and overweight because of his sedentary life. This has made it issues of obesity and overweight of Japanese women largely invisible.

Blurring Boundaries: Pharmacy as a Mediated Space of Healthcare and Wellbeing

Chamberlain, K., McGuigan, K.  
(Massey University)

Pharmacies are unique sites of healthcare and complex spaces of consumption, where the products and services of biomedicine intermix with the products and services of alternative medicine and other forms of commercialised wellbeing offered for sale. Pharmacies typically offer at least five intermingled services: dispensing restricted and regulated medicines; selling over-the-counter medicines, selling alternative medicines (homeopathic and ‘natural’ remedies); selling health-related products (dietary supplements, blood pressure monitors); and retailing other products (beauty products, gifts, photo-printing). This variety of function gives rise to boundary tensions between services and products and hybridizing solutions to such tensions.

This project examined the pharmacy as a site of wellbeing and commercial practice by examining the functions of pharmacy spaces and the visual representations of services and products offered in a variety of pharmacy types (franchise branded and privately-owned, large and small, inner-city and suburb-based). Data collection involved observations, mapping, photography and document collection, analysed to determine how pharmacies spaces are structured and how pharmacies represent themselves and their products to consumers (in branding, window displays, interior and exterior signage, product displays and product brochures).

We discuss how differing spatial organisation demarcates the marketing of pharmacy products and services, and how these are realigned and elided in mediated representations of the pharmacy. We discuss how these representations promote the hybridisation of allopathic and alternative medicines, and the medicalisation and pharmaceuticalisation of other services and products offered by pharmacies. We conclude that, although pharmacies contain therapeutic spaces of care, this is intensely complicated by interleaved practices of commercialisation and consumerism.
**Paper Abstracts**

**Thursday 11 September 2014 at 10:15 - 10:45**  
Patient-Professional Interaction  
Stafford 1, CAMS, Main Building

**Increasing Doctor-Patient Tension in China: Institution and Interaction**

*Chan, C. S.*  
(University of Hong Kong)

On March 23, 2012, a medical resident in Harbin, north China, was stabbed to death by an angry young patient. This was, unfortunately, not an isolated incident. The statistics released by the Ministry of Health in China indicates that violent incidents resulted from medical disputes increased by 70 percent from 2006 to 2010. A survey conducted among patients in 30 hospitals in east China in early 2013 reveals that only 10 percent of the respondents said they trusted doctors. How do we explain patients' escalating dissatisfaction with doctors' services and the increasing tension between doctors and patients? In this paper, I argue that there are multiple factors that contribute to the poor doctor-patient relation, and among which mismatch and distrust are the paramount factors. Mismatch refers to two levels of discrepancy. First, it refers to the discrepancy between what the public expects from ‘public hospitals’ and what the public experiences in these hospitals. This discrepancy is constituted by state policies and institutional factors. Second, mismatch also refers to the discrepancy between doctors’ expectation and patients’ expectation. Their discrepancy is produced by doctors’ increased exposure to the medical world in Hong Kong in conjunction with the general public's increased awareness of their rights in a society with conspicuous social inequalities. The two levels of mismatch result in increasing distrust between doctors and patients that shapes their interaction. A vicious circle is produced by the mutual distrust between doctors and patients in their interaction.

**Wednesday 10 September 2014 at 13:55 - 14:25**  
Embodiment and Emotion  
Stafford 2, CAMS, Main Building

**Living with a Urinary Catheter: The Use of Symbolic Interactionism to Understanding Embodiment**

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

Our aim was to explore the contribution made by theorists such as Cooley (1902) and Goffman (1963) to the understanding of embodiment in people who rely on a catheter to empty their bladder. Forty four people took part in a narrative interview. Most of our diverse sample had an indwelling catheter but some used intermittent self catheterisation. Four were carers. Narrative interviews were video or audio-recorded, transcribed and analysed thematically. Results showed that embarrassment was an issue for some people and the term ‘dehumanising’ was used to describe living with a catheter. Some tried to conceal their bag of urine so Goffman’s insights on how people try to minimize unwanted visibility were useful. Disability as well as the catheter affected self-esteem and feelings of masculinity or femininity. However, some said that having a catheter had not affected self-image. They seemed happy to talk to others about their catheter when asked. We interviewed some who campaigned to raise awareness of issues they faced. In conclusion, symbolic interactionism, and in particular Cooley’s concept of the ‘looking-glass self’, and his idea that “the imagination of how we appear to others is a controlling force in all normal minds” helped us understand our data. Very few people recalled instances of negative comments actually being made by someone else. Stigma appeared to be ‘felt’ rather than ‘enacted’. People seemed to imagine that others would judge their appearance in a negative manner.

On your abstract form you asked if there was a day when we couldn’t present the paper. Due to family problems IF my abstract is accepted I shall ONLY BE able to present the paper on the Wednesday. Sadly I can only attend the conference that day. I should be grateful if you could add that information to my form if the abstract is accepted.

**Thursday 11 September 2014 at 08:30 - 09:00**  
Patient-Professional Interaction  
B. Kendrick, Main Building

**Medical Tourism: Small-scale Healthcare Providers**

*Cheung, O., Holliday, R., Jones, M., Bell, D., Probyn, E.*

In the literature of medical tourism, transnational hospital chains and international hospitals in host countries have largely been discussed (Bochaton & Lefebvre 2009; Connell 2011; Whittaker 2013). The rapid growth of transnational
hospital chains and the significance of main medical tourism hospitals have drawn wide attention in academic work and studies. Yet, the picture of the industry cannot be completed without accounting little players in the industry. Aiming to provide an overview of small-scale healthcare providers, this paper examines the role of them in medical tourism, their business operation and potential problems with regulation. While marketing strategies and acquiring accreditations make main hospitals stand out from the list of medical tourism facilities (Ormond 2013), for a small-scale healthcare provider, running a business in medical tourism is a different story. This paper explores what marketing strategies small-scale providers use to attract medical travellers. Most of these providers often work closely with medical tourism agencies to promote their services to potential clients. Some of the surgeons however find that they are in an adversarial relationship with facilitators (Snyder et al. 2011). The interaction among patients, surgeons and facilitators is examined. The final part of this paper explores issues such as provision of information, informed patient choice, the ethics of business practices and the regulation of the industry.

Friday 12 September 2014 at 09:35 - 10:05
Ethics
White Hall 2, CAMS, Main Building

Ethics in Theory and Pseudo-ethics in Practice
Chew, S., Carter, P., Sutton, E.
(University of Leicester)

There are ongoing debates regarding whether systems of ethical scrutiny of qualitative health research are appropriate and effective. To contribute to these debates, we give an account of our experiences as non-clinical researchers expected to comply with research governance requirements. Our case study examples demonstrate mismatches between imposed institutional mandates and qualitative health research methods that result in a practice we term ‘pseudo-ethics’.

Regulatory regimes are designed as mechanisms and safeguards that ensure ethical research practice; thereby reducing potential harm to actors in the research process. However, the scientific paradigms embedded in these requirements appear to privilege a hypothetico-deductive, bio-medical form of research. Consequently, inductive and exploratory qualitative research is routinely judged against an inappropriate standard. More worryingly, these requirements can seem little more than institutional impression management devices. This mis-match between regulation and research practice fails to regulate, or directly address, the ethical and practical issues that pertain to qualitative research. Therefore, their function as legitimate safeguards is questionable. Certain regulatory processes resemble allowing a person to drive an HGV on the grounds that they have a pilot’s licence. Both may involve a journey to similar destinations, but the skills needed to get there are markedly different. Given this, we ask if harm does occur, who should be held to account? Inappropriate regulatory practices such as Good Clinical Practice may engender wastage of public money. We conclude that the assumptions underpinning the practice and regulation of non-clinical, qualitative health service research should be scrutinised and governance practices revised accordingly.

Wednesday 10 September 2014 at 13:20 - 13:50
Embodiment and Emotion
Stafford 2, CAMS, Main Building

‘She was Becoming too Healthy and it was Just Becoming Dangerous’: Health Affects, Body Work and Embodiment
Coffey, J.
(University of Newcastle)

This paper builds on recent theoretical developments in sociological and feminist theory to explore the embodied dimensions of ‘health’. Combining a Deleuzian theorisation of bodies and the concepts of affect and becoming, this paper draws on qualitative interview data with young people about their body work practices to unpack the complex ways ‘health’ is conceptualised and embodied. Health was described in interviews as a set of practices, activities or performances that involve the body. Health is commonly understood to entail a state of being that can be attained through a series of practices such as diet and exercise. However, as participants describe, the experience of ‘health’ is not the straightforward result of undertaking ‘healthy’ practices, and these practices require negotiation so as not to slip over and become ‘dangerous’ such as through under-eating or over-exercising. The paper argues that understanding health and embodiment as states of becoming (rather than being) can assist us to understand the complex and contradictory ways health is understood and lived. This approach can also assist in problematising links between health and ‘healthy’ practices, and health and appearance.
Protecting Patients and Upholding Trust Post-Mid Staffs: Developing a New Analytical Methodology for Exploring Epistemic Barriers to the ‘Raising Of Concerns’ by Healthcare Students

Cox, N. (Manchester Metropolitan University)

This paper presents the methodological work-up and early analysis of a pilot qualitative study that is currently in progress (Spring 2014).

BACKGROUND: The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis 2013) highlighted failures in the delivery of compassionate care. Recent research by the Care Quality Commission (2013) has shown that care staff may be reluctant to report the mistreatment of patients. Moreover, it is recognised that healthcare trainees, such as student nurses, have a vital role to play in the reporting of mistreatment (Francis 2013).

AIM: This in-progress pilot study aims to explore the epistemic injustices that may be implicated when seeking testimonies from nursing students wishing to ‘raise concerns’ about healthcare services and, in doing this, support the advancement of methodological and analytical practice in this context.

METHODS: Individual semi-structured interviews and focus groups are currently being used, however the indicative research proposal and institutional ethics application speculated a range of possible qualitative methods, to be selected pragmatically during fieldwork.

PARTICIPANTS: Ongoing recruitment, N=10 undergraduate nursing students currently participating.

ANALYSIS: Methodological/analytical development is a principal aim of this pilot study, although a candidate analytic methodology is Foucauldian discourse analysis. The researcher also aims to apply the emerging concept of epistemic injustice (Fricker 2007) to a new context (nursing/healthcare) and investigate its utility in respect of the ‘reporting of concerns’.

FINDINGS: The aims of the paper are principally methodological/theoretical; however, there will be scope to discuss preliminary findings as they arise from the fieldwork.

Managing Children’s Health in a Cold, Damp Home: Fuel Poverty and Childhood Asthma


Increasing rates of fuel poverty are having a worrying impact on excess winter mortality and morbidity. Children living in cold homes experience worse outcomes, for example more hospital admissions, worse asthma, worse mental health and poor infant weight gain. Little is known of the experience of families at risk of fuel poverty and how management of heating, bills and housing condition affects their children’s health.

The Warm Well Families research is an in-depth qualitative exploration of factors influencing the decisions and behaviour of vulnerable households with children regarding keeping well and warm at home. The study also identified the services and support they can access. Concentrating on households containing children with asthma, individual and group interviews were undertaken with 109 parents, children, young people and professional staff working with families. Hourly temperature measurements were taken in children’s bedrooms and household living spaces over a two week period. Framework analysis techniques were used.

This paper focuses on the competing priorities, preferences and needs in households of different ages, genders and health conditions in their negotiation of their thermal environment. These competing priorities have to be negotiated within the household as well as with the demands health and housing professionals advising the family on the health of the child and/or house. This is far more complex than the perceived ‘heat or eat’ scenario for fuel poor families. The paper concludes by showing how the findings on factors influencing heating management can be used to design interventions and policies to reduce the impact of cold, damp homes on children’s health.
‘Let Food be thy Medicine, but the Supermarket be thy Poison’: Ethical Dimensions in Non-expert Experiences of Dietary Health and Wellbeing

Cronin, J.
(Lancaster University)

For many consumers the ‘medicalization’ of food championed by nutrition experts and epidemiological researchers throughout late modern market-society no longer seems an adequate means of understanding dietary health or defining how to eat well. Important also in this context is the emergence of ‘communities of reflexive doubt’ who encourage and promote strategies that deviate drastically from the orthodox health risk-management guidelines offered by institutionally authorised experts in medicine and the marketplace. Drawing on theories of consumer empowerment and ‘people knowledge’, this paper reports from a series of ethnographic interviews conducted with 14 college-aged individuals to explore their reasons for embracing a primarily ethical, rather than medical, approach to food consumption. The findings demonstrate how in response to an alienating barrage of heavily promoted, industrialised – and, sometimes, medicalised – market offerings, young consumers increasingly turn to personal experiences, shared opinions and ‘neo-tradition’ as strategies for evaluating the ‘good’ nature of food. Furthermore, the study shows how these evaluations are anchored to broader market and environmental knowledge, and the identities and social relations that both guide and are derived from this knowledge. The findings indicate that young consumers are as much concerned with fighting the commodification of food and projecting their efforts to do so in a favourable image, as they are with fighting illness through food. By reinforcing that the market and health are intertwined constructs, the discussion contributes to the understanding that health identities may be rooted in consumption-driven identities permeated in everyday encounters with the market and social others.

‘It was an Amazing Team Thing, it Really did Feel Like we Were All in it Together’: South African Couples Narratives of Homebirth

Daniels, N.
(University of Cape Town)

This ‘work in progress’ paper presents findings from my Master’s thesis, drawing on semi-structured narrative interviews with five South African couples. While it has long since been established that women are unwilling to commit to homebirth without their partner’s support, couple’s relational perspectives have largely been ignored. Literature on gender and homebirth more often accounts for women, and in the few couple studies available, gender is not a key component. This research thus aimed to explore jointly and separately, the relational negotiations of couples who plan and have homebirths. Why do couples have homebirths; how do they experience the birth; and how do gender scripts mark and inform the co-construction of homebirth narratives? Acceptance of the psychosocial model of birth required an analytical approach, which privileges relationality. Use of ‘the listening guide’ operationalizes a form of narrative inquiry that traces intersecting realms of experience. These realms are negotiated between couples, their family networks, caregivers and practitioners, social positioning, personal histories and medico-legal frameworks. Broad socio-cultural motivations complicate the way these negotiations impact on couple’s decision-making before, during and after choosing homebirth. Tentative findings suggest homebirths may be undertaken as part of a wider parenting project where togetherness or disparateness seems to make or break connections between emergent mothering and fathering identities. Insights gained through longitudinal data suggest that as a joint undertaking, homebirths could have the potential to bind couples together more strongly or become an agent of separation. By tracing the interpretive work that couples do when telling birth stories, the symbolic value of the couple unit becomes explicit.
(Bio)medicalized Matching: Exploring Donor-recipient Selection in UK Fertility Clinics

Davda, P.
(Royal Holloway, University of London)

Despite being an integral stage in the fertility treatment of patients using donor gametes, the stage of donor-recipient matching in the UK has generally been taken for granted and under-researched. In the UK, matching is clinic-mediated, whereby a particular donor is allocated to a particular recipient by medical staff based on their physical and social characteristics. Matching thus provides both a method of resource allocation for the scarce commodity of donor gametes and is simultaneously the stage at which the potential genetic parent of an infertile couples’ child will be chosen. Whilst some attention has recently been given to donor-recipient matching by theorists of biomedicalization, commercialization and the family, there remains a paucity of literature and understanding as to how and why specific donors and recipients are selected and matched in practice. Little is known about the process of matching, the contextual factors which shape it or about the views and experiences of patients and clinicians which inform it. Existing empirical research has predominantly been undertaken outside of the UK context and has focused on recipients’ isolated experiences of selecting their own donor (non-clinic-mediated matching). In this presentation preliminary findings from a doctoral study of clinic-mediated matching in 2 private fertility clinics in England will be reported. Based on ethnographic observations and individual patient and clinician interviews, the processes and assumptions underlying clinic-mediated matching will be explored and the extent to which matching is a medicalized vs. biomedicalized process will be discussed.

Narratives of Culpabilities: Men and HIV in South Africa

De Wet, K. L., Diphokoje, B. C.
(University of the Free State)

Reflections on the manifold issues pertaining to HIV in South Africa are often essentialised in gendered terms: most notably depicting women as hapless victims and “good patients” and men as irresponsible and blameworthy agents of infection and “bad patients” (Natrass 2008). Even more in-depth accounts have a moral undertone, depicting how the illness and concomitant treatment sometimes leads to the “construction of responsible masculinities” (Skovdal et al. 2011) or to the exercise of “responsible manhood” (Mfecane 2012). South Africa is still a very patriarchal society – which adds to upholding “hegemonic” masculine views: both on a personal level (that of patients and health care providers) as well as on a public level (in academic texts).

A narrative of men’s experiences of living with HIV and being on lifelong antiretroviral treatment will supposedly provide a more nuanced version of these stereotypes, but these narratives are problematic given the “socialisation of HIV” dominant in South Africa. Accessing publicly funded treatment requires strict adherence to drug readiness treatment sessions and regular follow-up sessions at health care facilities to hand out treatment and to monitor progress. On the one hand, this intense medicalisation of HIV creates a normative discourse internalised by patients on antiretroviral treatment. On the other hand, the proliferation of research on HIV-positive men (and women) further entrenches these gendered stereotypes.

Through these troubled narratives with HIV-positive men, we intend to break with these stereotypes and will try to present these men’s narratives in a more complex manner.
Stigma in Inflammatory Bowel Disease: A Hermeneutic Phenomenological Study

Dibley, L.
(King’s College, London)

A stigma is ‘an attribute that is deeply discrediting’, often contravening social norms, and perceived by others as being undesirable. Inflammatory Bowel Disease (IBD) is a chronic illness characterised by symptoms of diarrhoea, urgency, and vomiting occurring in a relapsing and remitting pattern. Regular or temporary loss of bowel control is a prominent feature of disease and may lead to stigmatisation through infringement of social hygiene rules. Although stigma in IBD has been measured in quantitative studies, there is a dearth of qualitative evidence. This Heideggerian (interpretive) phenomenological study explored the lived experience of IBD-related stigma.

Using purposive stratified sampling, 40 members of a national IBD charity were recruited. Participants did or did not experience FI, and were or were not stigmatised. Unstructured individual interviews (digitally recorded and professionally transcribed) took place in consenting participants’ homes between May and November 2012. Data was analysed using Diekelmann’s hermeneutic method.

Seven relational themes (present in some transcripts) and three constitutive patterns (present in all transcripts) emerged. IBD-related stigma is a complex experience, mostly of anticipated or perceived stigma, which changes according to social setting. Stigma resistance is most likely in those with a positive sense of control, a support network which suits their needs, and mastery over life and illness.

IBD-related stigma occurs regardless of continence status, negatively affecting the chronic illness experience. Time, experience, and suitable support enhance stigma resilience. Further research is needed to develop stigma-reduction strategies that will improve quality of life for this patient group.

The Gender Earnings Gap in the Nursing Labor Market: A Case of Selection?

Dietrich, H., Muench, U.
(Institute for Employment Research)

Mean hourly wage for male nurses was 17.0 Euro and 15.3 Euro (deflated wage measures over time, basis 2012) for female nurses. Estimating a Mincer wage regression by regressing an increasing set of controls on the log of hourly wage reduces the female male earnings gap slightly to around 10%. The final model adjusts for demographic characteristics (age, education, marital and children status, living with spouse, being foreign), employment characteristics (firm size, firm tenure, job changes, position, tasks, region), and skill characteristics (problem solving expertise, competence in decision making and management). To test whether this earnings gap stays robust or changes when accounting for selection of individuals into occupations, we estimate a two-step Heckman selection model including individuals trained as nurses but no longer working in nursing. That indicates, gender specific selectivity within the group of active nurses. Oaxaca decompositions are employed to identify the wage differences between active nurses and former nurses.

We use the BIBB/BAuA-Employment Surveys 2006 and 2012, representative surveys on qualification and working conditions of the German active labor force. Our analysis includes 848 fulltime nurses from the 2006 and 2012 surveys.

This study provides evidence for gender specific selectivity. But even after selection into work setting characteristics and accounting for demographic and human capital attributes, a female-male earnings gap exists in nursing, a predominantly female occupation. Given the large numbers of women in nursing, inequality in wages can lead to disparities in living standards between genders. Beyond equity and fairness, it may also directly affect patient care through misallocation of resources.
Risk

What is Risk? Complexity and Uncertainty of Maternally Inherited Disease and its Technologies

Dimond, R.
(Cardiff University)

In this presentation I draw on interviews with patients with mitochondria disease and their partners to explore how understandings of risk influence reproductive decisions. Mitochondrial disease can be a complex, uncertain and primarily late onset condition, with limited options for preventing children inheriting the disease through the maternal line. Mitochondria donation is a novel IVF technique, but as a ‘germ line’ technique it has attracted extensive interest and concern, and is currently prohibited under UK law. Within the IVF process, mitochondrial DNA from a ‘donor egg’ would become part of the child’s genetic inheritance, alongside maternal and paternal DNA. Underlying much of the public debate is an assumption that these techniques can ‘stop children suffering’ and ‘eradicate the disease from families’. However, response to reproductive risk is complex, and can be highly contingent on the embodied experience of health and illness. How and whether women will opt for invasive reproductive technologies depends on the assessment of complex risk information about themselves and their families. Mitochondrial disease and its technologies evoke key sociological questions about the construction of risk, what kinds of behaviours are defined as ‘risky’ and how risk is assessed and managed. Little is known about how women with mitochondrial disease and their partners make reproductive decisions and how they perceive or make use of the reproductive technologies that are currently available. This presentation contributes to the debate by highlighting differences between public investment in the hope of new technologies and the private accounts of living with complex disease.

Experiences of Health and Illness

Wednesday 10 September 2014 at 12:45 - 13:15

Using Liminality, Stigma and Taboo to understand Mothers’ Experiences of Long-term Breastfeeding

Dowling, S.
(University of the West of England, Bristol)

Few babies in the UK are breastfed at 6 months; an unknown number continue to breastfeed beyond this time even though this is the recommendation of the World Health Organisation. Women who breastfeed older babies and children in our culture do so knowing that they are unusual. Little is known about their experiences although it is likely that many women who breastfeed long-term do so in secret, with profound implications for both mother and child. Cultural beliefs relating to breastfeeding (and to its appropriate duration), and to the use and function of breasts, contribute both to the ways in which long-term breastfeeding is seen and to the nature of the experience.

This presentation will draw on qualitative work using ethnographic methods which explored women’s experiences of breastfeeding long-term. Findings from a group of strong-willed and determined women show that breastfeeding long-term is a rewarding but challenging commitment, often undertaken in the absence of societal support. Theoretical concepts of liminality, stigma and taboo are explored and used as a lens through which to view women’s experiences. Previous work using these concepts to think about breastfeeding is drawn on and developed to further understanding of the experiences of long-term breastfeeding. The presentation will be illustrated with examples from the data and discussion of key themes arising from the analysis.

A Qualitative Research Study to Explore the Patients’ Experience of Returning Home Following Allogeneic Stem Cell Transplantation

Dunn, L., Arber, A., Gallagher, A.
(University of Surrey)

The emotional impact of cancer is well recognised and current health policy supports a focus on cancer survivorship. This study explores the experiences of 15 participants aged between 22-68 years who were treated with allogeneic...
stem cell transplantation (cells from a donor) for haematological cancer. The focus of the study was on participants’ experiences of returning home following a stem cell transplant. Participants were recruited from two major treatment centres and the study followed an interpretive phenomenological methodology using semi-structured interviews. Data were then analysed using interpretive phenomenological methodology to gain insights into participants lived experience following the transplant including their personal and social experience of the world following treatment. Burry’s (1982) concept of illness as a biographical disruption and the notion of liminality (Turner 1969) has significant resonance with the participants’ narratives. Many participants report a non linear recovery characterised by setbacks and uncertainty including facing their own mortality whilst maintaining hope, a positive spirit and a desire to help others. Some participants face long term changes in bodily function such as fatigue, the enduring risk of infection and adverse affects on the body organs such as skin, liver, lungs, kidneys, gastro-intestinal tract, the genital system, eyes and joints as a result of graft versus host disease (when donor cells attack those of the recipient). Social challenges include the renegotiation of relationships within the family, resuming social activities, education, employment and financial security.

Thursday 11 September 2014 at 15:10 - 15:40
Experiences of Health and Illness
- Stream Sponsored by Health Talk Online -
White Hall 1, CAMS, Main Building

Expectations and Experiences of Recovery in the Context of Leukaemia
Earth, S., Thomas, H., Slaney, J.
(University of Surrey)

It is well recognised that the completion of an acute phase of cancer treatment may signal only a partial exiting from the sick role. The concepts of remission - whether complete (the presence of disease is no longer detectable although recurrence is possible) or partial (the disease is stable or in abeyance but signs of disease remain) - and of survivorship (living with and beyond cancer) reflect this complexity. The notion of recovery has received less attention in the sociological literature on cancer; exceptions include Winterling et al 2009. Leukaemia, including as it does both acute and chronic forms, offers an opportunity to explore recovery within diverse states of remission.

The analysis presented here draws on an ESRC funded study of recovery (ES/K006037/1) involving secondary analysis of qualitative interview data from four datasets. The current paper focuses on the experiences of adults diagnosed with leukaemia (n=39) interviewed about their experiences by the Health Experiences Research Group, University of Oxford.

The paper argues for the usefulness of exploring recovery in terms of the lived and located experiences of leukaemia patients on exiting - completely or partially - from the sick role and associated status. Analysis identified that recovery is multi-dimensional involving both ‘recovery from’ (…the disease, treatment, being seriously ill) and ‘recovery of’ (…previous routines, responsibilities and pleasures). Patients’ expectations and experiences of recovery were located in relation to particular dimensions of identity and played out in diverse arena that included employment, physical activity, relationships and roles, (in)dependence and responsibility.

Thursday 11 September 2014 at 10:15 - 10:45
Health Service Delivery
White Hall 2, CAMS, Main Building

Developmentally Appropriate Healthcare for Young People: Conceptualisation and Practice
Farre, A., Wood, V. J., McDonagh, J. E., Parr, J. R., Reape, D., Rapley, T.
(University of Birmingham)

The need to provide health services for young people that are different from those usually provided for children and adults is receiving growing attention among healthcare professionals. ‘Developmentally Appropriate Healthcare’ (DAH) is one term that is being used to characterise the nature of these specific services and describe what they consist of.

Drawing on preliminary findings of an ethnographic study exploring the introduction of DAH for young people across three NHS Trusts, we contrast how DAH is being constructed as a particular approach to healthcare delivery in academic narratives and within managerial and clinical work.

Within the academic literature, DAH is a concept tied to the domains of adolescent medicine, young people, chronic conditions and transitional care. Within managerial work DAH relates to key organisational policies for young people and the boundaries and logic of the organisation of paediatric and adult care. Within clinical work DAH is mainly a
fundamental principle involving a particular mind-set and skill-set as well as the ability to align certain organisational and environmental aspects with such principles.

Despite the lack of a core definition, the heterogeneity of the concept enables us to explore the interstices between conceptualisation and practice, analyse their complementarity and identify a set of core ideas that can be taken as the base of a definition of DAH for young people that is both academically and clinically relevant.

Friday 12 September 2014 at 09:00 - 09:30
Critical and Public Health
Steelhouse 3, CAMS, Main Building

E-cigarettes and Vaping: Public Health Solution or Risk?

Farrimond, H.
(University of Exeter)

This discussion paper considers the phenomenon of e-cigarettes/ vaping as emerging medical technologies. E-cigarettes differ from existing medical nicotine products such as Nicotine Replacement Therapies (NRT) patches or gum in several ways. Their emergence in the market-place has been sudden; their growth exponential and consumer-driven. Dissemination and purchasing has primarily occurred through global social networks on and off-line rather than through pharmacies or medical experts. E-cigarettes are experientially similar to smoking according to users, in terms of the taste, ‘hit’ and feel of the device, whereas NRT is deliberately designed not to mimic smoking. There are several consequences to this. Firstly, national regulatory and public health responses have been uncoordinated and polarized, for example, Health Canada have banned the sale of e-cigarettes containing nicotine; with others holding a more liberal ‘harm reduction’ approach. The former appear to have been driven as much by moralization (Rozin, 1999) than evidence of risk. Secondly, part of the current attraction of e-cigarettes for users may be precisely their distance from the medical sphere; they are essentially consumer leisure products, chosen by smokers themselves to replace smoking, rather than medical treatments recommended by GPs and pharmacists. This positions the vaper as the socially responsible ‘biocitizen’ (Novas & Rose, 2005), in control of their addictive habit through their consumer choices. As such, vaping provides important identity benefits to a previously stigmatized group. This may change if and when e-cigarettes become incorporated into tobacco and medical regulatory regimes in the near future.

Friday 12 September 2014 at 10:10 - 10:40
Open
B. Kendrick, Main Building

Medicalization, Normalisation Practices and Negotiation in the Patient Career

Favretto, A. R., Fucci, S., Zaltron, F.
(University of Eastern Piedmont)

A qualitative research was carried out to reconstruct ‘moral career’ (Goffman, 1961) of patients suffering from colorectal cancer and cardiac decompensation, focusing on the identity negotiation, the social construction of care paths, and the perception of self in different health contexts. A total of 81 in-depth interviews with patients and 7 focus groups with medical and paramedical staff were realized. Three phases of the interviewees’ biography were investigated: the diagnostic phase, the treatment, and the management of chronicity or healing. We pay attention to patients’ and caregivers’ negotiation and resistance practices, as well as to difficulties emerging from medicalization and normalization processes, which characterize the construction of patients’ careers.

We concluded that ‘medicalization’ and ‘normalization’ of patients daily life - which in Western societies refer to biomedical knowledge – provide the patients’ and caregivers’ more accepted frameworks of sense. However, from the research emerged that these frameworks of sense are accepted and used in a manner adapted to daily life. They are therefore subjected to critique and redefinition, producing forms of resistance to biomedical knowledge and negotiation of care paths. Acceptance of biomedical knowledge, and the simultaneous resistance to it influence patients’ identity construction and relational life, as well as illness coping strategies adopted from ill people and caregivers. The innovativeness of this particular project lies in the integration of the analyses of two different diseases and their therapeutic process, with consequences on trading strategies, which are adopted by patients and their caregivers.
The Importance of Expectations and Sociality in Personal Genomics in the UK

Finlay, T.
(Cardiff University)

Direct-to-consumer genetic testing (DTCGT) has been available on the internet for a decade. Until recent action by the FDA in the USA caused them to suspend health-related tests, American companies that marketed DTCGT for common complex disease risk and genetic disease carrier status claimed they were empowering people to make healthy lifestyle choices, drawing on the neo-liberal idea of autonomy as a central argument. Scientists and clinicians highlight the lack of clinical validity and utility of DTCGT, and raise concerns about the potential for anxiety and inappropriate testing or intervention on the basis of contingent DTCGT results, and in the absence of counselling. However it was not clear what impact personal genomics marketing would have in the UK given our state-funded healthcare.

In this presentation I explore users’ experiences of DTCGT, drawing on data from interviews with members of the public who have bought a genetic test on the internet, conducted as part of my STS doctoral study on DTCGT in the UK. Analysis of the data revealed that Expectations and Sociality are key to people’s engagement with new technology by reducing its inherent uncertainty (Brown and Michael 2006) and providing supportive networks of others with similar interests and knowledge respectively. In contrast with Rabinow’s concept of ‘Biosociality’ (Rabinow 2005), the sociality demonstrated in these data precedes and facilitates the acquisition of genetic information and is more akin to Novas and Rose’s (2000) description of genetic identity practices that constitute only part of people’s identity within their multifaceted worlds.

Becoming Fat, Becoming Slim: BMI Scores, Neo-liberalism and the Political Economy of Calories

Fox, N.
(University of Sheffield)

This paper shifts fundamentally from an anthropocentric and individualised perspective on obesity, to explore assemblages of materialities and affects, including bodies, food, fat, physical environment, food producers and processing industries, supermarkets and other food retailers and outlets, diet regimens, and wider social, cultural and economic formations, along with the thoughts, feelings, ideas and human desires that can affect these material elements. Within this assemblage, there is a (political) economy of interactions, and a micropolitics of fat and slim bodies.

I report data from three studies of adults gaining or losing weight, exploring the relations of bodies with other material elements, the ways these elements assemble and affect each other, and the desires that produce fat and slim bodies. The paper explores the forces, flows and intensities in this assemblage of materialities, against a backdrop of neoliberal relations, to assess the circulations of matter, the forces and desires that shape bodies, and the production, distribution, accumulation and dispersal of fat.

What's Wrong with Meta-ethnography Reporting? A Systematic Review of Published Studies

France, E., Ring, N., Thomas, R., Jepson, R., Noyes, J., Maxwell, M.
(University of Stirling)

Synthesis of qualitative studies can inform sociological understandings of health and illness experiences. Meta-ethnography is a frequently-used, rigorous, systematic, interpretive synthesis approach. However, despite methodological advances since 2002, there are signs of problems with the quality of meta-ethnography reporting, particularly the analysis processes.
Aim: to investigate the application and reporting of methods in recent meta-ethnographies focusing on the analysis process and output.

Methods. To identify health-related meta-ethnographies published in 2012-2013, we systematically searched 6 electronic databases. We identified 32 relevant articles and examined their findings and how the methods were applied and reported.

Results. Most meta-ethnographies focused on experiences of health or healthcare. The method was applied in diverse ways. Most articles fully and clearly described the literature searching and selection methods. However, the analytical stages were poorly reported: less than a third of articles fully and unambiguously described how they had synthesised concepts from studies; only one explicitly described how the final model, theory or interpretation was achieved. In 12 articles it was unclear if the synthesis had achieved new interpretations.

Conclusions. Meta-ethnography is an evolving method. Current meta-ethnography reporting of methods and analysis lacks clarity and comprehensiveness. Inadequate reporting is a barrier to trusting and using meta-ethnography findings because it makes judging their rigour and credibility difficult. To realise meta-ethnography’s high potential value for enhancing sociological understandings of illness experiences requires reporting of sufficiently high quality that clearly conveys the methodology, analysis and findings. We suggest that tailored meta-ethnography reporting guidelines, developed through expert consensus, could improve reporting.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 1, CAMS, Main Building

Volunteers in Palliative Care: How is their Role Constructed?

France, R.
(The Open University)

This presentation introduces a proposed ethnographic study of volunteers in palliative care. As demand for palliative care increases, there is likely to be an increasing demand for volunteers, who already provide an important resource. Existing literature highlights a number of tensions and ambiguities in the volunteer role in patient- and family-facing roles, which warrant further investigation. I will describe some of these together with current thoughts on my theoretical approach.

Volunteers involved in hospices appear to occupy a ‘middle ground’ between patients and staff. On one hand, the role is seen as distinct and separate from that of paid staff, and on the other hand, there is evidence that volunteers’ role is unclear.

The relationship between staff and volunteers is important in framing the volunteer role. Some staff appear to feel volunteers may be taking over their jobs. There is evidence that staff ‘control’ the volunteer role, for example, by restricting access to confidential patient information.

Volunteering is traditionally informal and flexible, but hospice managers are under increasing pressure from statutory regulation.

How the context of death and dying affects the role will also be considered.

Whilst I am still clarifying my theoretical approach, this will likely include references both to poststructuralist thought, such as that of Foucault regarding power, and symbolic interactionism. It will involve an exploration of Simpson and Carroll’s re-theorisation of role theory.

The Broad Clinical Gaze in Paediatric Deep Brain Stimulation

Gardner, J.
(Brunel University, London)

An emerging body of work within the social sciences explores the cultural impact of the neurosciences and new neurotechnologologies. Much of this work explores what could be called neurosociality: a form of biosociality in which neuroscience-derived understandings of brain functioning are drawn upon by actors to make sense of health and illness, and are increasingly used by actors as a basis for self-understanding. This presentation contributes to this body of work by exploring the way in which a multidisciplinary clinical team providing deep brain stimulation to children with movement disorders socially constructs, or ‘enacts’, their patients and their patients’ illnesses. Drawing on interview and observation data, this presentation will illustrate that deep brain stimulation has become implicated in clinical activities that perpetuate neurodevelopmental narratives. Within these narratives, a child’s physical and social engagement within the world is seen as vital to healthy brain development. The team understands deep brain stimulation as a tool for ‘unlocking’ the body and enabling patients to engage in the world, and it is this engagement in the world which is seen as being essential to wellbeing. I will argue that that the team subjects their patients to a ‘broad clinical gaze’; a clinical interest that extends from the shapes and structures of the brain, to the subjective thoughts and emotions of their patients, to the internal dynamics of family life. This clinical gaze is also normative: patients and their families are prompted to adhere to particular biomedical and social norms.

Dementia and Sociology of Mind

Gjernes, T., Måseide, P.
(University of Nordland)

This is work in progress. With reference to sociology of mind, it would be relevant to ask, what is it like to be demented? And dementia does not mean being mindless. Our data show that individuals diagnosed as demented together and together with caregivers interact in ways that generate and reproduce shared meaningful situations that require minds. Data come from observations in a day care center for persons diagnosed as demented. The paper focuses on three situations or activity types generated but also challenged by interaction between patients and staff members. The individuals with dementia diagnosis involved are supposed to have cognitive incapacities because of lesions of the brain, and some of them have a limited verbal repertoire. They have bodily incapacities with supposed negative consequences for their participation in ordinary social situations. From our observations, however, this does not make them unable to participate as adequate and competent social members. Part of this is because of staff members’ involvement with scaffolding, when interaction order is threatened or broken, reconstructs situations as ordinary with ordinary participants. But more commonly, participants diagnosed with dementia are, in spite of communicative limitations, able to interact adequately. Even if their ‘verbal tool kit’ is limited or lacking, they may use analogue statements as communicative strategies together with adequate interactive moves to act as culturally and socially competent participants and to generate or recreate social situations as ordinary with shared meanings among the participants.

From Social Theory to Social Practice: Understanding Patient and Public Involvement as a Knowledge Space

Gibson, A., Welsman, J., Britten, N.
(University of Exeter)

Patient and public involvement (PPI) is now firmly embedded in the policies of the Department of Health in England. We suggest that PPI can be understood as a particular form of ‘knowledge space’ (Elliott and Williams, 2008), i.e. a social space where scientists, policy-makers and the public interact in order to deal with a particular issue or concern and where traditional boundaries of expertise become blurred. Drawing on the relevant theoretical and empirical work
Paper Abstracts

of Habermas, Bourdieu and Fraser, we will present a four dimensional theoretical framework for analysing the nature of the interactions that take place in these spaces (Gibson, Britten and Lynch, 2012).

This paper will then discuss the process by which researchers worked collaboratively with three patient and public involvement groups to turn this theory into a practical workshop. The presentation will share findings from these workshops, showing how ratings from individual participants can be combined into a visual representation of ‘patterns’ of involvement within a knowledge space. We will also present findings from an analysis of the qualitative data generated by the workshops and the issues that these raise. We discuss how these results and outcomes can be used as a starting point for conversations about understanding a group’s position within a knowledge space, what factors might be supporting, or presenting barriers to, public involvement and how these discussions can be used to plan future involvement. We conclude by drawing on this empirical and practical work to reflect back on our original theoretical framework.

Wednesday 10 September 2014 at 12:45 - 13:15
Open
B. Kendrick, Main Building

Can Death Investigators Save Lives? The Molecular Autopsy for SADS

Goldsworthy, C.
(Cardiff University)

Genetic testing for Sudden Arrhythmic Death Syndrome (SADS), when performed post-mortem can lead to the prevention of deaths in the same family. Although this testing is the most accurate way of establishing the true cause of death it is rarely utilized by the Coroner or pathologist. By asking whether death investigators can save lives this paper extends the death investigation process beyond the medico-legal domain into that of medical practice and public health. This is achieved by implicating the information gained during the inquest into external processes of diagnosis and treatment. In doing so this research also extends debates around ‘Geneticization’ beyond the clinical setting as Coroners are asked to consider not only the effect of disease and illness on the deceased individual but also the potential effect upon family members who may share the same genotype. This paper will discuss how and when the molecular autopsy could be used as well as examining the social organization of the expert professional groups involved in the process of conducting post-mortem genetic testing as a way of preventing future deaths. This will be discussed with reference to preliminary findings from qualitative interviews with Coroners across England and Wales, in which Coroner’s were asked to discuss their duties and priorities when investigating SADS related deaths as well as their experience and understanding of genetic testing in suspected SADS cases.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 1, CAMS, Main Building

Foodways and Futures: A Participatory Action Research Approach to Exploring the Food Choices of Former Young Homeless People in the North East of Scotland

Gombert, K., Douglas, F., Carlisle, S., McArdle, K., McNeill, G.
(University of Aberdeen)

In Scotland, over thirteen thousand young people become homeless every year, food poverty is on the rise and concerns about the influences of the recent welfare reform are being raised. Young people experiencing homelessness can face severe economic and other difficulties on an everyday basis. They can struggle to eat healthily, which has implications for their ongoing development. The project draws on and is shaped by a number of disciplines: health promotion; nutrition; education; and sociology. It is guided by underpinning values of egalitarianism, emancipation and empowerment. It is designed, firstly, to explore the food choices of homeless and vulnerable young people. The research aims to address (and challenge) policies targeted at reducing food-related health and socio-economic inequalities. Secondly, the project is designed to engage homeless young people in the co-construction of knowledge and the co-creation of action, through the use of participatory research methods. The presentation focuses on early findings and insights gained during the first exploratory phase of ethnographic fieldwork; as well as other insights gained by then through interviews and photo voice method. There have been indications of a ‘clash of cultures’ at the organisation; in terms of different life worlds, values and lifestyles coming together. Furthermore, the research experience in the beginning of the first phase indicates that value loaded investigations of food choices would be inappropriate. This gave reason to think about the relativity of ‘wellbeing’ and ‘health’, and how much choice
one really has. The presentation reflects critically on the possibilities and limitations of the ‘healthy expectations’ of the researcher, the organisation, and policy-makers.

Friday 12 September 2014 at 11:55 - 12:25
Embodiment and Emotion
White Hall 1, CAMS, Main Building

Unsettling Experiences: Post-mortem Examinations in Medical Education

Goodwin, D., Machin, L., Taylor, A.
(Lancaster University)

Dissection has held a privileged position in medical education although the professional values it inculcates have been hotly debated. Claims vary from it generating a dehumanising level of emotional detachment, to promotion of rational and dispassionate decision-making, even to being a positive vehicle for ethical education. Sociologists have argued that dissection equips medical students with emotional ‘defence mechanisms’ (Hafferty, 1988) but, potentially, at the cost of a disengaged approach to medical practice (Regan de Bere and Petersen, 2009).

Pressure for medical schools to revise their ‘overloaded’ curricula has inspired debate about the style and quantity of anatomy teaching which, when coupled with societal attitudes that challenge the medical profession’s norms towards ownership of bodies and body parts (Regan de Bere and Petersen, 2009), has engendered a situation where dissection is no longer seen as an essential route to understanding anatomy. As dissection recedes in prominence, however, observation of post-mortem examinations - a long established, if underutilised, practice – has re-emerged.

There are many similarities between post-mortems and dissection, however, there are also important distinctions, namely that ‘The autopsy is more upsetting to students’ because of the body’s apparent closeness to life (Smith and Kleinman, 1989:58).

We draw on focus group data to explore students’ experiences of observing post-mortem examinations. We discuss the role it plays in the emotional socialisation of medical students, the embodied nature of these experiences, and how the uncertain status of the body troubles professional norms and ethics, as well as revealing concerns about bodily integrity and wholeness.

Thursday 11 September 2014 at 10:15 - 10:45
Lifecourse
Steelhouse 3, CAMS, Main Building

Physical Activity in Low Socio-economic Status Older women

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

Research in the UK suggests that there is an association between physical activity (PA) and socio-economic status, with the lowest levels of activity being undertaken by those occupying the lowest socio-economic positions. Further, there is a sharp decline in rates of PA with increasing age, so that the number of older adults (=65 years) who are physically inactive is high relative to other age groups, with women less likely to undertake regular PA than men. Yet the need for PA remains important to this group, where it is understood to support healthy ageing and active independent living.

This paper seeks to explore the meaning of PA and exercise amongst older people from low socio-economic groups, drawing on findings from a qualitative study conducted with 20 older women living in Sheffield. The study used narrative interviews to investigate the everyday contexts associated with PA and exercise, and to contextualise this within the life-history of each participant. In our analysis we focus on how life-course social inequalities shape PA behaviours, reflecting on how this has impacted across different domains (including work, family and / or leisure time), and also intersects with gendered expectations of ageing. In particular, we use Heijrup’s structural life mode analysis as an organising concept to show how PA and exercise reflect and sustain wider social inequalities amongst this group.
**Paper Abstracts**

**Wednesday 10 September 2014 at 15:05 - 15:35**

Methods
White Hall 3, CAMS, Main Building

The Role of Ethnography in Healthcare Quality and Safety: The Case of High-volume, Safety-critical Routines in UK General Practice

Grant, S.
(University of Dundee)

Within the sociology of healthcare quality and safety, ethnographic methods have been increasingly employed to examine the nature of risk and safety across a range of healthcare organisational settings (e.g. McDonald et al. 2005; Mesman 2008; Swinglehurst et al. 2011). Drawing on ethnography’s ability to provide rich, holistic insights of everyday lived practices, these studies have highlighted the complexity of socio-technical systems and the importance of socio-cultural and infrastructural contexts for how safety is understood and enacted by healthcare professionals in everyday practice (Allen 2013; Iedema 2009; Rowley & Waring 2011). The aim of this paper is to reflect on the role of ethnography in this context by examining its application to high-volume, safety-critical routines within UK general practice. The paper then goes on to explore ways in which ethnography can be further developed as a safety improvement methodology within healthcare organisations. This paper will reflect on ethnographic fieldwork conducted across 8 UK general practices from 2010-2014 involving 1,683 hours of observation of high-volume routines (e.g. repeat prescribing, test results handling, medicines reconciliation), 74 interviews with clinical, administrative and managerial staff, and documentary analysis of key practice documents. Reflecting on the data collection and analysis processes for this research, this paper seeks to contribute to current methodological understandings of the role of ethnography within the sociology of healthcare quality and safety, and to explore ways in which ethnography can be further developed as a safety improvement methodology through the application of Video-Reflexive Ethnography (VRE) (Iedema, Mesman & Carroll 2013).

**Wednesday 10 September 2014 at 13:55 - 14:25**

Open
White Hall 1, CAMS, Main Building

Trusting the Views of Medical Men: Medical Evidence and the Social Construction of Incapacity for Work in the Development of Incapacity Benefits in the 20th Century

Gulland, J.
(University of Edinburgh)

Over the course of the 20th century social security benefits have been available to people who were assessed as ‘incapable of work’. The meaning of this phrase changed over time and legal and policy interpretations have been developed in response to concerns about controlling the numbers of people eligible for benefits. These policy changes have often focussed on the role of GPs and the ways in which other forms of medical evidence have been used as gateways to the system.

In this paper I consider how the definitions of incapacity for work have changed over the 20th century and the ways in which understandings of the meaning of ‘work’, the social construction of disability and the role of age and gender interacted with the definitions. The paper focusses particularly on the assessment of people with chronic health conditions or disabilities. While assessors often recognised that these were genuine impairments and that claimants faced barriers to paid employment, this did not always lead to an assessment of ‘incapacity for work’.

This paper represents work in progress from research on the changing meanings of incapacity for work from 1911 to the present. The research is funded by the Leverhulme Trust and is based on analysis of archive material on appeals against refusals of benefits. These appeal papers provide access to detailed information about individual claims for sickness benefit, providing a window onto thinking about the meaning of incapacity for work across the 20th century.
Care Pathways as Boundary Objects: Experiences from Norwegian Home Care Services

Håland, E. (Norwegian University of Science and Technology)

The need for integration of healthcare services and collaboration across organisational boundaries is highlighted as a major challenge within healthcare in many countries. Care pathways are often presented as a solution to this challenge, even though the evidence of their ability to solve this challenge is inconclusive. In a research project following recent coordination and collaboration initiatives in Norway, we study a project of developing, introducing and using a care pathway across healthcare levels focusing on older home-dwelling patients in need of home care services after hospital discharge. In doing this, we use the concept of boundary object, as described by Star and Griesemer, to explore how a care pathway can act as a tool for translation between specialist healthcare services and home care services. Based on interviews with participants in the project, we find that response to existing needs, local tailoring, involvement and commitment are all crucial for the care pathway to function as a boundary object in this setting. Further, the care pathway, as we argue, can be used to push boundaries just as much as it can be used as being a tool for sailing across them, thus possibly contributing to a more equal relationship between specialist healthcare services and home care services.

“If Syndromic Surveillance is the Answer, What is the Question”: Influenza Surveillance in Germany as a Visibility Regime

Hall, K. (Goethe-Universität Frankfurt am Main)

Nearly 20 years ago David Armstrong (1995) observed “The rise of surveillance medicine”. With the outbreaks of highly pathogenic avian influenza H5N1, SARS, pandemic influenza H1N1, MERS-CoV and most recently the outbreaks of Ebola hemorrhagic fever in Guinea the development of surveillance medicine has gained considerable momentum. National systems of health surveillance increasingly experiment with various forms of syndromic surveillance and combine them with classic public health data to yield an early warning system for infectious disease outbreaks.

Following Paul Rabinow in studying contemporary forms of problematization I take Arthur Reingold’s (2003) question “If syndromic surveillance is the answer, what is the question?” as a point of departure for my analysis of the German influenza surveillance system. The Robert Koch-Institute as the national agency responsible for infectious disease prevention together with the German Green Cross have developed the once rather passive influenza surveillance system in Germany into an actively operating and expanding sentinel surveillance network consisting of general practitioners, hospitals and even individuals registered on a website. In my paper I discuss how harmonisation, standardisation and multiple translations and transformations are employed in aggregating data from such disparate sources and visualising the influenza activity in Germany. Drawing on the visibility regime concept from surveillance studies and STS I want to analyse how the threat of influenza is made visible and used in the construction of a risk identity of the population.

Gendered Influences on Non-participation in FOBT Bowel Cancer Screening: A Qualitative Exploration

Hall, N., Brown, S., Robertson, S. (Durham University)

Colorectal cancer screening is the only population-based cancer screening offered to both men and women in the UK. Gender differences in the uptake of Faecal Occult Blood Test (FOBT) screening for colorectal cancer have been reported, but little is currently known about social processes surrounding non-participation. Furthermore, differences in the use of health services between men and women are recognised as being more complex than previously thought.
This study aimed to examine and understand non-participation in a population-based FOBT colorectal cancer screening programme from a gendered perspective.

In-depth face-to-face interviews were conducted with 27 purposively sampled ‘non-participants in screening’ (14 women and 13 men) as part of a study on the barriers to FOBT screening. Participants were diverse in terms of age, gender, socio-economic status and reasons for non-participation. We report on a secondary analysis of the interview data using thematic analysis to explore the question ‘what role does gender play in non-participation in colorectal cancer screening?’

Our analysis suggests that there are many more commonalities in the reasons for non-participation between men and women than differences. We offer some contradiction to conventional ideas about gender and screening behaviour focusing on five main themes: screening talk, legitimisation of health engagement, good citizenship, nature of the test and risk surveillance. We demonstrate how actual gender differences in terms of screening behaviour may be more subtle than they are often perceived to be, which helps to explain the diminishing gender differences in non-participation rates with age.

Thursday 11 September 2014 at 16:20 - 16:50
Risk
Stafford 2, CAMS, Main Building
Explaining Risk-taking in Context: Kidney Transplant Patients’ Interpretation and Negotiation of Treatment Risk
Harrington, J., Morgan, M. (King’s College London)
When treatment ‘risk’ is involved, what do patients take into account when making their decision? We examine this issue in relation to the development of a biomarker test that aims to identify those patients who may be ‘tolerant’ to their graft and require less immunosuppression (IS), although such tests are not 100% accurate. The benefits of reducing hazardous and potentially life threatening IS side effects therefore requiring to be weighed against the risk of graft rejection, with this decision incorporating and reflecting patients’ values.

We employed a modified Standard Gamble (SG) task to identify kidney transplant patients’ risk preferences, followed by 30 qualitative in-depth interviews to elicit explanations for different levels of risk taking. Using the results of the SG task we classified patients as ‘low’ (<2% risk) or ‘high’ risk takers (up to 50% risk), with both groups varying in symptom burden. Qualitative analysis focused on the cultural framing of risk, its fluidity, layering and negotiation in describing commonalities and explaining variations.

Risk perceptions formed an amalgamation of experiences and rationales involving the interrelationships of prior medical experience, life circumstances and responsibilities, and sometimes implicit trust that the medical team will safeguard their graft. However following Lupton, variations in decision-making were often shaped by patients’ over-riding concerns and emotions. Families’ weighing of risks also often required negotiation. Low risk taking in the medical realm could be juxtaposed with high risk activities (e.g. extreme sports, gambling, etc.) reflecting Lyng’s notion of ‘edgework’ and the context dependent nature of risk perception.

Thursday 11 September 2014 at 10:50 - 11:20
Patient-Professional Interaction
Stafford 1, CAMS, Main Building
The Development of Human Papillomavirus (HPV) Scripted Consultations: A Focus Group Study
Hendry, A., Pasterfield, D., Hiscock, J., Burgess, C., Campbell, C., Clements, A., Clutterbuck, A., Fox, R. (Bangor University)

Human papillomavirus is the most common sexually transmitted infection. High risk HPV types can cause cell changes which may lead to cervical cancer. Cervical screening programmes in the UK are changing to incorporate HPV testing and triage. Borderline or abnormal screening cell samples will be tested for HPV; positive results will be fast-tracked to colposcopy, women with negative results will return to routine screening.

HPV can be a sensitive topic; previous research has demonstrated poor knowledge of HPV in the general population. HPV test results, both positive and negative, have been shown to lead to distress, confusion, and anxiety.

Scripted consultations are a proven way to effectively deliver evidence-based information about difficult and sensitive topics to patients and to reduce associated anxiety. Such consultations therefore have the potential to alleviate the
psycho-social burden on women associated with sexually-transmitted infections, and cancer and screening-related anxiety.

This study aims to produce evidence-based scripts for consultations with women tested for HPV.

A qualitative study using focus group methodology is being undertaken with women of cervical screening age, recruited from two general practices in different Socio-economic areas. The focus group data will be used to develop scripts which will be further refined through cognitive interviews with women tested for HPV.

We anticipate the resulting evidence-based scripts will be tested in future randomised controlled trials to establish the impact on screening related anxiety, and uptake of cervical screening in the UK.

The focus group findings will be presented in full at the conference.

**Wednesday 10 September 2014 at 13:20 - 13:50**

**Open**

**B. Kendrick, Main Building**

**The Sociology of Dementia Diagnosis: An Ethnographic Study of the Memory Clinic**

*Hillman, A.*

*(Cardiff University)*

Current UK policy (DoH Prime Minister’s challenge on dementia 2012) is focused on achieving early detection in the care of those with dementia while at the same time there are no tests that can definitively diagnose it. This paper draws on an ethnographic study of a UK memory clinic where patients with memory problems are assessed and diagnosed. Observations of clinical consultations and interviews with memory clinic staff are presented to explore how diagnoses are accomplished. Drawing on an emergent body of work in the sociology of diagnosis, the study examines the implication of uncertainty in the diagnostic process. In particular, the study highlights the fuzzy boundaries that define conditions such as mild cognitive impairment and Alzheimer's disease and shows how gaps between symptoms and disease are experienced and communicated in the assessment process. The negotiation between clinical knowledge, diagnostic technologies and the views and experiences of patients and families in the reaching of a diagnosis is explored in the context of these uncertainties, illustrating how decisions about what is the underlying cause of a patient’s memory problems are collectively made. This paper suggests that the current policy agenda assumes greater certainty of diagnostic categories in dementia care and fails to recognise the socially mediated nature of diagnosis and the interest of those involved in its accomplishment.

**Friday 12 September 2014 at 10:10 - 10:40**

**Inequalities**

**White Hall 3, CAMS, Main Building**

**Using Social Network Analysis to Map Participation and Non-participation in Health Promotion and Community-building among Vulnerable Populations**

*Hindhede, A. L.*

*(Steno Health Promotion Center)*

In empowerment and asset-based approaches to community development, the ability to change local residents’ perception of themselves and their neighbours from that of persons with needs that can only be met with the help of professionals to that of a more self-reliant group with assets and capacities for collective and collaborative problem solving is seen as key to successful community building (Kretzmann and McKnight, 1993).

By using social network analysis and Bourdieu’s definition of capital, this study aimed to identify patterns of participation and non-participation in a community-building project aiming at increasing upward mobility and social capital within the area and increase equity in health.

This presentation will outline the tensions and contradictions which accompany policies and interventions that seek to strengthen local communities as a means of promoting health. Emerging findings from the network analysis and the factors that promote or hinder participation in voluntary activities will be presented. Particular focus will be on the range of factors that hinder widespread voluntary participation in community building with residents having limited opportunities for developing and maintaining more heterogeneous social networks outside the stigmatised neighbourhood.
Paper Abstracts

Wednesday 10 September 2014 at 13:20 - 13:50
Experiences of Health and Illness
- Stream Sponsored by Health Talk Online -
White Hall 2, CAMS, Main Building

The Relational Dynamics of Interacting about Health among Friends and Family

Hiscock, J.
(Bangor University)

This paper will argue that when we interact about health with friends, family or others in our social networks, what we are doing is not only contributing to the improvement and management of our health, but also to the relationship. The paper will argue that these health interactions should be viewed relationally and conceptualised as interactions and not solely as support.

The paper is based on a qualitative study about interactions in health amongst friends, relatives and informal social connections. The purposive sampling included: gender; age; condition; severity of condition; levels of deprivation and urban/rural. Data were gathered through qualitative interviews. A case study analysis was conducted to inform the development of codes and to identify broad themes which could not be segmented into codes. Transcripts were coded, organised using NVivo and interpreted, guided by the research questions and research team discussion.

The 'health interactions' which are explored in this paper are informal lay health interactions (outside the formal NHS) and include contact, communication or interaction between two or more people that is loosely or directly related to health in its broadest definition.

We will analyse the ways that these health interactions affect the relationships between people as well as affecting health and wellbeing. The paper will argue that entwined in the enactment of health interactions are relational practices which are a part of the way we develop our relationships with others and the way we experience our social world.

Thursday 11 September 2014 at 12:00 - 12:30
Lifecourse
Steelhouse 3, CAMS, Main Building

Dying Spaghetti: Exploring Healthcare Practitioner Accounts of Hospital Admissions for Patients Close to the End of Life

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

Using data from my current PhD study I will explore this assumption by examining the experiences of healthcare professionals (HCPs) from community, ambulance and hospital settings who were involved in admissions of elderly patients close to the end of life. Drawing upon literature from the sociology of organisations I will argue that current policy represents the management of dying as a process which can be controlled through mechanical interventions. In contrast, HCP accounts suggest that the organisation of dying patients happens within an organically structured scenario, involving complicated interactions with multiple professional groups, each with its own identity and language. HCPs are constrained by the organisations in which they work, their own professional formal and informal codes of conduct, the groups they encounter and national guidelines. In regard the latter, the disjuncture between the linear trajectory implied in national policy and their own experience appears to add to the complexity of helping patients and challenges their professional authority. HCPs also identify moral issues in the transfer of patients to hospital, often because patients’ attachments to significant others means they cannot transit the system as single ‘units’. Dying, ultimately, is portrayed as a tangled spaghetti of actors, groups and processes.
The Representation of Social Science Approaches in Public Health Intervention Research

Holman, D., Lynch, R.
(University of Cambridge)

Public health intervention research is criticised for paying scant attention to the social situatedness and practices constituting health, which often remain conceptualised as the background ‘context’ of a study or a mere ‘variable’ to be taken account of. Furthermore, the conceptual understandings and theories central to the development of disciplines such as sociology and anthropology are underrepresented, with employment of social scientists being more akin to a sticking-plaster approach to the social, rather than an active engagement. On the other hand, psychological approaches, representing a crossover with STEM subjects, are comparatively dominant. Yet the nature and extent of the representation of sociology, anthropology and psychology in health intervention research is unknown. We sought to explore this representation by: firstly, carrying out database searches to track disciplines, theories and methods cited in the field and how this has changed over time; secondly, profiling researchers working in the stated disciplines in prominent UK public health institutions and departments to map their backgrounds, position, and, using recent methods (Bastow et al. 2014) their academic impact; and thirdly by using HESA and ESRC figures to show which type of health intervention research gets funded and the stake that social science has in it. We go on to situate these findings within theoretical contributions from sociology and anthropology to take a critical view not only of the field, but of the current and potential influence of social science within this.


Long Term Weight Gain Following Stroke: Exploring Incidence and Explanations

Homer, C., Allmark, P., Bhanbro, S., Ibbotson, R., Tod, A. Lynch, R.
(Sheffield Hallam University)

Stroke is the leading cause of long term disability and third leading cause of death (Curioni et al, 2009). Survival rates are increasing. Approximately 900,000 people in England live with the effects of a stroke (NICE 2010). Health behaviour modification can be crucial in stroke rehabilitation and in avoiding long term impairment. Consultation with stakeholders identified increased numbers of patients experiencing long term weight gain following a stroke.

This study aims to explore i) the existence of weight gain following a stroke ii) factors contributing to weight gain and iii) implications for the stroke rehabilitation pathway.

A mixed method study incorporating i) a survey of South Yorkshire Health Cohort participants (n=87); ii) interviews with staff (n=18) and stroke patients (n=12). Data were analysed using framework analysis methods.

Across the care pathway inconsistencies exist in the recognition that weight gain is an issue for patients post stroke. The findings draw on components of the Theory of Integrated Care (Kodner & Spreeuwenberg, 2002). Applying the theory to the findings provides a means to explain how patients may become lost across the different aspects of the stroke care pathway. Fragmented communication between health care professionals across the pathway limits opportunities to address the risks and realities of weight gain. Ambiguity arises for patients because weight gain following a stroke can be both a sign of progress and of a problem.

Individualising care and integration of weight management advice across the whole pathway (acute, community and primary care settings) may prevent weight gain in stroke survivors.
An Exploration of Facebook and Mental Health

Howard, K. (Bucks New University)

This paper will report on the initial findings of a study exploring the relationship between use of the social networking site Facebook and mental health. Drawing on qualitative semi-structured interviews and focus groups (currently being conducted) with people in the UK diagnosed with a variety of mental health conditions, the paper will explore the positive and negative aspects of using Facebook on individuals’ mental health. This study aims to fill a gap in the research which has begun to explore the complex ways in which interaction with SNS may affect the mental health and wellbeing of users and has suggested some positive, negative and more complex ambivalent effects, but as yet has rarely touched on the specific issues that people with diagnoses of mental health conditions may deal with.

Emergent themes from this partially grounded and participatory study exploring peoples’ accounts of their lived experiences will be detailed alongside key themes raised that draw on the social media literature. For example, the study explores the usefulness of core concepts to explain people who experience mental health issues’ encounters with Facebook, such as the ways in which people have negotiated the blurring of public and private; experience social capital through ‘networked publics’ and engage in identity management on the social networking site.

As well as asking about the impact of Facebook on mental health, the research aims to explore the strategies people use to enhance their wellbeing and manage their mental health on the social networking site.


Huxley, C., Griffiths, F., Atherton, H. (Warwick Medical School)

Digital and networked communication technologies, such as email, SMS and video conferencing, have become widespread in day-to-day life. These technologies have been slow to integrate in healthcare care settings, and robust NHS information governance structures act as barriers to patients’ use of digital technologies for clinical communication purposes. Where they are available they offer patients a potential choice of communication medium with their general practice, in line with an aim to offer patients better access and convenience. The aim of this realist review is to explore how digital and networked technologies impact on patient access to GP services by groups considered hard-to-reach by healthcare and groups potentially marginalised by their ability to use these technologies. Systematic searches were conducted to identify key access issues for hard-to-reach groups, and relevant literature for the review. Realist synthesis of evidence suggests that digital communication technology between patients and GPs could ameliorate access issues relating to patients’ feelings of stigma and embarrassment, perceived hostility or discrimination by healthcare staff and other patients, practical access issues (such as transportation and unknown waiting times) and population mobility. It is less likely to improve access for those experiencing language and cultural barriers, or for people who do not view themselves as candidates for healthcare. Therefore, the use of digital communication technology could improve some barriers to healthcare access for hard-to-reach groups. However, older people and people with no educational qualifications are potentially marginalised by their ability to use communication technologies, particularly if digital consultations replaced traditional consultations.
Medical Professionalism in an Online World

Ignatowicz, A., Kotzee, B.
(University of Birmingham)

Much has been written about the importance of medical professionalism and about the need to define, teach and evaluate professionalism in medical schools. An acknowledged problem in the area is the broadness of definitions of medical professionalism: what counts as aspects of professionalism and what are the boundaries between a doctor's professional and private lives? One manifestation of this 'boundary' problem is growing attention by the profession to doctors' and medical students' behaviour online. In March 2013, the General Medical Council in the UK released its first guidance advising on the use of social media, reflecting a growing concern about what may be seen as unprofessional behaviour by doctors and medical students that compromised responsibility and social trust in the medical profession. Similarly, more emphasis has been placed on the role of medical schools in providing an environment where students can learn professional behaviours, understand the standards expected of them, and are fit to practise upon graduation. This paper presents work in progress and will explore some of the challenges faced by the medical profession as it grapples with questions such as how to prepare medical students to embody the characteristics of professional standards and values and how to maintain trust in doctors, while giving due attention to the principle of free speech. It will aim at broadening the debate around medical professionalism more generally by engaging with the socio-political implications of professionalism in an online world.

Disability, Self-injury and Ethnodrama: A Case for Creative and Embodied Research Methods

Inckle, K.
(Plymouth University)

Disability and self-injury are unmistakably embodied experiences. They are also experiences which have been subject to medicalization, social stigma and marginalisation. These themes remain present in much research which purports to 'explain' these experiences, and which ultimately does little to challenge such constructions or to benefit the individuals whose lives they appropriate. This paper is drawn from a current research project in which I use creative methods – ethnodrama – to explore the experiences of people with physical disabilities who self-injure in the context of enforced medical treatment/abuse as young people. Ethnodrama is a process through which research testimonies are constructed and performed as dramaturgical vignettes to audiences of practitioners, researchers, community members and policy-makers. Ethnodrama has proven particularly important in providing an embodied and empowering method through which to explore complex, sensitive and embodied issues and also to disseminate them in accessible and productive ways. For example, ethnodrama has been used to explore topics including abortion and terminal cancer and it also mirrors some of the ethos of crip performances which embody new perspectives of disability, gender and sexuality. As an embodied and creative method which is accessible to a wide audience ethnodrama also challenges the cognitive-privileging, abstract and elitist formats through which medicalised research is traditionally published and disseminated. As such in both ethos and practice ethnodrama embodies an alternative to normative perspectives and practices of research which are essential to the integrity of researching the experiences of people with physical disabilities who self-injure.

Incorporating Social Science Theory into Primary Care Research

Isaacs, A., Burns, N., Macdonald, S., O'Donnel, K. I.
(University of Glasgow)

My PhD research will look at the primary prevention of cardiovascular disease (CVD) in migrant communities. Part of this study will comprise an exploration of whether and how theory and method from critical social sciences can inform primary care research. Drawing on critical social science theory in primary care work can provide a means to i)
understand how individual and cultural factors interact with wider political, social and economic contexts; ii) problematize notions of ‘culture’ and ‘cultural difference’ in health care and guard against the ‘othering’ of migrants and ethnic minorities; iii) elucidate factors influencing health behaviours that can be obscured by traditional health research methods; iv) understand how attitudes towards migrants are formed and how these implicitly or explicitly inform approaches to their healthcare and v) expand understandings of risk beyond the individual to appreciate how certain risks are conferred on populations. A particular focus will be placed on the theory of ‘structural violence’ (Galtung 1975; Farmer 2006), which has been used in critical medical anthropology as a lens through which to understand the health of marginalized groups. Approaches informed by critical social science theory may be able to contribute to the development of preventive interventions that more comprehensively address the various levels at which health behaviours are influenced and thus aid in reducing health inequalities. This is particularly pertinent to the field of primary care, which puts the achievement of social justice at its core (Alma Ata 1978).

Thursday 11 September 2014 at 16:20 - 16:50
Professions
White Hall 3, CAMS, Main Building

Patient Medical Records in Pharmacy: Negotiating Risk, Politics and ‘Juicy’ Data
Jamie, K.
(Durham University)

Patient medical records are a ‘fascinating and crucial focus for sociological research’ (Berg and Bowker, 1997). Despite this, there is limited research examining the specific nature, and consequences, of patient medical records within particular medical professional groups.

To address this gap, this paper examines patient medical records in English community and hospital pharmacy at a time when access to patient medical records is particularly high on the profession’s agenda. In doing so, the research speaks to Haland’s (2011) recent call for more case studies into professionals’ own experiences of medical records in everyday practice. Drawing on semi-structured interviews with 10 community pharmacists, 10 hospital pharmacists and 2 general practitioners, it is shown that medical records are highly divergent across hospital and community pharmacy practice. Despite these differences, medical records are framed by discourses of risk in both sectors of the profession. In community pharmacy practice patient medical records are understood to produce increased risk to patients through data confidentiality breaches whilst in hospital pharmacy, patient medical records are represented as managing risk. These different framings of risk, I argue, both reflect and reproduce the inter-professional relationships and management of the patient body within these sectors of practice.

In community pharmacy in particular, I suggest that patient medical records form a key part of the boundary work and jurisdictional expansion which has characterised the sector’s recent history.

Wednesday 10 September 2014 at 15:05 - 15:35
Lifecourse
Steelhouse 3, CAMS, Main Building

‘Maternal Diabesity’: The Disconnect between Policy/Practice and the Material Realities of Women’s Lives
Jarvie, R.
(Plymouth University)

There is increasing prevalence of ‘maternal obesity’, Gestational Diabetes Mellitus (GDM) and Type Two Diabetes Mellitus (T2DM) in pregnancy. Increasing prevalence of GDM/T2DM in pregnancy is widely attributed to the dramatic increase in prevalence of ‘obesity’ in women of childbearing age. Co-existing ‘maternal obesity’ and GDM/T2DM or ‘maternal diabesity’ is likely to complicate increasing numbers of pregnancies in the UK.

Pregnancies complicated by these ‘conditions’ are associated with adverse maternal and fetal outcomes and are designated ‘high risk’. Recent research indicates an ‘obese/diabetic intrauterine milieu’ may epigenetically programme the fetus to ‘obesity/diabetes later in life. This is seen as a key factor in the perpetuation of the ‘diabesity pandemic’. Biomedical/policy discourses emphasise amelioration of the issue through lifestyle change: pregnancy planning, weight loss, adherence to diabetic regimen and lifestyle change. Epidemiological data shows clear associations between these medical ‘conditions’ and lower socio-economic status/deprivation. However, this issue is somewhat under-discussed in the literature. My doctoral research explored 30 women’s experiences of pregnancy complicated by co-existing ‘maternal obesity’ and GDM/T2DM in pregnancy. Women were predominantly of low socio-economic status and some were experiencing considerable material
deprivation. Women’s social class position/material circumstances mediated experience and management of pregnancy complicated by these ‘conditions’. The empirical data evinces a lack of resonance of pregnancy ‘planning’ discourses, disidentification with the ‘obese’ label, low risk perceptions, lack of social support, housing insecurity and food poverty. I argue that there is a disconnect between policy and practice and the material realities of women’s everyday lives.

Thursday 11 September 2014 at 09:40 - 10:10
Lifecourse
Steelhouse 3, CAMS, Main Building

End of Life Conversations: Clinicians’ Perspectives on the Challenges and Opportunities
Jones, K., Baines, B., Lang, I.
(University of Exeter)

Engaging patients nearing the end of life in discussions about their subsequent treatment is regarded as important to the provision of effective and cost-effective palliative care (Department of Health, 2011; NICE, 2012). There is little research to date which suggests how such discussions can be easier to initiate or how clinicians can optimise their communication with patients and their families on end of life care.

These issues have until more recently been addressed using Advanced Care Plans such as the Liverpool Care Pathway or a locally developed Treatment Escalation Plan (TEP) for the delivery of care for patients in the last hours or days of life.

In this paper, I discuss clinician’s accounts of the barriers and facilitators to initiating conversations about advanced care planning at the end of life with patients and their families and their approaches to overcoming these barriers.

Data collected from 15 qualitative in-depth interviews with doctor’s and senior clinician’s adopt a variety of ways in which to engage people in these discussions. These domains include developing a trusting relationship, adopting opportunistic conversations as well as engaging in ongoing discussions concerning malignant and non-malignant disease.

Clinicians who then engaged patients and their families in multiple conversations about their needs and treatments, and who sought to include psychological and social as well as biomedical aspects of care reported providing this aspect of end of life care as a core part of their day to day role.

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 3, CAMS, Main Building

I’ve Always Been Brought up with a ‘Don’t Tell Everybody’: The Loneliness of Keeping Intersex Quiet
Jones, C.
(University of Sheffield)

Loneliness and isolation can affect the lives of many people with an intersex condition (also known as disorders/divergence of sex development). Intersex scholars argue that, despite changes in treatment guidelines in the last decade (Lee et al., 2006), the orthodox medical approach continues to foster shame and secrecy (Feder, 2011). This means that individuals often hide their diagnoses/identity, sometimes from their partners and closest friends, fearing judgement and misconceptions. In addition, the social stigmatisation of non-binary bodies and marginal variations of gender/sex means that those diagnosed with intersex conditions can also find themselves lacking peer support, whether through their own fear of rejection and exposure, or through others’ limited understanding or acceptance.

The loneliness which I address may be of a social, psychological, ideological or physical nature; and one which may originate from social or medical trauma and/or one which may be cultivated to prevent future trauma. This notion of loneliness will be discussed alongside, and distinguished from, a desire for privacy, introversion, or time alone, which are to some extent discretionary and voluntary, and may or may not derive from histories of distrust or rejection.

This paper draws on my doctoral study into the social and medical experiences of people diagnosed with an intersex condition. The research utilises an initial stage of solicited diaries to form a basis for informal, unstructured and in-depth interviews. As the fieldwork is still ongoing, this paper and its analysis are a work-in-progress. Feedback and discussion to build on my ideas are very welcome.
Challenges for MSM in Understanding their Risk of HIV Infection

Kavanagh, B.  
(The Open University)

Many developments have been made in the area of HIV over the last thirty years, but while experts in the field of HIV can now define risk, they cannot reduce or remove it. Consequently, MSM have been encouraged to engage in self-surveillance and individual responsibility in relation to their sexual behaviour. Since the 1980’s, many MSM have engaged in surveillance of their sexual activities to protect themselves against HIV/AIDS. HIV has become a risk for them to manage with the individual left to make a risk assessment about their partners. This has given rise to various techniques used by MSM when seeking partners to assess HIV risk and minimise their exposure to the virus. For example, research has shown that people who look like they are promiscuous are often deemed to be so, while others are seen as ‘safe’ (Skidmore & Hayter, 2000). However, while visual cues were more visible during the early stages of the disease, the development of antiretrovirals and new prevention technologies have made the task of identifying risk increasingly difficult.

In the context of rising HIV infection among MSM, this paper sets out to discover how MSM understand their risk of HIV infection in the current climate by utilising the preliminary results of an online survey for my PhD research.

Informing Patients about New Therapies: A Case Study of Cultured Blood for Transfusion

King, E.  
(University of Edinburgh)

The Scottish National Blood Transfusion Service (SNBTS) carries out a dual role; it encourages blood donation and maintains acceptance of blood transfusions. One in three people will receive a transfusion during their lifetime. Concepts of the ‘patient’ are broadened to include altruistic donors, current patients, and expected patients, all of whom have an involvement with the transfusion service. The SNBTS-led BloodPharma project uses stem cell technology to produce red blood cells in the laboratory. An unlimited supply of O negative red blood cells would reduce or eliminate the need for blood donors. My findings are based on a number of years’ research with the BloodPharma project, including interviews, focus groups, and observation.

In this paper I will examine how ‘labouratory’ blood can best be publicised to the general population. The aim is to make the general public aware of this new product, but also to maintain support for the current transfusion system. Focus is placed on the BloodPharma product as an alternative to donated blood for specialist patients and third world countries. Potential problems with the current system are minimised in the publicity. Such problems include the potential for transfusion transmitted infections (TTIs) from altruistic donation. This new technology could offer therapeutic benefits for multiply transfused patients but it may be many years before this new blood product reaches the clinic. These patients need to be informed about this potential new treatment, while ensuring that existing treatment regimes are not abandoned in favour of the promised new therapy.

A Double-edged Sword: Families’ Perceptions and Experiences of Diagnostic Labels in Childhood

Kirk, S., Hinton, D.  
(University of Manchester)

Diagnosis is integral to modern medicine but has received limited attention in the sociological literature on childhood health and illness. It is not clear how a diagnosis, and diagnostic labels in particular, influence children’s and young people’s illness experiences or the experiences of those who care for them. This paper examines families’ accounts of obtaining and living with a diagnosis to highlight families’ perceptions of diagnostic labels, explore the role of a diagnosis in the lived experience of childhood illness, and identify families’ support needs pre and post diagnosis. In
depth semi-structured interviews were conducted with 23 families with a child with a rare long-term neurological condition (paediatric multiple sclerosis) and analysed using a grounded theory approach. Families initially viewed the diagnosis as a ‘double-edged sword’; on the one hand signalling the formal recognition of a dysfunctional body while on the other hand legitimising young people’s health complaints and providing (temporary) relief from the uncertainty of living with unlabelled symptoms. In reality, however, the diagnostic label was misinterpreted and disputed by others who questioned the validity of the reported illness. Moreover, certainty about the condition remained elusive and families fell unable to gain control of the disease. Young people and parents were frustrated and disappointed by the unexpected consequences of the diagnosis, resulting in personal distress and the deliberate concealment of the diagnosis from others. Families require access to appropriate help and support to manage the apparent disjunction between families’ initial assumptions about and the lived reality of diagnostic labels.

Thursday 11 September 2014 at 14:00 - 14:30
Experiences of Health and Illness
- Stream Sponsored by Health Talk Online -
White Hall 1, CAMS, Main Building

‘I’d Always Seen Myself as Invincible but Suddenly I’d got this Condition that wasn’t Going to Go Away’: The Emotional Impact of a Diagnosis of Asthma in Adulthood

Kirkpatrick, S., Locock, L., Salisbury, H., Ziebland, S. (University of Oxford)

Introduction - In the UK, 5.4 million people currently receive treatment for asthma. While awareness of childhood asthma is high, fewer are unaware it can start in adulthood. Few research studies have explored the emotional impact of diagnosis in adulthood; how people understand the condition, and how it affects daily life. This paper draws on a wider study of asthma experiences to focus on adult onset and biographical disruption.

Methods - Narrative video/audio-recorded interviews with a maximum variation sample of 38 people with asthma. Interviews analysed thematically, supported by NVivo. Findings will be published on www.healthtalkonline.org in 2014. This paper focuses on the subset of 18 people diagnosed in adulthood.

Results - A diagnosis of asthma in adulthood can be a shock. Commonly asthma is thought of as a childhood condition that improves over time. People found it difficult to accept having a potentially life threatening condition which requires them to manage new medication. It can take people a while to accept the emotional impact of diagnosis and its implications for their daily lives.

Discussion - Adults diagnosed with asthma have no past personal disease experience to help them manage the condition. The process of finding the right level of medication, and learning self-management techniques can be lengthy. Newly diagnosed adults may need to adjust their personal sense of identity, and reassess their lifestyle and capabilities. It is important that health professionals acknowledge the emotional impact on individuals, and offer appropriate support and information. The paper will contribute to the emerging sociology of diagnosis.

Thursday 11 September 2014 at 15:10 - 15:40
Professions
White Hall 3, CAMS, Main Building

Activation Issues in the Rapid Response System: An Analysis of Professional and Interprofessional Socio-cultural Factors

Kitto, S., McMillan, S., Shearer, W., Buist, M., Grant, R., Finnigan, M., Ramsay, W., Marshall, S. (University of Toronto)

The rapid response system (RRS) is a patient safety initiative instituted to allow healthcare professionals to promptly access help when a patient’s status deteriorates. Despite patients meeting the criteria, up to one-third of the RRS cases that should be activated are not actually called, constituting a ‘missed RRS call’. Ten focus groups of senior and junior nurses and physicians across four hospitals were conducted to gain greater insight into the social, professional and cultural factors that mediate the usage of a RRS call. Participants’ experiences with the RRS were explored using theoretical constructs from the interprofessional practice, sociology of professions and technology literature. Health professionals’ reasons for not calling a RRS activation included: distinct intraprofessional clinical decision-making pathways when deciding whether to activate the RRS; a highly hierarchical pathway in nursing, and a more autonomous pathway in medicine; and interprofessional communication barriers between nursing and medicine. In our findings, the RRS can be seen as both a patient safety technology that purportedly attempts to flatten hierarchies...
(while in practice it both facilitates the imposition of asymmetrical power differences amongst health professionals), and ironically, acts as a "work around" tool for nurses to negotiate traditional medical dominance embedded within healthcare practice settings. Rather than relying simply on the instrumental implementation of a formal tool such as the RRS, an understanding of the socio-cultural factors that shape the professional and interprofessional pathways to making RRS calls (ie. if they are made, the nature of how they are made) is required.

**Friday 12 September 2014 at 11:20 - 11:50**

**Inequalities**

White Hall 3, CAMS, Main Building

**Recruiting Members of the Pakistani Community: Using Social Networks and Culturally Sensitive Material to Overcome Gender Differences, Generational Gaps and Language Issues**

Kokab, F., Gill, P., Greenfield, S.

(University of Toronto)

Exploring the experiences of marginalised groups, such as Pakistanis living in the UK can be a methodological challenge where recruitment is affected by inter-generational and gender differences in norms and values. Often, researchers have relied on written methods for recruitment e.g. posting letters or invitations. These methods are problematic for poorly educated communities and little is known about recruitment within the 2nd or 3rd generations.

We developed novel approaches to participant recruitment through a study investigating lifestyle choices associated with cardiovascular disease risk in the Pakistani community. Social networks, cultural norms and trust are important factors for understanding how individuals engage with one another. For the Pakistani community, this is affected by migrant status (1st, 2nd or 3rd generation), gender, occupation and education.

Qualitative interviews (n = 42) provided progressive insight in to the development and significance of social bonds within local and wider community settings. Adopting a reflexive approach and gathering feedback from participants via culturally-lay perspective informed how the study should be advertised. Confidence in Pakistani etiquette and rapport with participants was developed by engaging with research advocates in business districts and community centres to further promote the research. The application of social mediums such as Facebook facilitated recruitment of 2nd and 3rd generation members.

Comprehensive recruitment was established by advertising through diverse recruitment pathways, beyond literacy or gender barriers in this “seldom heard” group. By incorporating culturally-diverse views, healthcare services can facilitate the provision of culturally appropriate and accessible care.

**Thursday 11 September 2014 at 14:35 - 15:05**

**Health Care Organisation**

Stafford 1, CAMS, Main Building

**The Dynamics of Professionalism and Managerialism in Nursing Practice**

Kristiansen, M.

(UIT The Arctic University of Norway)

Norwegian health care organizations are going through extensive changes from being dominated by professionalism to being controlled by managerialism. This paper reports an ethnographic study which seeks to explain how the dynamics of professionalism and managerialism are given meaning and brought into existence in nurses’ everyday practice within nursing homes. The aim of the paper is to explore how nurses make sense of everyday practice influenced by managerialism as a new framework for control.

The paper presents the analysis of 18 semi-structured interviews and 100 hours observation of registered nurses and assistant nurses from three nursing homes. The study draws on the concept of sensemaking as seen from an institutional logic perspective. In the analysis we searched for the nurses’ ‘meaning creations’ in their struggle for making sense of contradicting management rationalities in everyday practice. The data were analyzed using both content and template analysis, supported by NVIVO software.

Our analysis shows three forms of meaning creation; managerialism as a new component in work, professionalism as an instrument of resistance, and conservation of professional boundaries. Both the managerial adaptation and the reorientation of professionalism took place through formalization of nurses’ work, i.e. new forms of documentation and clarification of professional boundaries. The study demonstrates how nurses play a critical, but often invisible role in
processes of managing contradicting requirements, and contributes with new insight in how managerialism intervenes and change practices within nursing homes.

Thursday 11 September 2014 at 10:15 - 10:45
Politics of Health
Stafford 2, CAMS, Main Building

‘Making the Right Choices’ When it Comes to Differences in Health
Kriznik, N.
(Durham University)

Health inequalities are a persistent problem in developed countries like the UK with numerous social policies designed to reduce their levels. Policy analysis tends to focus on evaluating and improving solutions to a given problem, in this case health inequalities, rather than questioning the seemingly taken-for-granted nature of policy problems and examining the underlying assumptions of what the problem is. Using the ‘What’s the problem represented to be?’ approach developed by Bacchi (2009) this sociological research analysed 31 years of health policy in order to understand more about the problem of ‘differences in health’ in social policy in England. The analysis found that one of the main problems that public health aims to solve in relation to health inequalities is the issue of how to ensure that people make healthy choices about their lives in order to prevent future illness. Four perspectives on why individuals do not make healthy choices were discovered: a lack of information; the effect of surrounding social circumstances; the idea that healthy choices are not easy; and the influences of other people’s behaviour. While each perspective has a distinct focus, they also build on one another over time. From policy discussions of each perspective it is possible to reveal normative claims about how individuals behave and the impact this has on health. It is these normative claims which shape the form of interventions put forward in social policy to address health inequalities.

Wednesday 10 September 2014 at 14:30 - 15:00
Lifecourse
Steelhouse 3, CAMS, Main Building

Understanding Women’s Perspectives on Alcohol Consumption During Pregnancy
Laing, K., Kaner, E., Moffat, S., Rankin, J.
(Newcastle University)

Alcohol use in pregnancy is controversial in the UK; there is discord regarding how women should be advised and negligible attempts to incorporate pregnant women’s views within academic debates and medical practice. This research aims to explore pregnant women’s understanding of their decision regarding alcohol use. Twenty in-depth interviews with pregnant women across Newcastle-upon-Tyne were performed. Sampling was purposive according to socio-economic status, parity and drinking status. Interviews were halted when data saturation was reached. Thematic analysis is on-going, and is influenced by principles of grounded theory (staying close to the data and constant comparison). This has enabled the development of propositions about the research question and relevant pre-existing theory will be engaged with to help elaborate and enhance the findings. Three meta-themes have emerged. (1) The interplay of medical and social norms: social norms are dominant, with participants ‘just knowing’ that they need to alter their drinking behaviour. (2) Ideals of good motherhood: accounts are permeated by the need to be and be seen as a good mother. The stigmatisation of drinking in pregnancy was rooted in this, women judged themselves and others by these standards. (3) Understanding of alcohol as a ‘risk’ in pregnancy: risk was discussed in the absence of knowledge of the teratogenic effects of alcohol. In conclusion, these data indicate that pregnant women themselves are policing their own pregnancy and that of others according to socially sanctioned rules of good motherhood. The voice of the medical community is largely absent or ignored in their discourses.
Politics of Health
Stafford 2, CAMS, Main Building

(Assistive) Technologies of the Self and domination: A critical discourse exploring the use of Assistive Technologies in Dementia Care

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

Despite the cultural shift in North American and Europe to promote people with dementia as socially intact persons, the discourse of dementia as a ‘loss of self’ – the erasure of a person’s self-awareness and sense of personal and social identities - still remains. People with dementia face many challenges as the illness progresses from the inability to accomplish daily tasks of living, trouble with communication, forgetting recent events and, even, forgetting loved ones and themselves. As a result people with dementia have diminished independence and require support from a variety of health professionals and carers to manage daily tasks. Assistive technologies and telecare are another potential solution which is designed to increase independence for people living with disabilities enabling them to continue to live in their own homes and participate in activities of daily living. However, these technologies in dementia care are often designed with the person with dementia as a passive user. Sensors in rooms remotely send information on people with dementia’s whereabouts to call centres and carers with no direct input from people with dementia themselves. Additionally, people with dementia may be unaware or forget about installed assistive technology. This theoretical paper explores assistive technology through the use of Foucault’s technologies of the self and domination and his related concept of governmentality to suggest ways of understanding the relationships between people with dementia, their carers, health professionals and the assistive technology as ways of mediating specific discourses on independence and self-care in the face of memory loss.

Ethnocultural Diversity in Care of People with Dementia Disease

Larsen, L. S., Normann, H. K., Hamran, T. (UIT The Arctic University of Norway)

There is political consensus in Scandinavia that healthcare for people suffering from dementia disease should be home-based. High quality care requires trustful cooperation between various healthcare professionals, the patients and their relatives. Research indicates that in situations where such interaction is not established the persons with dementia disease risk delayed treatment and «worn-out» relatives. The Sami might have particular challenges with home-based care as some studies shows that they utilise health services to a lesser degree than the average population in Norway.

The purpose of this paper is to describe how healthcare professionals and relatives to Sami people coping with dementia cooperate. The study is based on qualitative interviews with seven relatives and ten professional caregivers.

The analysis relate to concepts from theories of trust, distrust and positioning theory, combined with discourse analysis. Trust and distrust are social phenomena, created and recreated in everyday encounters and understood as precautions in interaction shaped by positioning. They are effective as they form what is possible to do and achieve in practical situations.

Preliminary analysis shows that the positions «Sami» and «non-Sami» appear as stereotypes that creates mutual distrust. Stereotyping and distrust seems to transmit across generations, creating adverse barriers to cooperation and preventing access to health care services.

The findings indicate that cultural awareness in itself does not constitute a sufficient condition for trustful cooperation. The relationship between stereotyping, trust and distrust must be discussed if suitable models of dementia care for minority groups are to be developed and implemented.
Consumption as Care: Exploring the Role of Food and Provision at a Youth Centre in the North West of England

Laverty, L.
(University of Liverpool)

Feminist theorists have attempted to bring forward the notion of care into ontological thinking and away from generalising care through gender divisions. Gilligan (1995) introduced the term ‘ethic of care’, through which she challenged the notion of care as feminine. Tronto (1995) and de la Bellacasa (2011; 2012; 2010) have extended this claim, by pursuing the idea that care is essential component of human activity and the social world. In this view people are understood as constantly embedded in relationships of care. This paper will look at broadening out the literature on care, and how this is connected to respect, responsibility, and obligation.

Based on 18 months of ethnography at a youth centre in the North West of England I will describe the practice of food consumption, and how provision comes to be associated with care. Unlike previous literature on food and care (and health and care more broadly) the findings of the current study extend beyond domestic practices and the home as the primary site of care. Lastly I will focus on my own role in producing care within the setting. As I will show I quickly became socialised into a role as a provider. In socialising me to this role, the young people and youth workers constantly tested me into proving that I cared. This provision also became a form of exchange in the production of my data.

Responding to the Mental Health and Wellbeing Agenda in Adult Community Learning

Lewis, L.
(University of Wolverhampton)

In the UK, changes in the policy, funding and commissioning landscape for mental health and wellbeing are posing opportunities and challenges for adult community learning (ACL). Opportunities include increased recognition of and funding for the ‘wider benefits’ of learning whereas challenges included the risks of ACL provision becoming hijacked by a health and wellbeing agenda that compromises its primary educational purpose and values. This paper engages with these policy debates through reporting on a study of mental health adult community learning that employed the Capabilities Approach along with two other complementary areas of social theory – recognition theories and theories of capitals. Its aim was to explore the processes through which ACL impacts mental health and to draw out implications for policy and practice. Findings from focus groups with adult learners and tele-discussions with ACL practitioners revealed three main processes through which the provision helped generate inter-linked mental health and educational capabilities: providing recognition, generating resources (capitals) and enhancing agency freedom. Elaborating these findings, the paper sets out an argument for interpretation of the mental health and wellbeing agenda in ACL in terms of a humanistic, liberatory pedagogy that encompasses feminist praxis, and draws out other implications for policy across the areas of ACL and mental health.

“The Clinicians’ Perspective”: Decision-making Following Suspicion or Diagnosis of a Severe Congenital Anomaly

Lotto, R., Armstrong, N., Smith, L., Budd, J., Draper, E.
(University of Leicester)

Objectives: To explore the experiences of clinicians involved in counselling women following suspicion or diagnosis of a suspected fetal anomaly to aid understanding of Socio-economic variation in rates of termination for congenital anomalies.
Paper Abstracts

Participants: 18 clinicians involved in the care of women following suspicion of a congenital anomaly

Design: Qualitative study using semi-structured interviews.

Methods: Data analysed using constant comparative method to identify key themes.

Preliminary findings: Two key themes emerged: 1) risk and uncertainty; 2) active decision-making. Clinicians highlighted that uncertainty relating to prognosis was difficult to manage. Parents’ ability to understand and accept risk is influential in the decision-making process and was perceived to vary between Socio-economic and cultural groups. Despite consensus on a theoretical definition of ‘severe’ in terms of anomaly, there was individual clinician variation in relation to when a termination would be offered after the 24 week legal threshold. The same variation is not apparent prior to 24 weeks. With regard to active decision-making, some clinicians expressed concerns regarding the ability of some parents to make an active decision, continuing an affected pregnancy being perceived as the ‘default’ position.

Conclusions: The findings emphasise difficulties faced by both clinicians and parents when managing a pregnancy affected by a severe congenital anomaly. Issues relating to clarity and application of legislation, and its potential to perpetuate variations are also discussed.

Thursday 11 September 2014 at 09:40 - 10:10
Politics of Health
Stafford 2, CAMS, Main Building

The Characteristics of Drinking Occasions, and How These Might be Amenable to Policy Intervention

Lovatt, M., Holmes, J., Meier, P.
(University of Sheffield)

Proposed changes to alcohol policy in the UK are often framed within a context of the policies’ likely impact on the nation’s drinking culture. However, ‘drinking cultures’ are rarely defined, and policy makers fail to provide definitions of what a ‘responsible’ drinking culture would entail. Previous research into drinking cultures has emphasised excessive, public drinking by youth populations, and there has been little research into the everyday drinking occasions that make up a significant part of the population’s alcohol consumption.

In order to address this gap, this study focuses on one key aspect of drinking cultures – the occasions in which people drink alcohol. We conducted four focus groups with male and female adults of varying ages, and from various socio-economic backgrounds. We asked them to describe in detail the motivations and characteristics (for example location, who they drank with, and how much they drank) of their drinking occasions, and what factors influenced the characteristics of these occasions.

This paper reflects on two key themes identified in initial analysis of the data: 1) the complex interrelationship between different characteristics, and how this affects the nature of drinking occasions; 2) the ‘external’ factors (e.g. price and availability) and ‘internal factors’ (e.g. family or work commitments) which affect the nature of drinking occasions. By investigating the relationship between the characteristics of the different drinking occasions, and the influences which act upon them, we shed light on the more problematic characteristics of drinking occasions, and which of these may be amenable to policy intervention.

Wednesday 10 September 2014 at 12:45 - 13:15
Lifecourse
Steelhouse 3, CAMS, Main Building

What the Papers Say: Exploring the Social Construction of Joint Pain in British Print Media

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

As illness is experienced within a social world, the perceptions, beliefs and understandings encountered within that world can profoundly influence how a condition is seen and experienced. The media play an important role in both influencing the public health agenda, and shaping the public’s understandings about health, illness and disease. Understanding how a particular condition is portrayed in the media allows insight into how that condition is constructed, and the impact of this on illness actions and identity.

Previous research has highlighted that negative attitudes and beliefs exist about osteoarthritis, with perceptions of the condition linked to wider negative connotations of ageing and disability. In order to gain insight into societal
perceptions of osteoarthritis, this on-going study explores how the condition is constructed within British newspapers. A total of 1043 articles were included within the study and both thematic and discourse analyses were conducted.

Competing discourses about ageing were found within the sampled articles. Language of ‘successful ageing’, including anti-ageing messages and products, were commonly found; however these sat alongside understandings of ageing as a time of frailty and expected chronic illness. Such dichotomous perceptions were also found in relation to disability, where impairment due to arthritis was seen as both something that could be overcome and something that inevitably progressed. This paper explores how these wider social issues, and subsequent political actions (for example benefit reform and austerity measures), have shaped public understandings of osteoarthritis.

Thursday 11 September 2014 at 10:15 - 10:45
Patient-Professional Interaction
B. Kendrick, Main Building

Dementia, the Elephant in the Room: Observations from a Clinical Trial

Lyle, S.  
(University of Oxford)

Researchers calling for a critical analysis of Dementia have argued for the recognition of the socially constructed elements of the disease and consequently for research, analysis and medical treatments that are underpinned by the social model of disability as well as a theory of care that promotes person-hood and wellbeing. This paper will contribute to debates around the socially constructed nature of Dementia by drawing on qualitative research carried out within a clinical trial designed to evaluate an exercise based intervention for people with mild to moderate Dementia.

Based on 20 in-depth interviews with trial participants, their carers and physiotherapists as well as observations, this paper will present the ways in which physiotherapists deliver an exercise intervention by ignoring the ‘elephant in the room’- the participants’ Dementia. It will be argued that ignoring the elephant in the room is coterminous with participants’ own experiences of Dementia which often leaves them feeling stigmatised, at odds with their diagnosis, unable to connect it to their perceived capabilities and a desire and some capacity to function well in social interactions. By eschewing participants Dementia when engaging with them and delivering the exercise based intervention I argue that physiotherapists are implicitly operating with a model of Dementia that recognises the socially constructed aspects of the disease, they are actively promoting person-hood and wellbeing whilst simultaneously not denying the bio-medical symptoms and consequences of the disease. This way of working with Dementia patients may offer insight into good clinical and research practices.

Friday 12 September 2014 at 10:45 - 11:15
Screening and Diagnosis
Stafford 1, CAMS, Main Building

What can ‘Candidacy’ Tell us about Symptom Appraisal? Accounts from Colorectal Cancer Patients

Macdonald, S., Conway, E., Browne, S., Macleod, U., Campbell, C., Robb, K., Steele, B., Welller, D.  
(University of Glasgow)

Timely diagnosis of colorectal cancer (CRC) in symptomatic patients can greatly improve outcomes. Early diagnosis may be impeded by patient, provider and system factors. Awareness of the warning signs of CRC is low typically and failure to appreciate seriousness of symptoms is well documented. Making causal links between symptoms and cancer requires individuals to first consider their cancer risk during the appraisal period.

‘Candidacy’ is essentially a heuristic device that shifts emphasis from individual risk attribution to a shared understanding of risk. By drawing on an amalgam of evidence from personal, social and socio-cultural spheres ‘candidates’ are identified as those who are most, or least, likely to suffer illness.

Here we present findings from a secondary analysis of 24 interviews with CRC patients. As the interviews contained unanalysed narrative accounts of responses to diagnosis we sought to explore whether cancer ‘candidacy’ featured in CRC patients’ retrospective accounts and whether this influenced symptom appraisal.

Few participants identified themselves as candidates. The nature of their symptoms – mild and/or vague – reinforced this. Indeed many had a history of bowel symptoms though accounts of delayed help-seeking are rare. All reacted to a CRC diagnosis with ‘shock’. Importantly, shock was contextualised by three issues: the ‘hazy’ and mild nature of symptoms; expectations, based on previous experience of benign bowel diagnoses; a feeling of general ‘wellness’.
We conclude that the problematic nature of symptom appraisal: mild, vague symptoms do not tally with the pervasive socio-cultural perception of cancer as the most serious of diseases.

**Thursday 11 September 2014 at 11:25 - 11:55**
Patient-Professional Interaction  
Stafford 1, CAMS, Main Building

**The Social and Ethical Aspects of Patient Discharge Against Medical Advice**

*Machin, L., Warriner, D., Ford, E., Siby, S.  
(Lancaster Medical School)*

Past studies have found that up to 1.5 per cent of patients decide not to follow health professionals’ advice and were known to have discharged themselves from hospital. This is significant when almost 15 million patients were admitted in the UK between 2009 and 2010. The reasons given for self-discharge include long waiting time, poor bedside manner, and failure of communication amongst hospital staff. As a result, self-discharge has been framed in negative terms particularly as these patients have higher readmission and in-hospital mortality rates. Yet, self-discharge could be perceived as an expression of patients’ rights. If patients are perceived as duty-bound to follow medical advice, self-discharge could offer a way of ‘equalising’ the balance of power between the two. So, how do self-dischargers and health professionals understand and make sense of the concepts ‘self-discharge’, and ‘self-dischargers’. Findings from an interdisciplinary two year pilot project will be reported. The findings are based on 32 qualitative interviews with self-dischargers (15) and health professionals (17) at two Northern Hospitals. The interview transcripts have been analysed for emerging themes and theoretical literature surrounding Patient-Professional Interaction have been drawn upon to offer insight into the perceived position of the hospital patient, and the perceived role of health professionals within the hospital and community settings.

**Thursday 11 September 2014 at 14:00 - 14:30**
Health Service Delivery  
White Hall 2, CAMS, Main Building

**Managing Acute Illness in Medical and Maternity Settings: The Significance of Boundary and Categorisation Work, and Rescue Trajectories for Patient Safety**

*Mackintosh, N., Mackintosh, N., Sandall, J.  
(King’s College London)*

The normative position within acute hospital care is to ‘rescue’ unless ordered otherwise. However, reports have highlighted problems with timely recognition, treatment and referral of patients’ whose condition is deteriorating while cared for on hospital wards. International policy has focused on safety system solutions to help facilitate management of clinical deterioration.

Our research draws on the patient trajectory (Strauss et al 1985) as a useful theoretical resource for the study of rescue. We consider the concepts of boundary and categorisation work within the contexts of medical and maternity care, given differences in population, models of care, cultural norms, rescue trajectories and user experiences of involvement in safety.

Data collection involved ethnographic fieldwork in two UK NHS Trusts, (2 wards in medical directorates, 2 obstetric units and one alongside midwifery unit). This included observations (270 hours), interviews (80) with health care assistants, nurses, midwives, doctors and managers, and documentary analysis.

Our findings demonstrate that safety systems reinforce the dominant rescue imperative in both maternity and medical settings. Potential as well as actual clinical instability influences the location of patients on specific wards, access to specialist care and the allocation of resources. Jurisdictional claims over management of the acutely ill are linked to the socially constructed space between physiology and pathology in maternity care, and between rescue and palliative care in medical settings. Data differences between settings reflect wider political and socio-cultural influences, notably the legitimacy of user involvement in rescue trajectories, and trade-offs between quality, choice and equity in practice.
"It was my Opportunity to Show Him That I Will Support Him": Men’s and Women’s Accounts of Negotiating Change During Men’s Participation in a Weight Loss and Healthy Living Programme

MacLean, A., Hunt, K., Gray, C., Bunn, C., Smillie, S., Wyke, S. (University of Glasgow)

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 programmes are seen as women’s spaces. The randomised controlled trial of Football Fans in Training (FFIT) showed that the professional football club setting acted as a powerful symbolic ‘draw’ that successfully engaged overweight and obese men, a group difficult to reach, in a weight management and healthy lifestyle programme. An analysis of FFIT participants’ accounts (collected through 10 session observations and 9 focus group discussions) revealed how men’s female partners, mothers and mothers-in-law were constructed as influential actors in the negotiations of change in food and eating practices that men undertook within the family context and more broadly. Men portrayed the roles played by the women in their lives variously as: facilitative or detached allies, undermining change, or resistant to or threatened by change. In providing these accounts, men drew on notions of hegemonic masculinity to position themselves in relation to their engagement in ‘healthy’ eating practices. In this paper, we build on this work by analysing semi-structured interview data from seven participants in a similar weight management programme delivered in 2013-4 at a professional rugby club (RuFIT) and separate interviews with their female partners. We compare men’s and women’s accounts of the negotiation of changes to family practices and explore how these accounts contribute to understandings of how gender roles, relations and expectations influence, and are influenced by, such negotiations.

The Donor Citizen: Blood Donation and Citizenship, Challengeing the Notion of Altruism

Mahon-Daly, P. (Bucks New University)

Using data from an ethnographic study, the paper re-examines new discourse about blood donation, challenging the orthodoxy of altruism, giving new understanding and justification for blood donation. Using data from 80 blood donors to elicit real-time ideas about blood. Issues of trust were examined via the lens of deferment as increasingly it is not good enough to just donate blood without societal, as well as techno-medical, surveillance. Donating blood is shown to be a form of active citizenship, and to be deferred from doing so has a direct impact on individuals’ freedom to donate and thus community membership.

The concept of citizenship has become the cornerstone of the contemporary public health agenda according to Petersen and Lupton (2000:61) they argue that the concept of citizenship is a term that is contingent with the demands of the surrounding society. As a result, modern citizenship is a both conscious and increasingly corporeal attribute. Petersen and Lupton (2000:62) argue that ‘The contemporary meanings of citizenship are closely aligned with notions of the civic and the civil and are intertwined with the relationships between citizens, the common public life and the city.’. Citizenship has developed from its early associations with community and solidarity to being linked to obligations and regulation of the individual over the majority (Miller and Rose, 1993:98 cited in Petersen and Lupton, 2000:63). A key aspect to this new representation of citizenship is the relationship with self discipline, and it is this aspect that will be applied to the concept of being a blood donor in contemporary British society.
A Market in ‘Futures’? A Critical Analysis of the Online Promotion of Commercialised Digital-image-based ‘Health MOT’ Services

Malson, H., Kent, J., Woodley, J., Fannin, M. (University of the West of England, Bristol)

In the context of a neo-liberalised and globalised healthcare market, sales of pharmaceuticals, healthcare products and services ‘direct to consumers’ have increased significantly. Amongst these are a wide range of ‘health checks’ or ‘health MOTs’ targeted at asymptomatic individuals. Many of these commercially packaged services use digital imaging technologies such as CT Scanning, MRI Scanning and Ultrasound to ‘map’ and ‘screen’ the body for signs of illness. A number of problems associated with the sale of these particular services have already been identified. These include failures to draw attention to the risks of screening, the possibility of false positive and false negative results and the potential to cause confusion and unnecessary anxiety amongst consumers, leading to potentially inappropriate clinical intervention. However, there has been little exploration to date of the specific ways in which these services and their potential consumers are discursively constituted in promotional/advertising contexts. In this paper we therefore present a preliminary analysis of the promotional websites of commercial health care providers offering digital-image-based ‘Health MOTs’ in the UK addressing how these services and their potential consumers are discursively framed, and in particular the ways in which relationships between ‘images’, ‘results’, bodies and consumers’ futures are thereby constituted.

Parental Resistance to Mandatory Childhood Immunization: The Role of Subjective Conception of Body, Health and Individual Responsibility

Marhankova, H. J. (Charles University in Prague)

The Czech Republic is one of the countries with a system of mandatory vaccination. In the eyes of the law a person who refuses to have their child vaccinated commits a civic misdemeanour, and endangers the public health. This paper focuses on parents who challenge this system with their decision to refuse their child’s immunization. Twenty-two parents whose children were not vaccinated were interviewed and several participant observations were conducted at public lectures concerning immunization and on meetings of parent critical to vaccination. The paper analyzes the decision to refuse mandatory vaccination in the context of parent’s conception of body, health and illness. In accordance with the work of Nikolas Rose, it analyzes how the parents construct their conception of body and health and how those conceptions became integrated into the governmental ‘regimes of self’ and inform the choices the individuals make throughout their life-course. The process of decision making concerning the child’s immunization functions as an arena where the parents articulate their somatic individuality. The individual body and health emerge as a space where the individual works on himself, and places new ethical demands on himself. To refuse the mandatory vaccination was by the parents conceptualized in term of this never ending work on one’s own (and their children’s) health that is articulated through the individualization of responsibility and risk. Simultaneously, the paper examines how their conception of health became a site of activist engagement and resistance to biomedical authorities and knowledge.

Beyond Metrics? Utilising ‘Soft Intelligence’ for Healthcare Quality and Safety

Martin, G., McKee, L., Dixon-Woods, M. (University of Leicester)

Following Francis, there have been calls for healthcare policymakers and administrators to make greater use of insights into quality of care deriving from professionals, patients and carers, given acknowledged limitations of quantitative data. However, there are unanswered questions about how such insights might be collected, interpreted,
and put to use. We draw on 107 in-depth qualitative interviews with senior stakeholders in the NHS, including those in clinical and managerial roles, to address the question of what forms this ‘soft intelligence’ might take, and its utility and limits as a source of knowledge for diagnosing and addressing problems of healthcare quality and safety.

Participants saw value in soft intelligence and in the way it could reveal issues often obscured by conventional metrics, but struggled with the challenge of collecting and interpreting it to produce valid and reliable insights. The approaches they described risked replicating the limitations of hard, quantitative data. We highlight alternative approaches that suggested ways of obtaining, interpreting, and utilizing soft intelligence that make best use of the unique insights that it offers, drawing on ideas from organisational sociology and psychology. The value of soft intelligence lies not only in its ability to substantiate issues identified through conventional ways of knowing, but also in its potential to disrupt taken-for-granted assumptions about quality and safety and organizational performance. Using soft intelligence in this way is challenging and discomfiting, but offers, we argue, an important defence against the complacency that can precede calamity.

Thursday 11 September 2014 at 14:00 - 14:30
Gender
Steelhouse 2, CAMS, Main Building

What are the Implications for Performances of Masculinity of Taking Part in a Football-based Gender-sensitised Healthy Living Group Programme in a Male Prison?

Maycock, M., MacLean, A., Gray, C., Hunt, K. (University of Glasgow)

When delivered in a community setting (Scottish Professional Football League football clubs), the Football Fans in Training (FFIT) programme (a group-based, gender-sensitised weight management, physical activity and healthy lifestyle programme) has attracted overweight and obese men and helped them to lose weight, improve their diet and increase physical activity. Following expressions of interest from other stakeholders, we are investigating whether FFIT can be translated to other settings, and is successful in engaging different target groups in these settings. Men living within prisons experience many challenges to their mental and physical wellbeing, some of which are specific to prison settings. Furthermore, male prisons are largely all male environments, in which performances of masculinity are structured in hierarchical ways in reference to hegemonic manifestations of masculinity that relate to the prison context. This paper considers the ways in which participants in an adapted delivery of the FFIT programme talked about the ways in which their participation changed their position and relationships within the prison. This paper also explores the implications of being (un)able to lose weight, improve diet and increase physical activity within this environment. On the basis of qualitative interviews and observations of weekly programme deliveries, we report the experiences of the prisoners in trying to make positive changes to their health within this context.

Thursday 11 September 2014 at 08:30 - 09:00
Ethnicity
Stafford 1, CAMS, Main Building

Irish Migrants to England and Scotland: Health and the Transformation of Habitus

McGovern, P., Nazroo, J. (University of Manchester)

We explore the question: to what extent do people of Irish heritage, living in Great Britain, constitute a cohesive group that has distinctive health outcomes? Over the last two centuries, Irish migration to Britain has dwarfed that of any other overseas group. For much of that time, they have occupied the lowest rung of the social hierarchy and suffered disadvantage and discrimination. Up to the 1980s, there was an assumption that ethnicity was based on visible difference and that the Irish did not constitute a distinct group. Political pressure in the 1990s led to the inclusion of ‘Irish’ as an ethnic category in the 2001 censuses of Great Britain, but debate remains about the extent to which this classification is sociological meaningful.

We use data from the Health Survey for England 1999/2004 and the Scottish Health Survey 1998/2003 to investigate economic inequalities, education, health and wellbeing in two generations of Irish migrants to England and Scotland. We explore the extent to which these generations are distinctively different from each other and from the reference groups of English and Scottish heritage in habitus. If, as many believe, the Irish are rapidly assimilated and do not retain a distinct identity or cohesive cultural practices, second generation migrants may be more similar in habitus to their English and Scottish counterparts than to the first generation Irish migrants. Key questions arise about whether
this process is different in each reception country and whether Irishness continues to be racialised through the signifier of Catholicism.

Thursday 11 September 2014 at 14:00 - 14:30
Health Care Organisation
Stafford 1, CAMS, Main Building

Normalizing Electronic Messaging in Norwegian Healthcare: Home Care Nurses’ and GPs’ Experiences

Melby, L.
(University of Oslo)

Communication and information exchange across organizational borders is a challenge that needs to be addressed in order to provide more seamless treatment and care for patients. In Norway electronic messaging (e-messaging) is being introduced in order to simplify information exchange and strengthen communication between municipal care services (e.g. home care), general practitioners (GPs) and hospitals. In December 2013, 261 municipalities (61 %) had implemented e-messaging with GPs. There is, however, a long way from implementing a technology to full scale use and integration into existing work practices. In this paper I discuss the continuous efforts being made by homecare nurses and GPs in order to make e-messaging a normal part of practice.

The paper draws on insights from Normalization Process Theory (NPT), as developed by May and colleagues. NPT addresses the process of implementation and embedding new technologies into organizations, and it is concerned with ‘how and why things become, or don’t become routine and normal components of everyday work’ (May & Finch 2009; May et al. 2009). The data material consist of interviews with 43 persons: 23 nurses, 11 GPs, 5 medical secretaries and 4 project managers. Observations of homecare nurses’ work serve as background knowledge.

In the analysis three elements of the normalization process is highlighted: (1) enrolment of users (cognitive participation), (2) users idea of e-messaging as a meaningful practice (or not) (coherence), and (3) routine development and refinement (collective action). Users are overall satisfied with e-messaging, but much work has been invested before reaching this point.

Friday 12 September 2014 at 10:45 - 11:15
STS
G63, Main Building

Generation, Degeneration and Regeneration: Doing Disease in a Dish

Milne, R.
(University of Cambridge)

Diseases of ageing including Alzheimer’s and other neurodegenerative diseases represent a significant global health challenge. This paper presents work in progress from ethnographic research in a neuroscience laboratory to consider the intersection of neurodegenerative disease and regenerative medicine, and the practices of producing diseases ‘in a dish’.

The paper considers how the meaning and value of age in relation to neurodegenerative disease are reconstituted within the practices of research using induced pluripotent stem cells. Age is a feature of bodies within populations from whom the cells are taken, valued for their contribution for research but not for the social and economic ‘burden’ of ageing. It is also an accumulated quality of ‘mature’ cells which have lost their youthful potential to differentiate. Thirdly, age is an epigenetic feature erased during the ‘reprogramming’ of cells to an embryonic state. Finally, age is a temporal process that has to be recaptured within the time constraints of research. Youth and ageing thus become repeated states in a cyclical cellular re-enactment of neurological lives in vitro.

Major expectations of future medical benefit have been attached to IPS cell technology, in which skin and other adult cells can be ‘reprogrammed’ and their ‘fate’ changed. This paper contributes to understanding the bodies, populations and practices that constitute and complicate this promise. In addition, it contributes to exploring how the emergence of ‘epigenetics’ opens up new questions for both biological and social research.
How the Sausage gets Made: An Ethnographic Study of Producing Data on Quality in Healthcare

National clinical audits in the United Kingdom now cover many diverse medical, surgical and mental health conditions. An enduring concern of the literature on the ‘Audit Society’ is that attempts at transparency may, instead of providing clarity, offer a ‘legitimized aura of precision in the measurement process’ (Power 2004) and degrade into mere ‘certificates of comfort’ (Power 1997). Yet field studies of how audit actually takes place – or how the data sausage gets made - remain remarkably rare. This paper seeks to address this deficit through ethnographic study of data collection practices in two national clinical audits and by drawing on the conceptual frameworks of Garfinkel (1967) and Hughes (1958) in tandem to examine the social processes of measurement. We ask a key practical question: how might the ‘normal, natural troubles’ of data collection occur in the production of national clinical audits, and what implications might there be for achieving the ideals of accountability and the policy goals of enabling control and scrutiny of professional and organisational practices? Our findings indicate ‘troubles’ associated with: the ambivalent status of data collection as a ‘respectable’ professional activity; the mismatch between clinician and management utility in data collection; and practitioners’ knowledge that the data they collect may be used for uncertain and potentially ominous future purposes. We propose that these social and cultural influences on data practices are more relevant to explaining how data are generated for large-scale audits than are currently dominant assumptions of ‘gaming’.

With Whose Consent? Decision Making in Research Ethics Committees
Morton, J. (University of Salford)

This paper argues that reviewers in Research Ethics Committees (RECs) engage in complex negotiations with each other when reviewing research with people deemed to lack capacity. This is in contrast to perceptions held by researchers which are frequently based on anecdotes of negative experiences of attending. RECs in the United Kingdom are charged with making decisions about what constitutes ethical research and have the power of veto over whether research takes place or not. Sociological researchers have raised legitimate concerns about the dominance of consent requirements as these impact greatly on the type and range of studies undertaken. However, there is limited research on the real-life, every day negotiations which take place at RECs where such judgements are made. With a focus on Health Research Authority RECs which are ‘flagged’ to review studies involving ‘incapacitate’ subjects, this paper describes preliminary findings from observations of six RECs as well as interviews with reviewers and researchers. These have revealed that panel members take seriously their responsibilities to research and the production of knowledge. They are often keen to find ways to support research by aiding the researcher to conform with official procedures. Discussions and debate within the REC demonstrate thoughtful and nuanced understandings about consent in general and for ‘vulnerable’ research participants, with reviewers expressing concern about the exclusion of people from research. The paper concludes by proposing that it is official procedural requirements which constitute the barriers to research with people who lack capacity and not necessarily the REC reviewers.

Who and Why Take Part in clinical Trials? A Sociological Analysis of Healthy Volunteer Demographics and Motivations for Involvement in First In-human Clinical Trials in the UK
Mwale, S. (University of Brighton)

This paper examines the demographics and motivations of healthy volunteers in first in-human clinical trials in the UK. It draws on data from an on-going PhD project on human involvement in clinical trials focused on regulatory and
Paper Abstracts

ethical dimensions of first in-human clinical trials in the UK. While it is commonly assumed, even among academics in medical research, bioethics and social sciences, that money is the primary motivating factor for human involvement in clinical trials and that most participants in clinical trials are from poor backgrounds, this paper examines the complexity of human involvement in clinical trials. Specifically this paper explores ways in which personal financial and social circumstances may act as drivers for human involvement in clinical trials. It also examines the demographic characteristics of healthy volunteers, and why they get involved in clinical trials. In doing so the paper aims to demonstrate the complex relationship between society, monetary rewards and motivation in clinical trials. Using data obtained from a quantitative survey and interviews with healthy volunteers in first in-human clinical trials, the paper aims to challenge commonly held assumptions about people who take part in clinical trials and their motivations for doing so.

Friday 12 September 2014 at 09:00 - 09:30
Experiences of Health and Illness
- Stream Sponsored by Health Talk Online -
Stafford 1, CAMS, Main Building

Paradox of Diagnosis: The Positive Effects and the Limit of Diagnosis in ME/CFS and FM Patients

Nojima, N.
(Osaka University)

There has been ongoing debate about the meaning and the function of diagnosis for patients. One important point is how patients and other people around act when the patients receive the diagnosis. MUS (medically unexplained symptoms) is often discussed as an outstanding example indicating that receiving a diagnosis constitutes a critical event. This paper reports on the qualitative study of 17 participants diagnosed with ME/CFS or FM, the representative diseases of MUS. I analyze how diagnosis impacts on the illness experience of these patients, how this impacts will change in the course of illness experience and how the other people around react to the diagnosis. I will focus on the positive effects of the diagnosis and its limit for the patients. The positive effects include liberation of the patients from their guilt-sense, validation of suffering and opening access to medical treatments, as have been indicated by the previous research. However, in the case of MUS, there is clearly a limit of these diagnosis effects, which eventually are dependent on social recognition of the disease categories. My data suggest that for people around the patients including their family members, ME/CFS or FM diagnosis, at least in Japan, not only does not prove the authenticity of the patient’s suffering but also is sometimes denied its legitimacy as a disease. As a result the diagnosis brings confusing situation to the patients in their relationship with other people around. It can fix the other people’s suspicion about the legitimacy of the patient’s sufferings.

Wednesday 10 September 2014 at 13:55 - 14:25
Gender
B. Kendrick, Main Building

The Continuous Configuration of Age, Gender and Technology through Circuits of Nursing Practices

Obstfelder, A., Lotherington, A. T., Pope, C.
(UIT The Arctic University of Norway)

Feeling old at work is related to our ability to manage tasks we have always done and to handle the changes associated with modernity and biology. While some workers capitulate and retire early, others ‘take care’ of themselves in order to stay in employment longer. This paper explores how nurses in critical care medicine manage working in later life. Theoretically we draw on feminist understandings of technology and Science and Technology Studies for insights into the mutual shaping of gender and technology, and also on critical gerontology which alerts us to socially constructive features of ageing.

Our analysis is based on interviews with 10 older nurses about technological change in their work. The nurses portrayed nursing and technology as inexorably linked. They were less concerned with conquering devices but wanted to manage the dramatic and intense work environment. Technologies and their own bodily and emotional wellbeing were closely bound up in these management processes.

Our analysis shows that gender, technology and age are interconnected in nursing practices, and that they interact to produce gendered ageing in nursing work. Ageing challenged individual nurses’ professional identity and forced adjustments to work arrangements and employment relationships. When their management strategies were successful the bodily processes of ageing were neutralized, and the gendered nature of ageing disappeared from
sight. Technologies were implicated in how these nurses managed ageing at work and our research highlights how aging is formed differently in and through circuits of nursing practices.

**Friday 12 September 2014 at 11:55 - 12:25**

Inequalities
White Hall 3, CAMS, Main Building

**How Lifestyle Became the Dominant Explanation for the Causes of Type 2 Diabetes Related Morbidity and Mortality: A Historical Analysis**

O'Donnell, S.
(University College Dublin)

Since the emergence of diabetes as a public health threat around the middle of the 20th century, accounts of disease causation have focused on lifestyle and/or genetics, while the role of broader structural issues, such as psychosocial distress, were downplayed. Yet, in the years prior to this emergence, when diabetes remained the preserve of the wealthy, medical experts drew upon multiple explanations for the origins of the condition, with the role of social organisation and interplay between mind, body and environment among the most popular.

This paper is based on a discourse analysis of the writings of the most prominent diabetes experts between 1870 and 1950. It aims to highlight why lifestyle, and not social organisation, became the prevailing research interest as diabetes made the transition from being a disease of the rich to one of the poor. The results show that until the 1920s, diabetes was predominantly characterised as a nervous malady caused by overwork and job strain. However, this applied only to those who held important positions in society, while less advanced ‘races’ (e.g. working class or ethnic minority populations) were understood to be relatively immune. It was not until the 1940s, when diabetes became more common among those lower down the social hierarchy, that lifestyle became the dominant explanation. The paper concludes by arguing that this shift in the definition of the illness was shaped by the dynamics of class relations rather than any new forms of scientific evidence which may have developed at the time.

**Thursday 11 September 2014 at 10:50 - 11:20**

Mental Health
Steelhouse 2, CAMS, Main Building

**Public Discourse on Mental Health and Illness: Representations and Perspectives in Swedish Newspapers 2009**

Ohlsson, R.
(Department of Education)

Mass media plays a central role in the continually changing public discourse on health and illness. In order to examine how shared knowledge is produced and transformed in mass media the ways mental health related issues were represented in the two major Swedish daily newspapers in 2009 were subjected to a qualitative analysis. Drawing on the theory of social representations the analysis focuses on how different perspectives are applied in the articles and how issues concerning mental health are represented. The results show that this discourse can be characterized as a dialogue with salient argumentative features: the perspectives of lay persons are supplemented by views of medical experts and others in what constitutes a field of contestation (Crossley 2006) where a number of conflicts are made explicit and central issues concerning authoritative knowledge are addressed. Among the underlying conflicts that are identified, the distinction between normal and pathological is central and processes of medicalization are addressed as problematic issues. Questions are also raised in the texts whether mental health problems are becoming increasingly common in contemporary society and, in that case, why. Further, the results indicate an ambivalence regarding the authoritative role of expert knowledge concerning mental health as critique and expressions of distrust are juxtaposed with signs of confidence and dependence on professionals. The implications of the study applies to the relations between lay persons and ‘psy-professionals’ (Rose 1999) and the expectations that are placed on expert knowledge in a wide range of societal issues and in peoples’ everyday life.
Redistributing Expert Tasks: Responsibilisation without Jurisdiction

Olsvold, N.
(Lovisenberg Diaconal University College)

Background - Skill mix initiatives and demands for functional flexibility in carrying out work processes in healthcare are claimed to change traditional boundaries between professions. Acquiring knowledge about how exactly they are changed and with what consequences for who demands that we study the work practices of health care professionals in local contexts. Furthermore, we need theoretical discussions that stimulate the development of conceptual frameworks that can aid our understanding of the effects of new work arrangements on professional practice.

Study and methods - This paper is based on an ongoing study of the implementation of a change in the care of patients receiving extracorporeal membrane oxygenation (ECMO) in a cardiac ICU. Data was collected by observations as well as by individual interviews with nurses, doctors and perfusionists.

Overview of paper - The purpose of the paper is to discuss how to interpret the different meanings attached to the responsibility of doctors and nurses affected by the change. The term responsibilisation is used in the governance literature to describe a neoliberal governing technology aimed at controlling individuals and institutions by decentralising and individualising responsibility for various states of affairs. Here I suggest that it may used in a slightly different way to describe the excess but largely invisible responsibility that follow from the practice of downloading expert tasks from higher paid professionals to professionals lower down in a hierarchy without allocating formal responsibility for new tasks. Jurisdictional boundaries between professions are maintained but practical expertise is dispersed.

How Empowered are Patient Organisations in Poland? A Comparative Analysis of Five Condition Areas

Ozieranski, P., King, L.
(University of Bath)

We explore patient organisations’ role in Poland’s drug reimbursement policy, drawing on the growing body of research on patient activism and policy involvement in Western countries. We considered the general mechanisms of reimbursement policy, including patient involvement, using 91 interviews with public officials, politicians, regulatory scientists, the pharmaceutical industry and journalists. We then conducted 31 interviews with patient organisations and medical experts from five condition areas covered by drugs targeting relatively large (diabetes and cardiovascular diseases) or small (cancer, inflammatory and rare metabolic conditions) populations. We analysed the interview data based on the constant-comparative method, combining the results with a quantitative analysis of organisational websites. We found that, first, patient organisations’ emergence and policy activity were primarily triggered by developments in reimbursement policy. Better access to medicines was associated with minimal policy activity of cardiovascular conditions, contrasting starkly with rare metabolic diseases. Second, patient organisations enjoyed broad policy access as citizens. There were few structures, however, encouraging patient participation, except for rare and inflammatory diseases. Third, patient organisations sought to influence decision-makers directly, through formal meetings and protests, and indirectly, through influencing other stakeholders and the public opinion. Fourth, limited financial and organisational resources entailed patient organisations’ greater dependence on other stakeholders, particularly drug companies. Finally, patient organisations’ policy success depended on charismatic leadership, disease ‘newsworthiness’ and personal connections with other stakeholders, while the membership base appeared less important. Overall, while patient organisations sometimes clearly influenced reimbursement policy, they were still structurally less empowered than in countries like the UK.
‘To Feel Healthier’ and ‘to be Normal’: Multiple Obesities and Meanings of ‘Success’, Weight Loss Surgery (WLS) as a Weight Loss Tool

Parsons, J., Pinkney, J., Letherby, G. (Plymouth University and Peninsula Schools of Medicine & Dentistry)

This paper draws on ‘one’ aspect of an exploratory study into psychosocial experiences of weight loss and diabetes management practices, notably narrative accounts from weight loss surgery (WLS) patients who had undergone a range of WLS techniques between 2005 and 2013. Potential respondents were recruited via an online advertisement on a WLS information website and 32 former WLS patients (30 women and two men) engaged in a series of in-depth, online asynchronous interviews over six months in 2013. The majority (80%) were extremely positive about their WLS and all considered themselves active agents in seeking treatment. They were not passive or seeking to relinquish ‘control’ but wanting treatment for a multiplicity of ‘obesities’, with surgical intervention considered an appropriate tool for weight loss. This was driven by a desire to engage in ‘normal’ weight loss management techniques, alongside other ‘normal’ activities as one respondent account exemplifies: ‘to be able to move more, to be in less pain, to fit into clothes, to not be rejected for jobs because of my appearance, to not be treated as unintelligent because of my appearance, to stop the bullies, to be normal’. WLS was therefore (mostly) considered a ‘successful’ medical solution to a medical problem, even when co-morbidities did not improve or got worse after surgery. Respondents resisted the notion of WLS as ‘cheating’ as they still had to work at managing weight loss. Successful weight loss therefore continues to be a moral category that needs to be carefully negotiated and managed.

Organ Donation, Boundaries and the Gift Relationship

Parsons, S. (Anglia Ruskin University)

Recent literature suggests that ‘gift relationship discourse’ is used to promote and encourage organ transplantation and donation (Shaw 2009). The usefulness of this discourse is challenged by Berking (1999) and Holtkamp (2002) who suggest that the literature on giving presents it as a ‘one way transaction’ and emphasises the noble act of the altruistic individual. This portrayal it is claimed, detracts from the highly complex relationship between organ donor families and organ recipients and their different perceptions of the donating process. My paper aims to add to our knowledge of this relationship. In particular, I will be discussing the preliminary findings of my own primary research which draws out the processes by which all parties construct ‘boundaries’ between the donors and recipients. I am interested in the ways these boundaries appear to separate donor and recipient and in turn connect them insofar as they are often left with questions about the ‘invisible other’ at a fantasy level within their own narratives. I am interested in discussing the effects of such boundaries in terms of revealing more of the ways in which experiences of suffering, loss and altruism are both construed and denied in the organisation of organ transplantation and donation.

Smoking in Vehicles Carrying Children: A Case Study of Newspaper Reporting of Public and Scientific Opinion Driving the Policy Debate


Smoking in enclosed public spaces has been prohibited in the UK since 2007. Interest has since grown in other microenvironments that future action to reduce second-hand smoke (SHS) exposure might target. We analysed newspaper coverage of the policy debate around legislation to protect children from SHS exposure in private vehicles. Our analysis incorporated articles from UK and Scottish national newspapers in the decade preceding votes in Parliament empowering ministers to introduce legislation prohibiting smoking in vehicles carrying children.
**Paper Abstracts**

We investigated how articles represented public and scientific voices in the policy debate. Articles were identified using the electronic database NexisUK and coded in NVivo. Three researchers developed and cross-checked thematic categories. Emergent themes included rationales for legislation, feasibility of legislation, and arguments presented in opposition to legislation.

The frequency of articles reporting on the topic of SHS in vehicles increased throughout the sample period. Legislation was largely reported as necessary and enforceable, and presented as having public support. While the public were portrayed as aware of the harms associated with SHS, drivers were portrayed as insufficiently aware of the harms presented to children in vehicles.

Scientific and public interest in legislative solutions to children’s exposure to SHS in vehicles appeared to grow over the past decade. We suggest that when promoting potential interventions, public health media advocates might benefit from drawing attention to successes of existing smoke-free legislation, which promoted changes in attitudes, behaviours and norms. We also suggest that advocates highlight children’s developmental vulnerability to SHS exposure, and make clear that reducing SHS in vehicles would reduce harm to children.

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**Friday 12 September 2014 at 10:10 - 10:40**

Critical and Public Health

Steelhouse 3, CAMS, Main Building

**Unavailable for Prevention: Smoking Hookah as a Temporal Normative Challenge**

*Pelters, B.*

*(Karolinska Institute)*

Hookah smoking has been called “the second global tobacco epidemic since the cigarette”, an image which immediately triggers demands for prevention. Yet this seemingly unimportant item presents a veritable challenge to the rationality of prevention.

Drawing on the findings of a qualitative interview study about the understanding of hookah smoking in young adults, the intertwining of the notions of time and sociality in hookah smoking are outlined as characteristics of a counter reality which undermine the common rationality of prevention and function as a productive free zone for identity work. In particular, it will be shown that the combination of a present resembling Hannah Arendt's vita contemplativa and a reciprocal sociality created by a process reminding of Marcel Mauss’ gift contribute to the construction of a hookah “bubble” which is defended by strategies of control and processes of othering.

This bubble is presented as the eye of the storm in a reality characterized by an optimization of oneself and one’s CV, a reality reflected in a rationality of prevention which is understood from a norm-critical perspective as characterized by norms of individual health, of performance and of future-focused potentiality. Contrasting the preventive notions of a hedonistic or fatalistic present with deleterious health effects, the contemplative, socially embedded hookah-present presents adolescents with an environment for constructive health identity work which contests the expectations of a risky illness temporality dwelling on pre-emption and calling for agency. The temporality of relations is discussed as a riposte to the temporality of surveillance which asks for new approaches in public health.

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**Thursday 11 September 2014 at 11:25 - 11:55**

STS

G63, Main Building

**Performance Targets, Mental Health Services, and the Transformation of Psychological Care**

*Pickersgill, M. D.*

*(University of Edinburgh)*

NHS practitioners are increasingly subject to the requirements of performance targets and measures. In the area of mental health, these align with a larger policy focus on increasing patient access to psychological therapies. However, an increase in the expected numbers of patients being treated has not been matched with increased resources (other than in particular specialist services). In this paper, drawing on 40 interviews with NHS clinical psychologists working in a range of services across England and Scotland, I consider professional responses to new performance targets and measures. Departing from a conventionally evaluative idiom (i.e., are targets being met?), I consider targets as a kind of ‘technology’, enabling and propelling sociotechnical change within organizations. This paper thus contributes to debates in medical sociology and STS around the transformative effects of innovations, the governance of (health)care, and the links between epistemic practices and processes of subjectification. Specifically, it asks: what is it that targets do? I document three key effects. First, the production of anxiety about failures to meet targets,
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changing psychologists’ relations with their work (and patients). Second, the development and implementation of novel frameworks for assessing patient need and processing demand (impacting on which kinds of patients are seen, when, and by who). Third, and most profoundly, the accommodation of performance measures into clinical practice in ways that rework the nature of therapeutic practice. This transforms the content and meaning of ‘care’ in order to meet targets – and hence reshapes the kinds of subjectivities assembled through therapy.

Thursday 11 September 2014 at 11:25 - 11:55
Patient-Professional Interaction
B. Kendrick, Main Building

Giving and Receiving Healthcare Advice and Information in a Second Language: A Comparative Study

Pilnick, A., Zayts, O.
(University of Nottingham)

Healthcare encounters involving participants from diverse cultural and linguistic backgrounds are becoming more common due to the globalization of health care and increasing migration levels. Research suggests that this diversity has a significant impact on health outcomes; however less is known about how it is managed in the actual consultation process. This paper presents a preliminary comparative analysis of 120 antenatal screening consultations recorded in the UK and Hong Kong. The existing dataset comprises subsamples of: consultations conducted in the first language of both participants, consultations conducted in the first language of one but second or subsequent language of another, and consultations conducted in a second or subsequent language for both participants. However, the data have not previously been analysed from this comparative perspective. The key research question to be addressed is: how does use of a second or subsequent language impact on advice and information giving and receipt?

Recorded consultations have been analysed using Conversation Analysis. Basing our analysis in naturally occurring data means that findings can be directly translatable to practice. By providing information on the impact that linguistic diversity has on the activity of advice and information giving, the findings will address the lack of applied research specific to delivering healthcare to diverse populations. However, they will also make a significant contribution to the sociology of health and illness, by shedding light on how issues of diversity are encountered and managed on a microsociological level.

Wednesday 10 September 2014 at 15:40 - 16:10
Methods
White Hall 3, CAMS, Main Building

Using Joint Interviews to Add Analytic ‘Value’: A Review and Case Study

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

In this paper I draw on data from a project involving joint interviewing in order to highlight two ways in which joint interviewing can add analytic value compared to other methods.

First, I present the finding that data from joint interviews are a particularly fruitful source of clues to the discursive frameworks within which accounts are located, offering ‘added value’ compared to individual interview data; very few authors describe using this analytic approach with joint interview data, although it is widely used in general.

Second, I problematise the widespread tendency to treat data from joint interviews as observational or ‘natural’, but suggest that if handled with care and reflexivity, such data can be used as a valid basis for claims about practices, thus giving a second analytic advantage of joint interviewing compared to other methods of data collection.

I situate these findings within the small but growing body of methodological literature about joint interviews and related methods, and also within the much larger group of literatures in which research using these methods is reported. Many authors describe using joint interviews to study aspects of a couple, such as their interactions and relationships, and in the methodological literature the main usefulness of joint interviewing has been identified as ‘for studying interactions’. I demonstrate that data about interactions also gives particularly useful analytic purchase in relation to a wider range of objects of study. Couple interviews are not only good for studying couples.
Rethinking Social Exclusion: Using Figurational Sociology to better understand why people living in More Socio-economically Deprived Areas Experience Worse Health

Powell, K.
(University of Sheffield)

In UK public policy, explanations for the health gradient between more and less socio-economically deprived geographical areas often pivot around the concept of 'social exclusion.' In popular and political discourse this has served to locate the problem of health inequalities in the networks of relations between residents within deprived areas, and often in the networks between residents and local service providers. Significantly, the impact of wider, longer-term social processes – the origins of which extend beyond perceived geographical and social borders of more deprived areas – has been obscured by this emphasis. This paper demonstrates how process sociology facilitates a conceptualisation of disadvantaged communities as figurations of interdependent people in order to bridge the conceptual divide between local and broader social processes that shape worse health outcomes in deprived areas. The paper draws on ethnographic data from a 3-year case study of an area-based health improvement initiative. An historical perspective was taken in order to better understand the social processes that influence worse health among residents in areas targeted by such initiatives. The study identified that, rather than being excluded from mainstream society, residents in the targeted area were embedded in networks that were heavily imbalanced in terms of decision making power, which shaped their health and wellbeing. 'Living on the periphery of a network' provides a way of understanding how mistrust between residents and local service providers might develop. More nuanced understanding about the conditions in disadvantaged areas could provide insight into the processes that constrain resident participation in services that might benefit health.

Involving Patients in the Development of a Handbook as Part of an Intensive Management Intervention for Intermediate Rheumatoid Arthritis

Prothero, L., Georgopoulou, S., De Souza, S., Simpson, C., Williams, R., Bosworth, A., Lempp, H.
(King's College London)

Background - Treatment Intensities and Targets in Rheumatoid Arthritis Therapy, The TITRATE Programme, aims to improve clinical outcomes for patients with intermediate Rheumatoid Arthritis (RA) through a combination of intensive drug treatment, psychological support and a Patient Handbook.

Methods - For the handbook two researchers collated publicly available information about RA from various sources including the National Rheumatoid Arthritis Society (NRAS), Arthritis Research UK (ARUK), publications, and academic centres. The information covered a range of relevant topics including intensive drug treatment, self-management techniques, coping with pain, fatigue and exercise. The collated material was organised into a draft Patient Handbook. Six patients with RA were recruited from two treatment centres to take part in an audio recorded Workshop. Participants were asked for comments on each chapter by initiating discussion through a series of questions. Feedback was captured through notes taken during the workshop and audio recording of the session, and thematic content analysis was applied.

Results - Patients were direct in their suggestions and requested for example less information on RA, specific life style and self-management advice, colourful diagrams, pictures of people from diverse background with RA and links to relevant websites. With participants' agreement, anonymous testimonies were included to personalise the content of the Handbook to provide patients' insight into the experience of others with RA.

Conclusion - Involving patients in this developmental process of the Patient Handbook increased the likelihood of including relevant information, useful to patients managed intensively within the TITRATE Programme and will be evaluated following completion of the trial.
When is a Clinician not a Clinician? When They are a Qualitative Social Scientist!

Rathbone, A., P., Jamie, K., Husband, A. K., Todd, A.
(Durham University)

‘White coat syndrome’, the disjointed interaction between clinicians and patients arising from unequal power and expertise, can also occur in research encounters. Identity management, such as adapting what researchers wear and the ways in which they speak, can have significant effects on the research encounter and data collected. For clinicians engaged in research, identity management can be particularly challenging given the added potential for ‘white coat syndrome’. Drawing on my own experiences as a registered pharmacist undertaking qualitative research, I suggest that identity management is not just a matter of optimising data collection but also has ethical issues. Given my dual role as pharmacist and researcher and the often competing ethical frameworks which accompany this duality, I argue that this pulls clinician-researchers in opposite directions during fieldwork; that is to say they must manage their clinical responsibilities whilst adhering to expected social research practices and norms. Ethics, epistemology and outcomes of disclosure differ between social researchers and clinicians, making clinicians’ entry into social science research particularly challenging. In the clinical paradigm, a clinician is always a clinician and always bears some clinical responsibility, and so is obligated to manage their identity in a particular way (i.e. disclosing clinical identity) regardless of the context. This creates a number of challenges during social science research in which context is central to questions of identity management.

A critical question is, then, if and when the pharmacist-researcher should inform participants of their clinician status and what influence this would have on the research.

The Home within the Hospital: Birth Centres as Domestic Spaces

Rayment, J., McCourt, C., Rance, S., Sandall, J.
(City University London)

Birth centres have been developed to offer a ‘home-from-home’ environment for birth, giving women at low risk of complications an alternative to birth in an obstetric unit. The proportion of women birthing in Birth Centres has rapidly increased in recent years and Alongside Birth Centres (midwife-led birth centres within a hospital) are being promoted as a ‘best of both worlds’ between the comforts of home and the perceived safety of the hospital. The interior of birth centres are almost always designed to incorporate ‘homely touches’ not found on a conventional Delivery Suite, like soft furnishings, murals or ornaments.

This presentation explores the role of these ‘domestic’ spaces within the hospital. The paper draws on the findings of four ethnographic case studies of Alongside Birth Centres across England, including interviews with postnatal women (n=47), staff and managers (n=54) and external stakeholders (n=35). The study was a follow-on from the Birthplace in England Research Programme.

The birth centres’ décor manifested, visually, the cultural, professional and ideological boundaries that intersected the hospital. It reflected the birth centre staff’s ideas about models of birth and women’s agency, as well as being part of a therapeutic landscape. Birth Centres are, what Maria Fannin calls ‘a hybrid space, ambivalently situated as a site of domestic comfort and technological sophistication’ (2003). In this presentation we enter these hybrid spaces, to explore what the domestic interior offered to labouring women and to the professionals who worked in them.
Sociological work on the professions has analysed the jurisdictional strategies used by developing professional groups to achieve a sphere of authoritative influence or professional closure. Professional territory has, however, rarely been marked out in spatial terms, rather than in terms of legal, credential, patriarchal or bureaucratic authority. The development of midwifery units could be described as a professional project by midwives, to mark out or defend a space in which to practice according to a midwifery model and with a level of professional autonomy they rarely experience in a typical hospital setting. They are being promoted as a ‘best of both worlds’ between the comforts of home and the perceived safety of the hospital. Prior to this recent policy shift in the UK towards choice of birth setting, we (CM & JS) studied caseload midwifery as a more autonomous model where midwives manage a defined caseload of women, following the women rather than working in a single setting. This presentation is therefore based on reflections from our earlier studies of caseload midwifery practice, the Birthplace in England Study and an organisational ethnographic study of AMUs. While midwives have high satisfaction with their work within these new models of care, we identified a high rate of intra-professional tensions and preoccupation with areas of ‘competition’ opened up by the creating of new boundaries and professional territories. We will discuss these in the light of more macro-level considerations about the culture of health care, attitudes towards birth, and issues of gender and power.

How do Stereotypes of Gout Affect People’s Experience of the Condition?

Richardson, J., Liddle, J., Mallen, C., Roddy, E., Hider, S.
(Keele University)

Background - Gout affects 2-3% of women and 7% of men over 75 in the UK. Despite evidence suggesting that it is not (solely) a disease of rich, old men, current popular understanding still draws on these aspects. Newspaper articles invariably include humorous reference to Tudor monarchs, port and overweight men. Lay understandings frequently draw on media presentation and may lead sufferers to trivialise the impact of the disease, leading to under-treatment. This presentation draws on research conducted to produce a section on patient experience of gout for the website Health Talk Online. We focus here on how the stereotypes of gout affect people’s experiences of the condition.

Methods - We used qualitative research methods to explore patient’s experience. We conducted semi-structured interviews with 43 people from across the UK. Interviews were audio or video recorded, following informed consent.

Findings - People found it frustrating when others made jokes about gout without understanding the causes and the pain. People who got gout at a younger age were often surprised at the diagnosis and could feel embarrassed. Being female could affect the speed of diagnosis and cause anxiety, affecting women’s identity. Younger women with gout were particularly likely to find their diagnosis difficult to accept.

Conclusion - The common stereotypes of gout, in terms of humour, age and gender, are not restricted to the media, but influence patients’ understanding and experience of the condition, from diagnosis to daily life.

“[My] Dirty Little Secret”: The Moral Cosmology of Antidepressant Taking

Ridge, D., Kirkpatrick, S., Anderson, C., Tanner, C.
(University of Westminster)

A meta-ethnography of antidepressant studies has previously identified a “moral career” pursued by users, with a focus on illness experience, help seeking, conflicting moments, and types of emerging selves (Malpass et al. 2009).
Yet, no study has specifically asked the question: What does the moral universe(s) that antidepressant users inhabit look like, and what are the implications? We draw on Bourdieu’s concept of ‘field’ to interpret the way that participants in the UK and Australia understand this complex cosmology. Using a qualitative secondary analysis approach with over 100 narrative interviews collected in three samples of people with depression in Australia and the UK. Users asked the question: What is the right way to live?, against dramatic backdrops like “horror stories” about medication, anxieties like loss of self (e.g. becoming “sheeplike”), as well as enhancements (e.g. “I Can Be The Me I Want To Be”). As substances that are taken home and administered (usually) in solitary, variations include loneliness, divided selves (e.g. “I don’t really accept it, I kind of half do”), and relief (e.g. “I began to laugh out loud again”). People variously come to feel like: their best self; they are taking the easy way out; are in a ‘love-hate’ relationship with their meds; as if they are illicitly on a “chemical high;” and even like they have a quasi “criminal record”. This cosmology is entangled for users, and our paper develops a complex cosmology, drawing out ways in which professionals could usefully assist people inhabiting such spaces.

**Thursday 11 September 2014 at 14:35 - 15:05**

Professions
White Hall 3, CAMS, Main Building

**Paediatric Bipolar Disorder in the US vs. England: Clinicians’ Representations of an Emerging and Contested Diagnosis**

Roberts, J.
*(London School of Economics and Political Science)*

The diagnosis of paediatric bipolar disorder (PBD) has emerged as an object of controversy in the last decade as it continues to expand despite a lack of consensus surrounding what exactly clinicians should be looking for in order to make a diagnosis. The rapid increase of PBD in the US is in contrast to comparative resistance in the UK, where the idea of labeling and medicating young children with something so poorly understood shapes diagnostic practice. Sociological literature has made significant contributions to the medicalization of childhood, and the construction of related diagnoses such as ADHD and Autism, however much of the literature on PBD remains in the clinical realm. As a disorder still attempting to establish itself, an exploration into the processes behind how PBD emerges and takes hold is warranted. This paper will present findings from an analysis of 18 in-depth interviews with child psychiatrists in the US and England, exploring what social and cultural factors shape their conceptualisations of PBD, and thus their acceptance or rejection of the diagnosis. Using a socio-psychological framework, I argue that the positioning of clinicians negotiating a wider social and institutional hierarchy, in which top-down pressures from the local medical and pharmaceutical systems encounter bottom up psychological pressures, from anxious parents for example, which influences clinical perspectives. This project, through closely examining how a new diagnosis is constructed by clinicians in two separate cultural contexts, provides insight into why certain disorders are perpetuated, while others continue to be resisted.

**Wednesday 10 September 2014 at 16:15 - 16:45**

LifeCourse
Steelhouse 3, CAMS, Main Building

**Commercial Ultrasound Scans: A Technology of Reassurance?**

Roberts, J., Griffiths, F., Verran, A.
*(University of Nottingham)*

Commercial ultrasound scans are increasingly available in the UK and elsewhere on a self-referral basis. This paper presents findings from an interview study investigating why women in the UK seek such services during low-risk pregnancies. ‘Reassurance’ emerged as one of the main reasons that women and families book commercial scan at various stages of pregnancy. We build on existing literature that notes the role of ultrasound in reassurance by exploring this finding in detail, contrasting those women who express the need for reassurance in very general terms, with those who have more specific fears about their pregnancy, and noting how an expressed need for reassurance can be combined, apparently without contradiction, with other motivations including finding out the sex of the foetus and obtaining family pictures. Findings will be contextualized within current NHS practice of routine ultrasound scans, feminist critiques of ultrasound, medicalization and commercialization of pregnancy and risk discourses. We conclude that ultrasound is widely understood as a technology of reassurance but that it has significant limitations as such that women and families may need to be aware of.
Paper Abstracts

Thursday 11 September 2014 at 12:00 - 12:30
STS
G63, Main Building

Negotiating the Meanings of Electronic Cigarettes: Ambiguity, Risk and Trust
Rooke, C., Cunningham-Burley, S., Amos, A. (University of Edinburgh)

Interest in, and debate over, ‘electronic cigarettes’ has increased sharply in recent years. This interest is spurred by these devices' proposed potential as a less harmful alternative to smoking tobacco, their growing popularity despite uncertainty around safety and efficacy, and ambiguity in relation to medical and legal categorisations. Electronic cigarettes are battery-operated devices that produce a vapour (usually, although not always) containing nicotine, which the user inhales – some types are designed to look like cigarettes. In the UK they fall neither into the category of tobacco nor medicinal products, so are currently regulated under consumer protection legislation. At this point in its history, studying understandings of the electronic cigarette has the potential to provide a fascinating glimpse into a technology-in-the-making, as its meanings and legitimate uses are negotiated by users, public health experts, policy-makers and the media.

Drawing on ideas from science and technology studies about classification, ambiguity and the ways that technologies are co-constructed, this presentation will report on findings from a qualitative study whose aim was to explore how electronic cigarettes are understood and experienced by smokers. Twelve focus groups and eleven semi-structured individual interviews were undertaken with purposively selected groups of smokers and recent ex-smokers. We examine how participants negotiate the various ambiguities around electronic cigarettes, how they understand their risks and benefits, and how these understandings shape their attitudes towards and experiences of short and long-term use of these technologies.

Wednesday 10 September 2014 at 13:55 - 14:25
Lifecourse
Steelhouse 3, CAMS, Main Building

‘It’s the One Thing you Really Want to Tell People’: Understandings of Risk and ‘keeping the Secret’ in Early Pregnancy
Ross, E. (University of Edinburgh)

Though women’s experiences of reproductive technologies and childbirth have frequently been the subject of sociological and anthropological study, recent literature has called for attention to the mundane experiences of ‘ordinary’ pregnancy. This research responds to such calls, focusing on a phenomenon familiar to many pregnant women in the UK today: the convention of keeping their pregnancy a secret until they reach 12 weeks gestation. This can be difficult to sustain, often entailing deception of friends and family, and the suppression of pregnancy symptoms in the workplace. However, adhering to this convention is important to women, who explain their motives with reference to miscarriage statistics and descriptions from medical literature, but also to notions of ‘tempting fate’.

This paper draws on interview data from a longitudinal study exploring women’s understandings of their relationship with the foetus. My presentation will focus on data from interviews conducted during participants’ first trimester of pregnancy, a period characterised by secrecy and silence both in women’s lives and in academia. I will discuss the reasons given for maintaining this secrecy, drawing on risk literature and the concept of biomedicalization. I will also explore the emotion work described by interviewees in early pregnancy, who found themselves trapped between ‘two realities’; preparing both for a possible miscarriage, but also for a future baby. I hope to demonstrate that studies considering seemingly unremarkable pregnancies have much to offer the social sciences.
A Qualitative Research Study to Explore the Patients’ Experience of Returning Home Following Allogeneic Stem Cell Transplantation

Russell, S., Arber, A., Gallagher, A.  
(University of Surrey)

The emotional impact of cancer is well recognised and current health policy supports a focus on cancer survivorship. This study explores the experiences of 15 participants aged between 22-68 years who were treated with allogeneic stem cell transplantation (cells from a donor) for haematological cancer. The focus of the study was on participants’ experiences of returning home following a stem cell transplant. Participants were recruited from two major treatment centres and the study followed an interpretive phenomenological methodology using semi-structured interviews. Data were then analysed using interpretive phenomenological methodology to gain insights into participants lived experience following the transplant including their personal and social experience of the world following treatment. Bury’s (1982) concept of illness as a biographical disruption and the notion of liminality (Turner 1969) has significant resonance with the participants’ narratives. Many participants report a non linear recovery characterised by setbacks and uncertainty including facing their own mortality whilst maintaining hope, a positive spirit and a desire to help others. Some participants face long term changes in bodily function such as fatigue, the enduring risk of infection and adverse affects on the body organs such as skin, liver, lungs, kidneys, gastro-intestinal tract, the genital system, eyes and joints as a result of graft versus host disease (when donor cells attack those of the recipient). Social challenges include the renegotiation of relationships within the family, resuming social activities, education, employment and financial security.

Addressing Ethnic Inequalities in Healthcare Experiences and Outcomes: What is the Role of Research Evidence?

Salway, S., Mir, G., Turner, D., Ellison, G., Carter, L., Gerrish, K.  
(University of Sheffield)

Persistent ethnic inequalities in healthcare access, experiences and outcomes, as well as concerns regarding inefficient resource use, have prompted growth in ethnicity and health research. There is a need for complementary attention to how resultant evidence is mobilised and utilised within policy and practice. While theoretical and empirical work highlights a range of obstacles that can hamper knowledge translation processes within health systems, these issues have rarely been explored in relation to evidence on ethnic diversity and inequality. This paper contributes new understanding by presenting findings from a large-scale study of the healthcare commissioning arena. Our conceptual framework integrated micro-, meso- and macro-level factors, drawing on Davies’ notion of ‘knowledge interaction’ and Weiss’s multiple modes of evidence use, as well as socio-cognitive models that focus attention on the values, assumptions and worldviews of actors. A combination of: 19 national-level key informant interviews; 3 local case studies (involving 70+ interviews, extensive observational work and detailed documentary analysis) and 3 national-level workshops, generated rich data. This allowed detailed description of knowledge mobilisation and utilisation practices and exploration of influences at individual, team, organisational and wider system level. Despite some pockets of good practice, we found limited organisational engagement, low priority and inadequate skills. Fears of ‘privileging’ minorities, introducing unnecessary complexity or ‘getting it wrong’ were common and remained unchallenged by organisational cultures. In common with work in Canada and the US, the paper highlights an urgent need to increase demand for evidence on ethnicity through reframing, and increasing legitimacy, of this work.
**Paper Abstracts**

**Friday 12 September 2014 at 10:10 - 10:40**

**Embodiment and Emotion**

White Hall 1, CAMS, Main Building

**Narratives of Regret and Responsibility in Breast Augmentations**

Sanchez Taylor, J.  
(University of Leicester)

Breast augmentations are an increasingly popular procedure and an important and profitable part of the cosmetic surgery industry. In 2012, 11,135 procedures for breast augmentations were undertaken in the UK, a growth of 13% from the previous year despite the Poly Implant Prothese (PIP) scandal (BAAPS Statistics, 2013). This market is increasingly 'normalised' in mainstream popular culture (Heyes, 2007; Tait, 2007). In data gathered from women who had breast augmentations before the PIP scandal, one thing that stood out, was how happy they were with their decision to have surgery and that they felt that as consumers and women, they had made the right decision to go ahead with their surgery. Popular debates on the PIP implant scandal however, problematised women who had elected to consume breast implants to enhance their appearance. Women with PIP implants who had elective breast augmentations were labelled as 'bad' consumers, who were often blamed for their predicament because they had turned to the market to buy femininity. This paper examines data from 10 interviews with women who had breast augmentations before the PIP scandal. Undertaken to obtain their views on a breast implant registry, interviewees discussed their views on the registry and also were in the process of developing new narratives about their decision to have breast augmentations in the light of the PIP scandal. This paper will explore the shifts in narratives around their consumption and their embodied experience of having breasts implants to think about questions of consent, consumption and capability in medical markets.

**Friday 12 September 2014 at 11:55 - 12:25**

**Politics of Health**

Stafford 2, CAMS, Main Building

**Lifestylisation of Medicine and Medicalisation of Lifestyle: Developments Engendered by Consumer Culture and Digital Media**

Saukko, P.  
(Loughborough University)

This presentation discusses the increasing blending of medicine and consumer culture—or what I call lifestylisation of medicine and medicalization of lifestyle—exemplified by e.g. ubiquitous health foods, mobile health ‘apps’ and online diagnostic tests. I argue that this trend rearticulates traditional notions of disease, knowledge, patient and emotions, associated with medicine. Drawing on Jewson’s and Armstrong’s classical work on medical cosmologies I argue that the process of lifestylisation, first, changes the notion of ‘disease’ from a bodily lesion or ‘risk’ into a speculative claim about products, which ‘may’ indicate a health risk of benefit. Second, the emerging lifestyle products are not primarily grounded in scientific evidence (even if evidence is evoked) but on multiple, expert, lay and commercial knowledges. Third, lifestyle products do not configure their customers as passive patients or active health-seekers but as ‘co-creators’ of health products, who change and ‘customise’ them. Fourth, whilst lifestyle products evoke health concerns they are not primarily grounded in negative emotions, such as anxiety, but often offer their customers pleasures. Medical sociologists have traditionally critically discussed ‘medicalisation’ i.e. rendering more areas of life ‘medical’ issues. I argue that the new commercial health or lifestyle products render medicalization more light-hearted in that they are not associated primarily with scientific ‘truth’ and anxiety but configure knowledge as speculative and multiple and patients/consumers as creative and pleasure driven. However, I suggest that such products, nevertheless, continue to ‘medicalise’ new areas of life and that to critically address this development calls for new concepts offered by sociology of consumption and new media.
Living through Numbers: The Spatial and Temporal Effects of Numbers in Diabetes Self-management Education

Schwennesen, N.
(Steno Health Promotion Center)

In today's chronic disease management, numbers play a vital role in the mobilisation of the chronically ill patient as a self-monitoring, active and responsible citizen. In response, it has been argued that patients need to have better numeracy skills (Perzynski et al. 2013) and a 'numeracy gap' between health care providers and patients have been identified (Pighin et al. 2011). As such, the concern has been with how to communicate and present numbers to patients, in order for them to become able to understand numbers correctly. While such studies are important in their own right, this paper argues that it is necessary also to give attention to the spatial and temporal effects of numbers, if we are to understand the implications of the increasing use of numbers in chronic disease management. On the basis of ethnographic material, I explore how numbers (indicating bloodsugar) are interpreted in diabetes self-management education and the process through which numbers become meaningful in participant's everyday life. I propose an understanding of numbers as an element of the chronic care infrastructure (Langstrup 2013) that interrelate the home and the clinic, and illustrate that numbers become meaningful only through the attachment to other elements in the infrastructure, such as standards, medication, everyday practices and social relations. I argue that numbers have both place-making effects (the sense of place), which demands the emplacements of various objects and activities in participants everyday life, and temporal effects (the sense of time), that creates a reorganisation of participants sense of the past and the future.

“İ can’t do Anything about That”: How Does Normative and Structural Legitimacy Impact on How Nursing Staff Act on Patient Feedback about Quality and Safety?

Sheard, L., Marsh, C.
(Bradford Institute for Health Research)

There is emerging evidence, an increasing policy focus and near universal agreement that gathering feedback from patients about the safety and quality of the care they experience is necessary in order to deliver high quality care. Despite this focus, little is known about the ways in which nursing staff choose to engage with patient feedback (or not) in order to enact change.

In a cluster randomised controlled trial across 33 acute hospital wards in the North of England, we aim to assess whether a patient safety intervention leads to improvements in safety outcomes over a 12 month period. The RCT is being evaluated via a rich, in depth process evaluation.

Based on empirical data from the process evaluation, we argue that proactively making changes based on patient feedback is a complex three tiered process and not something that nursing staff can simply 'do'. Firstly, ward staff need to have normative legitimacy - they need to genuinely believe that listening to patients is a worthwhile exercise to undertake. Secondly, imagined or real structural legitimacy needs to be in place - staff need to feel they have adequate agency, autonomy, ownership and resource to enact change. Thirdly, organisational readiness to change must exist at both the level of the ward and the hospital otherwise change will rarely be enacted. We will use illustrative case examples, demonstrating how wards approach similar patient centred problems in divergent manners. Understanding staff legitimacy to enact change is critical if patient feedback is to be acted upon.
Persuading the Last 15 per cent: Do we Need Sticks or Carrots to Achieve Full Infant Immunisation? Early Results from a Study of Parental Incentives and Quasi-mandatory Schemes for Increasing Uptake of Immunisations in Pre-school Children

Shucksmith, J., McNaughton, R.  
(Teeside University)

Strenuous attempts have been made to rebuild trust in immunisation since the MMR debacle of the 1990s. 95% coverage is needed for herd immunity. In 2011-2012, MMR uptake stood at 86% in England and epidemic ‘flares’ of measles occurred, 10% of cases involving hospitalisation. What level/type of inducement or penalty could be effective and acceptable as a way of drawing in the remainder of parents whose decision not to immunise may prejudice the health of their own children and others?

This paper reports ongoing work from an NIHR HTA funded study which is reviewing evidence on parental incentives and quasi-mandatory schemes (PI/QMS) to increase uptake in pre-school children, examining what stakeholders believe is/is not acceptable about PI/QMS and exploring preferences of parents for schemes designed to encourage uptake.

Offering people small amounts of money in the context of health promotion and medical care has been attempted in a number of settings in recent years and has attracted a degree of ethical controversy. One form of criticism is that such schemes interfere with the autonomy of the patient or citizen in an illegitimate way, though Ashcroft (2011) felt there was no good reason to think that such schemes did so inherently. Because a vaccinating parent is protecting not just her child but contributing to herd immunity there are echoes of Titmuss’s early work on ‘the gift relationship’ amongst others. Debates around this lock into notions of good citizenship and whether ‘bad or failing’ citizens should be rewarded or penalised.

Recovering from Unintended Injury: Biographical Disruption, Interruption and Reflection

Sleney, J.  
(University of Surrey)

The study of patients’ experiences of unintended serious injury remains an under-researched area within sociology compared with the extensive literature addressing experiences of illness; the few exceptions including Sacks (1984) and Oakley (2007). Biographical disruption (Bury 1982), and subsequent refinements to the concept, has an extensive presence in the literature on illness but not on injury. This paper explores the extent to which biographical disruption is useful for an understanding of experiences of injury and recovery.

The paper draws on a nested qualitative study of patients, carers and service providers within the Impact of Injury Study (Kendrick et al 2011); an NIHR-funded CLAHRC multicentre longitudinal study of the longer term impact of injuries in working age adults. Patients (n=45) who had sustained an injury requiring one or more nights in hospital were interviewed in four study centres (Nottingham, Bristol, Leicester/Loughborough and Surrey). The time that had elapsed between injury and interview ranged from one to 14 months.

For some participants, the experience of injury and recovery represented a biographical interruption rather than a disruption but others found it more problematic. Severity of injury was a factor but other aspects, including socio-demographic characteristics, resources and the location of identity, provide a more detailed understanding. The paper argues that, while the concept of biographical disruption provides a useful starting point, these data require a reconsideration of disruption within the context of partial or full recovery from injury together with the varied contexts of a life lived with injury.
A Conceptual Framework of How People Reference their Acute Pain: Preliminary Results

Slomp, F., Mayan, M.J., Dick, B.D., Lasiuk, G.C.
(University of Alberta)

Pain assessment is the key component to providing adequate pain management which remains an elusive challenge globally. Although numerical rating scales are commonly used in clinical practice to assess the intensity of pain, the pain scales themselves are problematic as it is not clear what referents patients’ use to formulate their pain score.

The research question guiding this inquiry is ‘how do people reference their acute pain event?’ The Interpretive Description method was used determine how people self-rate their pain. Seven participants were interviewed using a semi-structured format; the interviews were digitally recorded and transcribed verbatim. The Knafl method of data analysis was employed to identify themes in the data.

The preliminary finds suggest that the process individual’s employ to reference their pain is complex and occurs at two levels: internally and externally. Internal referencing first occurs as an embodied knowing which then is cognitively evaluated against prior pain experiences and the proximity of their current pain is to the most they can endure (maximum). External referencing is primarily carried out through a cognitive evaluation of others’ pain experiences. The complex interaction of social history with both internal and external referencing will also be discussed. By better understanding this process it is intended that more effective pain assessment and management protocols will eventually be developed. This inquiry is part of a larger study and will benefit clinical health care providers who are involved directly with the assessment of pain in a wide variety of clinical situations.

A Weber Inspired Analysis of Events at Mid Staffordshire NHS Foundation Trust

Slope, R.
(University of Southampton)

The final report into events at Mid Staffordshire NHS Foundation Trust, where poor care may have led to the deaths of between 400 and 1200 people, was published last year. An inquiry levelled criticism at Board level and implicated the medical and nursing professions but it did not explain how the descent into neglectful practice took place. The final report apportioned responsibility with an organisational culture that put achieving performance management targets before patients and a regulatory system which failed to detect anything untoward. Against a background of high mortality statistics the hospital was awarded Foundation Trust status for successfully meeting its targets.

According to Weber’s theory of rationalisation, dehumanising features are a tendency of bureaucratic systems which take on their own momentum and lead to an ‘iron cage’ of rationality. A managerial culture emerged at Mid Staffordshire that privileged quantitative outputs and targets over patients and saw healthcare professionals pressured to align themselves with the goals of the organisation rather than the interests of their patients. This led to the gradual dehumanisation of patients as their humanity slowed down and impeded the system.

The bureaucratisation of healthcare delivery in the UK is continuing but it is not yet complete, and a greater understanding of this process, and the impact of performance management targets, is urgently required. In the meantime, medical and nursing schools should teach a human rights based approach to healthcare delivery and prepare students for the conflicts between professional ethics and the demands of bureaucratisation.
‘You’re Stuck at a Crossroads and you can’t go Anywhere’: Accounts of Liminality in the Experience of Living with a Ventricular Assist Device

Standing, H., Rapley, T., MacGowan, G., Exley, C. (Newcastle University)

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=17) with a range of individuals on VAD support. Liminality appears to be a central feature of the experience of those living with VADs. Firstly, the VAD is presented by clinicians as a bridge-to-transplantation, a temporary measure rather than ‘answer’ to the condition. Secondly, after VAD implantation individuals may experience a sense of disparity between how they feel in themselves and their health status, as although many of the symptoms of heart failure had been alleviated the underlying disease is still present. Finally, liminality is experienced in terms of uncertainty surrounding the future, including the possibility of receiving a heart transplant and a sense of being stuck and unable to move on with their lives.

Are we Living in a Self-harm Culture? Non-suicidal Self-injury and the Belaboured Self

Steggals, P. (Newcastle University)

Self-harm, or non-suicidal self-injury, is a well-established and somewhat haunting presence within late-modern western culture regularly appearing in the social imaginary of newspapers and magazines, songs, TV shows, and movies. Celebrities confess, journalists and social commentators express concern, and the experts warn of a largely hidden facet of contemporary life affecting schools, universities, prisons, and homes. However in marked contrast to its evocative power and cultural presence its clinical analysis and scientific exploration have proven confused, fragmented, and faltering. As such, and as an alternative to the standard medical and psychological approaches to self-harm that have typically represented it as a largely individual psychopathology, I report in this paper on research that has modelled it instead as a socioculturally situated idiom of personal distress and emotional dysphoria; a pattern of meanings and actions which crystallize broader patterns of meanings or discourses active in late-modern society. In this way I argue that the current popularity of self-harm as a potent and meaningful method of experiencing and expressing personal distress tacitly implies a social critique in the same way that feminist arguments about the meaning of anorexia nervosa critiqued the representation of female embodiment and subjectivity in the 1980s. To this end I focus here in particular on the dissonant construction of the subject in late-modern consumer and therapy culture as one belaboured with expectations relating to agency and responsibility and yet characterised by a profound experience of powerlessness.

Futures Formed in the Womb: The Rise of Foetal Programming and a New Paradigm of Disease

Stelmach, A. (University of Nottingham)

This paper traces the emergence of foetal programming, a thriving interdisciplinary field in the biosciences, and its impact on the ways in which scientists conceptualise the origins of disease in adulthood. Drawing on epidemiological
data, animal studies and research in epigenetics, scholars in this field link social and historical circumstances preceding conception and birth - such as war, famine or poverty - to disease later in life. The memories of such adversities are said to be inscribed - or programmed - in the body of the foetus and result in disease in adulthood. Such memories can even be transmitted to future generations. Although research in this field has already informed debates in public health and medicine as well as health policies, foetal programming has received little attention from social scientists. By using the lens of the sociology of expectations (Brown and Michael 2003), this paper explores claims and promises in this field, in particular the promise of preventing disease in populations, as well as predicting and reversing pathological processes in individuals. It also examines the ways in which the future is imagined through discovery and (re)interpretation of the past. Finally, it explores the significance of this field to medical sociology and STS, including how it may reshape notions of risk and responsibility in pregnancy. Methodologically, this paper draws on textual analysis of scientific literature, interviews with scientists and media analysis.

Thursday 11 September 2014 at 12:00 - 12:30
Patient-Professional Interaction
B. Kendrick, Main Building

How does Discussion about Medicines Operate to Make a Problem ‘Doctorable’?

Stevenson, F.
(University College London)

It is well established that when people go to the doctor work has to be done in order to ensure their problem is judged to be ‘doctorable’ and their symptoms are not designated as a no problem diagnosis. Consultations for upper respiratory tract infections are particularly problematic in this regard. Drawing on conversation analysis we consider how discussion of the use of medicines may be used to display ‘doctorability’. The analysis is based on an in-depth analysis of a single case and considers what ‘work’ discussion of medicines does in the consultation and how talk about medicines is used by both the patient and the doctor to support their agendas. It focuses in particular on the presentation by the patient and management by the doctor of a medical misdeed in relation to medicine taking and an associated indirect request for a prescription. All this activity is managed alongside work to maintain the therapeutic relationship. The paper demonstrates the interactional complexity which is evident even in consultations for medically straightforward problems.

Thursday 11 September 2014 at 15:10 - 15:40
Citizenship and Health
Steelhouse 3, CAMS, Main Building

Minority Stress, Relationship Formalisation and Wellbeing: An Exploratory Analysis of the Life Narratives of Men in Civil Partnerships in the UK

Stocker, R., McKeown E., Hardy, S.
(City University London)

Epidemiological studies indicate that lesbian, gay and bisexual (LGB) populations are at increased risk of a range of mental health issues when compared to heterosexual populations. The predominant explanation for this disparity in mental health and wellbeing is minority stress theory which posits that LGB individuals experience an excess of social stress given their stigmatized social identities and minority status. This excess is produced by stressors including: internalised homophobia; lower levels of social support; and, expectations and experiences of stigma, prejudice and discrimination. Another contributing factor may be exclusion from full and equal civil marriage rights. This exclusion is not only a symbol of discrimination but also disadvantages same-sex couples by barring them from the economic, social, psychological, and health benefits of marriage which have been documented by a voluminous empirical literature on heterosexual marriage. The available U.S. literature on same-sex marriage indicates that married same-sex couples experience these benefits, higher levels of wellbeing, and reduced minority stress. To date, similar empirical evidence from the UK is lacking. This paper addresses this gap by drawing on personal narratives elicited through qualitative interviews with 28 individual men in civil partnerships from across the UK. Participants’ narratives revealed that, in general, civil partnership was a positive experience. Participants reported feelings of happiness, life satisfaction, inclusion and belonging, security and stability, increased commitment, validation of their gay identities and same-sex relationships, increased confidence and comfort is social settings and interactions, and increased social support. Overall, this study lends support to the idea that relationship formalisation may mediate minority stress and contribute to wellbeing.
“Sex is not Binary and Gender Confusion is Painful”: An Analysis of Reader Comments on Disorders of Sex Development

Sweeting, H., Walker, L., Maycock, M., Hunt, K.
(University of Glasgow)

In November 2013, an article on the BBC news website announcing that ‘Germany has become Europe's first country to allow babies with characteristics of both sexes to be registered as neither male nor female', thus creating ‘a new category of "indeterminate sex" invited reader comments. Disorders of Sexual Development (DSD) highlight ‘commonsense’ essentialist beliefs about binary sex distinctions. All 864 reader comments, mostly provided by people with no specialist knowledge or experience of DSDs, were captured using NCapture for NVivo, and imported into NVivo for analysis. Analyses suggest around one-third of comments included discussion of gender, sex and society, including factual debate relating to chromosomes and biology relating to sex and DSD, whether or not there were ‘only’ males and females, understandings of sex and gender, and confusion over sex and sexuality. More comments praised, than were critical of the legislation, generally suggesting it was enlightened and sensible; some suggested abolishing gender distinctions. Some comments by critics used strong language to suggest the legislation was incomprehensible, pointless or excessively liberal. Some discussion referred to religious understandings relating to the ‘naturalness’ of DSD; other comments mentioned Germany in both positive and negative terms. While not necessarily representative of public opinion, these comments illustrate society’s continued investment in gender dichotomisation, emphasising the continued relevance of Goffman’s description of “sex-class placement” as “almost without exception exhaustive of the population and life-long, providing an exemplary instance, if not a prototype, of social classification” (Goffman 1977).

Interprofessional Learning and End-of-life Care

Taplin, S.
(University Campus Suffolk)

This paper will provide an overview of an interprofessional learning programme for social work students in a hospice setting, demonstrating the importance of partnership working in the teaching of medical sociology in respect of end-of-life care.

End-of-life care remains a crucial aspect of medical sociology which is often sadly overlooked in curriculum development.

This paper will demonstrate how an interprofessional learning opportunity was developed between the University and the Hospice to bridge the gap in students’ learning about end-of-life care, and to ease the fears and anxieties which often exist about working with people who are dying, and their families and carers.

There will be an exploration of the themes of study and the teaching methods used, including how to encourage students to explore the meaning of loss and change, and the importance of learning how to manage one's own emotions in this sensitive and often challenging area of practice.

Emotional Labour in Nursing, ‘What it is and What it is Not’: A Critical Evaluation of the Application of Hochschild’s Concept

Theodosius, C.
(University of Brighton)

This paper presents the theoretical argument that Hochschild’s concept of emotional labour (1975; 1979; 1983; 2003; 2012) remains relevant to understanding the emotion work of nurses in the caring process. I contend that developing
Hochschild’s original notion of emotional labour, rather than replacing it with another term, such as ‘emotion management’ (Bolton 2000; 2005) or ‘emotion practices’ (Erickson and Stacey 2013), is not only preferable, but in the case of nursing essential. This is because key to Hochschild’s definition is how emotional labour comes from deep within the individual giving weight to her argument that it is in the transmutation of emotion work/management to emotional labour that the exploitation of the individual occurs. There has been much debate about the public/private distinction, and in the case of nursing whether or not managers oversee emotional labour, a key criterion for it. However, I shall argue that as a result of this debate the exploitation of the emotional labour of nurses has been ignored, thus despite many publications discussing its gendered nature and the lack of status and low financial remuneration of emotional labour workers, the desire to want to care in nurses is being almost negligently exploited despite well documented evidence that links it to compassion fatigue, sickness and absenteeism and retention problems within the profession. Arguably in light of the Francis Report (2013), understanding the process of emotional labour as Hochschild first envisioned it is more important than ever in its application to nursing.

**Thursday 11 September 2014 at 12:00 - 12:30**

**Methods**

White Hall 3, CAMS, Main Building

**Odd Man Out: The Male Researcher Studying a Female-dominated Hospital Setting**

*Thomas, G. M.*  
*(Cardiff University)*

Critical reflections and detailed confessionals are now a relatively common feature of the ethnographic craft. However, limited attention has been afforded to how male researchers actively position their gender role when ‘in the field’. This paper is based on a self-reflexive account of a male researcher during an ethnography of two hospital departments mostly employing female professionals. Influenced by the work of Erving Goffman, I draw on fieldwork data and personal musings to explore how I accomplished, managed, and negotiated my gender within situated occasions. By engaging in self-modification as an ethnographic tactic during ‘strategic interaction’ (Goffman 1969), I fruitfully deployed my gender to ease access, facilitate data collection, and foster meaningful research relationships. Simultaneously, my gender prevented access to certain medical rituals and changed some participants’ conduct. Accepting the argument that gender is not biologically determined but created collectively via social interaction, I reveal how a male identity in a female-dominated setting presents opportunities and obstacles for both participants and the researcher. To conclude, I recognise self-conscious reflexivity – urging us to think critically about roles and relationships, about ethics and responsibilities – as a fundamental characteristic of research. Describing the dramaturgical performance of a researcher’s gender identity, thus, is a valuable statement about the ethnographic craft and research more generally.

**Thursday 11 September 2014 at 09:40 - 10:10**

**Theory**

White Hall 1, CAMS, Main Building

**Exercise as Labour: Quantified Self and the Transformation of Exercise into Labour**

*Till, C.*  
*(Leeds Metropolitan University)*

The recent increase in the use of digital self-tracking devices has given rise to a range of relations to the self often discussed as Quantified Self (QS). In popular and academic discourse this development has been discussed variously as a form of narcissistic self-involvement, an advanced expression of panoptical self-surveillance and a potential new dawn for e-health. This paper proposes a previously un-theorised consequence of this large-scale observation and analysis of human behaviour; that exercise activity is in the process of being reconfigured as labour. QS will be briefly introduced subsequently some of its key aspects will be considered in relation to how these have so far been interpreted and analysed in academic literature. Secondly, the analysis of scholars of ‘digital labour’ and ‘immaterial labour’ will be considered which will be discussed in relation to what its analysis of the transformations of work in contemporary advanced capitalism can offer to an interpretation of the promotion and management of self-tracking of exercise activities. This will include a discussion of Marx’s conceptualisation of labour as ‘formative activity’ which requires the standardization and quantification of ‘socially necessary labour-time’. Building on this analysis it is proposed that a thermodynamic model of the exploitation of potential energy underlies the interest which corporations have shown in self-tracking and that ‘gamification’ and the promotion of an entrepreneurial selfhood is the ideological frame which informs the strategy through which labour value is extracted without payment. Finally, the potential theoretical and political consequences of these insights will be considered.
Qualitative Research as Stepwise-deductive Induction

Tjora, A.
(Norwegian University of Science and Technology)

Qualitative analysis requires elaborate thinking, a feeling for the aspects in empirical data that exceed the specific problems and expectations, as well as the aptitude for systematic working. Undoubtedly, analysis bears a major share of the potential for qualitative research, and numerous projects fail at it to produce in the end not more than a compilation of (in the best of all cases assorted) anecdotes. To repair, to some degree, such problems, I have during 15 years of teaching research methods to social science students at all levels, developed the idea of a stepwise-deductive inductive (SDI) method, to work in stages, starting from raw data and moving towards concepts or theories. The ‘upward’ process is to be understood as inductive, insofar as we start from the data and work our way forward to theory. The ‘downward’ control feedback mechanisms are to be seen as deductive, whereas verification starts from the more theoretical aspects towards the more empirical ones. The model has obvious parallels to the research school of Grounded Theory, but aims to bring inductive qualitative research ‘down to’ applicable systematic stages, rather than maintaining over-ambitious analysis/sampling iterations that have made qualitative researchers to suggest ‘being inspired’ by GT, rather than actually working within GT. In this paper, the stages of the SDI model are outlined, with examples from sociological research in the health field. Especially questions regarding theory development and generalization are developed and elaborated on.

The Single-option Dilemma: Findings from a Conversation Analytic Study of Choice in the Neurology Clinic

Toerien, M., Shaw, R., Reuber, M., Duncan, R.
(University of York)

The classic conversation analytic (CA) account of clinical decision-making focuses on the practice of ‘recommending’. This significant research demonstrates that both parties orient to recommendations as proposals (to be accepted or not) rather than directives to be followed ‘blindly’. Largely missing from the literature, however, is systematic analysis of how clinicians might work to avoid recommending in favour of giving the patient a choice – an approach that is increasingly advocated within the NHS. Based on a CA study of over 200 recordings of neurology consultations, we highlight a practice used to give patients a choice about a single course of action, which we call the ‘patient view elicitor’ (PVE). In our dataset, these fell into two groups: i) those where the course of action was introduced prior to the PVE, and ii) those where it was introduced through its use. We show how each can place the decision in the patient's domain. However, we argue that each raises a potential difficulty for patient choice: the first runs the risk of being treated by patients as recommendations because the information may be heard as indicating the neurologist’s preference. By leaving out the prior information, neurologists may avoid this risk but may, instead, leave the patient ill-equipped to make a decision. We explain this dilemma using the sociological concepts of epistemic and deontic authority, and conclude by highlighting the implications for models of shared decision-making that include an exchange of treatment preferences between doctor and patient as a necessary criterion.

Managing Self After Receiving a Heart Transplant between ‘a Patient’ and ‘an Individual’

Tomomatsu, I.
(Aozora Clinic)

Aim and background - The aim of this study is to explore the way in which experiences of Japanese heart transplant recipients’ (HTRs) chronic condition caused by receiving heart transplant surgery abroad affect recipients’ perception of self. HTRs need life-long medical treatment to control their immune systems after surgery. By overcoming heart disease by transplant operation, HTRs tend to think about themselves not as a patient, while doctors look at them as a patient. In
addition, some other people look at them in a various way reflecting the relationship between them and social context. Therefore, to develop understanding the experience associated with life-long chronic condition presents a difficult challenge for HTRs with an issue of self.

Method - The participants for this study were recruited by using ‘snowball’ sampling. Study inclusion criteria were age 20 and over where more than one year had passed since the heart transplant operation. Fourteen Japanese HTRs were interviewed. All interviews were recorded and transcribed into a simple text. Interview data was thematically analysed reflecting theoretical concepts of biographical disruption and narrative based medicine.

Result and discussion - Japanese HTRs’ perception of self is influenced by mainly time for it, and fund-raising support from the public or not. Under these situational conditions, recipients tend to experience stigma which is explained as ‘enacted stigma’ or ‘felt stigma’. Their stigma experiences are attributed by the relationship with: doctors, family, friends and colleagues and the public. HTRs have become to experience ‘felt stigma’ than ‘enacted stigma’ than before.

**Thursday 11 September 2014 at 14:00 - 14:30**

Professions
White Hall 3, CAMS, Main Building

**Occupational Closure in Carework: Healthcare Support Workers**

*Traynor, M.*, *Buus, N.*, *Nissen, N.*, *Lincoln, C.*
*(Middlesex University London)*

In healthcare, professional groups have adopted tactics to maintain control over their areas of work. Witz described the credentialist approach to occupational closure adopted by nursing during the 19th and early 20th centuries. The advancement of assistant, ‘non-qualified’ workers by governments and managers potentially threatens this closure. This research used focus groups with three cohorts of healthcare support workers undertaking assistant practitioner training at a London university from 2011-13 (6 groups, n=59) to examine how these workers talked about professional identity and demarcation. A thematic analysis revealed a complex situation in which participants were divided between articulating an acceptance of a subordinate role within traditional occupational boundaries and an usurpatory stance towards these boundaries. Participants had usually been handpicked by managers and some were ambitious and confident in their abilities. Many aspire to train to be nurses claiming that they will gain recognition that they do not currently get but which they deserve. Their scope of practice is based upon their managers’ and supervisors’ perception of their individual aptitude rather than on a credentialist claim. They ‘usurp’ nurses’ claim to be the healthcare worker with privileged access to patients, saying they have taken over nursing’s core work while nurses abandon it for largely administrative roles. Participants differentiated between their own occupational status and that of nurses but believed their roles to be highly similar suggesting a failure of occupation closure for nursing.

**Friday 12 September 2014 at 11:55 - 12:25**

Health Policy
Steelhouse 2, CAMS, Main Building

**Building Responsive Healthcare in Sweden and England: The Challenge of Differentiating the Patient from the Public**

*Tritter, J.*, *Fredriksson, M.*
*(Aston University)*

Central to health reforms in Sweden and England for more than a decade has been a commitment to patient and public involvement, promoting patient choice and creating a more responsive healthcare system. Despite such commitment the articulation and implementation of patient and public involvement has been limited and usually tokenistic. More problematic there is little evidence of public involvement despite the healthcare systems in both countries being publicly funded and universalist. In this paper we critically consider the distinctions between involving patients and involving the public and consider the implications for policy making and practice of distinct approaches to accountability and engagement.

The consequence of the reforms in both countries has been far less empowerment of patients, greater inequality between urban and rural populations and far more control for medical professionals and far more money for multinational private sector organisations. This suggests that the public accountability and governance are not operating effectively directly or indirectly via democratic mechanisms. This has consequences for considering the relative power of the medical elite in shaping health policy reforms and challenges the rhetoric of social solidarity as the basis for NHS health systems in Sweden and England. We conclude with a framework for differentiating the
benefits and distinctive contributions that engaging with the public and service users (patients and carers) can have on setting priorities and shaping health system reform and development of health services.

**Friday 12 September 2014 at 10:45 - 11:15**
Pharmaceuticals
White Hall 2, CAMS, Main Building

**Product Development Partnerships (PDPs) as ‘Social Experiments’: ‘Collaboration’ and the Moral Economy of Drug Development at the TB Alliance**

_Upton, M._  
_(Goldsmiths, University of London)_

Since the late 1990s there has been a proliferation of ‘product development partnerships’ (PDPs) in the field of global health in which commercial and philanthropic actors play an increasingly important role in delivering health goods. These partnerships are a response to the problem of ‘neglected diseases’ predominantly affecting the Global South, including tuberculosis, which kills 1.9 million people per year. This paper is based on ethnographic fieldwork conducted with one such partnership, The Global Tuberculosis Alliance. Funded by the Bill and Melinda Gates Foundation, the TB Alliance aims to develop a pipeline of new medicines that are affordable and accessible in the Global South. To this end, the organisation is engaged in a complex and highly choreographed practice of ‘partnering’ with commercial pharmaceutical firms in order to develop new and existing drug candidates. Drawing on anthropological gift theory, in this paper I unpack exactly what is being exchanged in these partnerships and the particular calibration of commercial and philanthropic ethics they produce. Thus while all parties trade on TB drug development as a philanthropic endeavour, I show that ‘collaboration’ is also dependent on the twin promises of ‘good press’ and commercial possibility in the form of intellectual property rights. I show how this moral economy conditions not only the outcomes of these partnerships in terms of specific medicines, but produces a parcelling up of the TB pandemic itself in ways that appear to sit in tension with public health orthodoxy regarding strategies for eradicating the disease.

**Thursday 11 September 2014 at 14:35 - 15:05**
Citizenship and Health
Steelhouse 3, CAMS, Main Building

**Negotiating Everyday Life: A Study of Younger People with Dementia and their Citizenship**

_Ursin, G._  
_(University of Nordland)_

There is an increasing interest in understanding citizenship related to individuals with dementia, and how they can be citizen with progressing cognitive disabilities. This paper uses a feminist lens of citizenship to understand how individuals connect to the society through practices in everyday life.

The aim of the paper is to explore the relations between younger persons with dementia and their next of kin in order to understand what these relations means for the safeguarding of citizenship of the person with dementia. This paper draws on data from semi-structured interviews with next of kin, and uses Social network analysis in the exploration of everyday life. Data shows that younger persons with dementia are highly dependent on next of kin, and as the dementia disease progresses, the relation change. I will give empirical examples of how next of kin perceive of and talk about negotiations of practicalities in everyday life, and how these negotiations change character as the disease progresses. In the discussion I underscore how relations in the social network both undermine and promote citizenship.

The social network emerge from everyday life is central for the citizenship of young people of dementia, and next of kin has an important coordinating position in this networks. In this context citizenship is understood as a relational and procedural term. This perspective on citizenship can expand the traditional view of organizing health care services.
What is Real about ‘Self’-management: A Mixed Methods Study of Social Network Support and the Value of ‘Strong’ and ‘weak’ Ties in the Management of Chronic Illness

Vassilev, I., Rogers, A., Kennedy, A.
(University of Southampton)

Background: There is recognition that long-term condition management (LTCM) is primarily taking place in people's social networks. Yet, the distribution of the roles and responsibilities between different network members and the contributions made by strong and weak ties remain under-investigated. The aim of this paper is to explore the disparities between expected and actual support, subjective and objective evaluations of network member involvement, and the process of negotiating available and acceptable support in relation to LTCM.

Methods: This is a mixed methods survey with nested qualitative study. A total of 300 people from deprived areas in the North West of England with chronic illnesses took part in the survey (2010-2011). A concentric circles diagram was used as a research tool with which participants identified and assessed the relative importance of 2,544 network members who contributed to illness management. Notions of ‘work’ were used to describe activities associated with chronic illness and to identify the contributions made by network members.

Results: Most of the chronic illness support is offered by strong ties and the factors responsible for over- and under-valuing support operate on three levels: ego (person with the condition), alters (network members), and network structure. While both strong and weak ties are highly valued by people with chronic illness it is in relation to strong ties where the disparities between subjective assessments and actual level of support are greatest. Weak ties are important for network stability and adaptability as they act as a bridge between moral identity and need.

Thursday 11 September 2014 at 09:40 - 10:10
Patient-Professional Interaction
Stafford 1, CAMS, Main Building

Developing an Evidence Base for Engagement: A Grounded Theory Study of Young People Interacting with Healthcare Professionals

Vickers, J., Long, T., Howarth, M.
(University of Salford)

Background: Young people’s health policies advocate the need for youth-friendly services that include young people’s values and views in their healthcare (DH, 2007). Yet the engagement of young people within health interactions remains a complicated process, often influenced by lived contexts, value systems and lifestyle choices (DH, 2010). The WHO (2011) suggests that successfully engaging young people ameliorates health-related behaviours, improves health outcomes and increases young people’s awareness of their own health. Yet a paucity of research exists for facilitating evidence-based practice for health professionals seeking to engage young people effectively in their health interactions.

Study Aim: To explore and define young people’s engagement in health interactions.

Methods: A grounded theory study was conducted of young people’s perceptions of their health interactions over a six month period.

Study results: Young people produce engagement-related behaviour by means of an interpretive process. Three interconnected theoretical categories emerged: prejudgment, the beliefs with which young people enter into health interactions; gauging approachability, the means by which young people assess healthcare professionals’ readiness to form engagement-related behaviour; and validation, the young person’s feelings of being appropriately heard and responded to. These theoretical categories identify engagement as a basic social process which can be targeted by healthcare professionals to facilitate practice.

Conclusion: Findings identify engagement as a psychological social process which occur through interactions with healthcare professionals. Developing an evidence base which explores and defines how young people produce engagement-related behaviour is necessary to understand the conditions by which young people engage with healthcare professionals.
Paper Abstracts

Thursday 11 September 2014 at 08:30 - 09:35
Pecha Kucha
White Hall 2, CAMS, Main Building

A History of Heroin Withdrawal and Some Thoughts on Contemporary Withdrawal Treatments

Walmsley, I.
(University of the West of England, Bristol)

The research presented in this paper is a work in progress. The paper aims to extend and develop a theme from my doctoral research on the historical construction of heroin withdrawal. Heroin withdrawal has become one of the many taken-for-granted concepts used in the regulation of problem drug users. The two main drug treatments used to manage the condition of heroin withdrawal are detoxification and substitute prescribing regimes, such as methadone maintenance. These interventions are approved and supervised by a range of experts in the field of drug treatment. This paper will be organised into two parts. The first part of the paper will examine the historical construction of opiate withdrawal in the second half of the nineteenth century. It will draw attention to an important convergence between the discursive fields of poison management and addiction treatments. This will demonstrate the influence of historical and social practices on the way we think about and respond to the problem of heroin withdrawal. The second part of this paper will offer some reflections on the current treatment of heroin withdrawal in light of the insights provided in the first part of the paper.

Thursday 11 September 2014 at 15:10 - 15:40
Risk
Stafford 2, CAMS, Main Building

A Study of the Social Causes of Over-medication in China

Wang, Y.
(University of Essex)

This paper seeks to examine the root causes of the pharmaceutical drugs over-use or over-medication in China. By this mean, there is considerable evidence of this overuse, and it appears to be more extensive than in western countries. I have applied “Countervailing Power” as a theoretical model to explore how this overuse relates and interacts with the power of government, pharmaceutical industry, medical profession and patient. The research is expected to contribute the strategies and recommendations to reduce this overuse and improve healthcare system with policy design, implementation, and evaluation, doctors’ prescribing behaviour, and the doctor-patient relationship. The research results of this research will also shed some critical light on the current global issues addressing the role of the state and effective healthcare policy implementation in the healthcare domain. The study has mainly used qualitative methodology. The primary methods of data collection are: 1) structured and semi-structured interviews and survey that focus on doctors in Shandong province, my home province, 2) review of documents and literatures obtained from government (e.g. MOH report and year book of public health) and non-government sources.

Friday 12 September 2014 at 10:45 - 11:15
Health Policy
Steelhouse 2, CAMS, Main Building

Circling the Square: An Ethnography of Private Sector Strategies in the Transformation of Public Healthcare

Waring, J.J.
(University of Nottingham)

This paper reports an ethnographic study carried out over five years with a private firm and its journey to transform the organisation and delivery of public healthcare in England. The antecedents are found in reforms initiated in the mid-2000s which have since evolved into a mixed economy of ‘qualified’ care providers. The study started with a single organisational case study of workforce reconfiguration and became a longitudinal multi-site investigation of management, culture change and service improvement. Although commercial viability and operational productivity remained influential drivers, service (re-)organisation was framed in terms of a commitment to core public values, especially serving patient need, and the restoration of professional values. Service leaders were typically ‘frustrated innovators’, disenchanted by public bureaucracy, who saw themselves at the forefront of a social movement that challenged the established management order and installing a new Operating System that guided, empowered and rewarded professionals to determine the best ways of delivering improvements. Change was often inspired by North American exemplars but also communitarian approaches to social and culture change. Despite some success in
influencing, or aligning with, national political discourse and securing further contracts, change at the ‘shop floor’ often remains complicated by a lack of leadership, cultural opposition to private healthcare and engrained ways of working.

**Friday 12 September 2014 at 10:10 - 10:40**
Health Policy  
Steelhouse 2, CAMS, Main Building

**Health Inequalities in the ‘New NHS’: Using ‘Sensemaking’ to Understand how Clinical Commissioning Groups are Approaching the Problem**

*Warwick-Giles, L.*  
*(University of Manchester)*

The current NHS reforms give Clinical Commissioning Groups (CCGs) a loosely defined ‘duty’ to tackle health inequalities. A qualitative case study was undertaken in three CCGs to explore how they were approaching the task. Early data collection established that current approaches to tackling health inequalities arose out of past experiences and activities. Weick’s (1995) concept of sensemaking was used as a framework to examine the wider influences on how the CCGs conceptualised health inequalities and the approaches taken to tackle the issue. Overall, past iterations of clinical commissioning, local histories and wider local relationships were influential on how health inequalities were conceptualised and tackled. In essence, it was found that people do not consciously make sense of situations, but act automatically in ways that are entrenched in their existing schemata and previous experiences. Sensemaking helps us examine underlying assumptions about observed behaviour. This could be a valuable tool for CCGs, allowing them to explore their actions and providing them with an opportunity to disrupt poor patterns of entrenched behaviours. Thus, the ways in which CCGs plan to tackle health inequalities can be examined and evaluated, providing insight of how the recent ‘duty’ is interpreted, and enabling them to see how they can tackle health inequalities more effectively.

**Thursday 11 September 2014 at 09:40 - 10:10**
Patient-Professional Interaction  
B. Kendrick, Main Building

**The Caring Relationship between People Living and Dying with Dementia and the Care Staff in a Care Home: Developing an Understanding through the Lens of ‘the Body’**

*Watson, J.*  
*(University of Edinburgh)*

This study used an ethnographic approach with appreciative intent to explore ‘what works’ in the caring relationship between people with dementia in the last months, weeks and days of life and the care staff in a care home. Participant observation in communal areas and during hands-on care was augmented with recorded conversations and group discussion with the staff. A focus on the body, not only in the need for assistance with bodily care and finding physical comfort but also in the way both people with dementia and care staff draw on the skilled habitual body, the wisdom of the body, body language and embodied selfhood, guided data collection. An ethnographic approach also allowed actions and events to be placed in context. Early findings indicate a care setting where the cumulative complexity of physical and neuropsychological needs in combination with the cumulative complexity of 40 people with dementia living in one place, and the changing nature of residential care in Scotland, create a precarious situation. In an attempt to maintain social order the organisation of care tends towards treating the body as an object. This compromises the caring relationship between the residents and front line staff which flourishes when the notion of body-subject is central. These issues are examined with particular attention being paid to palliative and end of life care and emotional work.
Paper Abstracts

Thursday 11 September 2014 at 08:30 - 09:35

Pecha Kucha

Stafford 2, CAMS, Main Building

Trying to Understand the Person Behind Challenging Behaviour: Examining Intellectual Disability Staff Interactions using a European Approach to Challenging Behaviour in a UK Setting

Webb, J., Pilnick, A., Clegg, J.
(University of Nottingham)

People with intellectual disabilities (ID) are more vulnerable to mental health problems and challenging behaviour than the general population. Challenging behaviour can negatively affect relationships as well as the likelihood of positive future interactions. This paper explores the use of an interactional intervention, Discovery Awareness (DA), which focuses on the relational nature of working with people with ID as a way of decreasing challenging behaviour. DA uses video analysis to act as a catalyst for staff to become curious about the personhood of the patient which may have become clouded by negative experiences and concerns as a response to challenging behaviour. The video footage is paused, slowed down and reviewed to reveal moments of interest for the staff which act as points of discussion. This paper arises from an ongoing study of the use of DA in one NHS site in the UK. Whilst DA is currently used in parts of the Netherlands, Germany, and Scandinavia, it has yet to be used in the UK other than in the pilot setting. Using conversation analysis, we examine DA meetings in an attempt to explore the interactional structures that underlie the sessions and discover how information about possible new ways of interacting with the person may be generated. This paper aims to detail the interactional approaches staff display in this context as they communicate and negotiate differing interpretations of the patient and try to move towards new ways of looking at the person behind the behaviour.

Wednesday 10 September 2014 at 14:30 - 15:00

Experiences of Health and Illness
- Stream Sponsored by Health Talk Online -

G63, Main Building

Children’s and Parents’ Perceptions of Anti-epileptic Drugs: Parallels, Differences and Modifications

Webster, M.
(Royal Holloway, University of London)

There is a substantial body of literature exploring the meanings adults attach to medications. However, there is a scarcity of research focusing on children’s perspectives of drug therapy. It has previously been found that children’s and adults’ experiences are not synonymous and it is, therefore, necessary to explore children’s own perspectives. This paper draws on research undertaken for a doctoral thesis. The data were collected using in-depth semi-structured interviews with 25 parents who had a child with epilepsy and photo-elicitation interviews with 10 children, aged 5-13 years. It will be argued that the meanings children attach to their Anti-Epileptic Drugs (AEDs) are often different from those ascribed by their parents. It was found that children tended to think about their medications as a symbol of difference – positive or negative – whereas parents rarely expressed this view. Additionally, it will be argued that when children and parents did attach the same meaning to AEDs, it was often the result of different considerations. Furthermore, there was evidence to suggest that the meanings attached to the child’s AED treatment were adjusted over time due to new experiences and information gleaned, and predominantly as a result of the chronic nature of the condition. This was particularly important for children who had to begin to think about AEDs as preventative measures rather than as a cure. It is intended that this research will add to the existing literature on medication meanings and begin to address the gap regarding children’s views of medications.

Wednesday 10 September 2014 at 14:30 - 15:00

Gender

B. Kendrick, Main Building

Re-working Biographies: Women’s Narratives of Pregnancy whilst Living with Epilepsy

Weckesser, A., Denny, E.
(Birmingham City University)

This presentation will report on findings from a qualitative study investigating the experiences of pregnant women living with epilepsy. This study forms part of the EMPIRE (Anti-Epileptic drug Monitoring in PREGnancy) Trial, a UK multi-centre, randomised controlled trial comparing proactive and reactive strategies for anti-epileptic drugs regimes
during pregnancy. Semi-structured interviews were conducted with 32 women from across the country. Participants were interviewed twice: once in the second trimester and once approximately six weeks after giving birth. Women came from diverse socio-cultural backgrounds. Most participants were first-time mothers, but some had at least one child previously. Women experienced varied histories with epilepsy, and had a range of neurological symptoms. Through the concept of biography this presentation will explore these diverse experiences and the multiple ways in which the biographies of women come to be re-worked by pregnancy, motherhood, and the ongoing management of their condition. A narrative analysis of data suggests that biographical disruption, continuity, and reinforcement are all useful in the conceptualisation of women’s experiences of pregnancy and epilepsy. Findings challenge previous work which argues that the presence of a condition over a long period of time leads to the normalisation of illness. To the contrary, participants’ narratives demonstrate that, for some, pregnancy and motherhood can be disruptive and raise concerns regarding an ongoing condition that may have previously been taken for granted. Such findings also highlight the need for a greater consideration of gender and care responsibilities in the theorising of biographies and chronic illness.

Thursday 11 September 2014 at 15:10 - 15:40
STS
G63, Main Building

Fleshing Out the Self in Self-monitoring: From Discourse to Practice
Weiner, K., Will, C.
(University of Sheffield)

The emergence of a lay consumer market for health monitoring devices means that people may be recording and tracking ever more aspects of their bodily status independently of health care services. Scholarship on self-tracking is only just starting to emerge, but there appears to be growing interest particularly in digital technologies and the quantified self movement.

In this paper we will focus on the theoretic resources that may be enrolled to understand self-tracking. One strand of scholarship has seen this through a Foucauldian lens, suggesting that self-tracking requires certain types of self-regulating and responsible subjects. Another strand has seen these developments through the lens of expertise and implied a more creative potential for tracking to engender new modes of collaborative, collective or lay-driven knowledge making and biomedical research. The status of embodied sensation compared with numeric data or visual representations (for example charts) has provided a further area of interest.

We suggest that being open to the mundane or everyday dynamics of health practices offers other potentially important concepts for understanding self-tracking. In particular we suggest an alternative to the rational and individual subject implied by other scholarship, seeing practices as potentially symbolic or concerned with affect, as well as potentially shared or distributed with household members, health care professionals and wider social networks.

To illustrate these ideas, we will draw on a study of the uses and non-uses of consumer products for heart health and ongoing ethnographic research on self-monitoring involving a range of high and low tech devices.

Thursday 11 September 2014 at 11:25 - 11:55
Mental Health
Steelhouse 2, CAMS, Main Building

Futile Calls for Attention: Adult Children of Alcoholics Share their Childhood Experiences
Werner, A., Kristvik, E., Malterud, K.
(Akershus University Hospital)

Numerous studies show that alcohol abuse puts heavy strain on family and children and that this effect may be long-term. Problem drinking is often kept as ‘family secrets’. To identify potential harmful drinking and help develop better services to those affected, we draw attention to the resistance to seeing and acknowledging these problems. Based on semi-structured interviews with adult children of alcoholics (ACA) recruited from treatment clinics in Oslo/Norway, we explore childhood experiences by asking about the professional help they were offered, and how they experienced that their needs were met.

Preliminary analysis indicates that ACA are ambivalent about revealing ‘the secret’. They felt betrayed that nobody asked them about their situation or did anything to help. Many of those in the position to detect incipient problems seemed reluctant to intervene. Only to a limited degree had the interviewees been offered professional help, and the
services available did not correspond well with their needs. Even when they tried to talk about their parents’ drinking problems, professionals seemed to ignore it.

So far, data indicate that treatment models focusing on individual symptoms neither seem to help professionals approaching the problem, nor to facilitate intervention from responsible grown-ups who may notice the situation. Goffman’s theory of ‘the interactional order’ and ‘civil inattention’ may offer an understanding of concealment that goes beyond personality traits, by regarding it as a way of observing cultural norms of social encounters.

Thursday 11 September 2014 at 10:50 - 11:20

STS

G63, Main Building

Consumers in a Market? Participants in Research? Food Allergy Sufferers Online

Will, C.
(University of Sussex)

This paper starts by considering the ways in which people suffering from food allergies may be imagined as ‘consumers’ of information, services and products. Drawing on a wider investigation of allergy in the UK, the paper focuses attention on a diverse set of websites offering advice to people who suspect they or their children may have a food allergy. Discourse analysis is used to explore the ways in which sites from professional associations, patient organisations, research groups and companies that offer health information alongside advertising, situate their readers in a range of markets: for biomedical or alternative therapies and for food and other consumer goods. Are ‘consumer’ practices appearing as a challenge to ‘patienthood’ in allergy? How are people encouraged and enabled to move between new commercial health products and services, CAM and biomedicine, which currently offers relatively little to sufferers? The paper also addresses the ways in which sites seek to enroll readers in the production as well as consumption of information, building on work by Deborah Lupton and others. The paper points to the different idioms of research using the web for recruitment, and potential links between engaging in research and ‘shopping’ for possible treatments or support. Drawing on proposals by Jeannette Pols, it also seeks to investigate the scope for new forms of knowledge to emerge online, which explicitly offer readers information about living with the condition and navigating this mixed economy of care.

Friday 12 September 2014 at 09:35 - 10:05

Health Policy

Steelhouse 2, CAMS, Main Building

Caught in the Current: Lifestyle Drift and its Everyday Antecedents in an Area-based Initiative

Williams, O.
(University of Leicester)

Historically, public health looked towards social and environmental explanations for the occurrence of illness and disease but increasingly new public health has shifted attention to how individuals ‘choose’ to behave. Despite the current trend towards moral individualism, area-based initiatives (ABIs) have been popularly used by neo-liberal governments to address the social causes of inequality. By highlighting the significance of structural inequalities, these initiatives appear to acknowledge the problematic nature of approaching social issues as matters of individual moral responsibilities alone. However, they also continue to draw heavily on the discourse of individualism. Therefore, these initiatives are particularly susceptible to the wider health policy trend known as ‘lifestyle drift’: a process whereby policies aimed at addressing structural inequalities tend, over time, to adopt a behavioural approach.

Although this drift is recognised at the level of policy little is known about how and why it occurs at the level of delivery. This paper draws from data collected during sixteen months of ethnography, involving observation, interviews with staff and participants and analysis of documents, in a deprived English community where ABIs have promoted active-lifestyles and significantly increased local physical activity opportunities. The analysis shows that over time the relevance of initially identified barriers to participation experienced by local residents was largely ignored and institutional responsibility became contested. This paper considers factors at the level of delivery which saw these initiatives follow the dominant trend of lifestyle drift and how research-based interventions could increase the robustness of future policies aiming to address health inequalities.
**Wednesday 10 September 2014 at 12:45 - 13:15**

Open

White Hall 1, CAMS, Main Building

**Cords of Collaboration: Political, Clinical and Third-sector Interests within the British Umbilical Cord Stem Cell Bioeconomy**

Williams, R.  
(University of York)

The paper explores attempts to redress ethnicity-based social inequities in health through collaborative governance of umbilical cord stem cell banking. This technology has enjoyed a growth in popularity among clinicians delivering treatment to cancer patients, partly because it is believed that ethnic minorities are more likely to find a tissue match in umbilical cord stem cell biobanks than in extant bone marrow registries. In response, clinical experts charities and policy makers have sought to develop an infrastructure to increase the public collection of immunologically diverse umbilical cord stem cells.

As such, we are witnessing the novel intersection of clinicians, charitable bodies, patient advocacy organisations and private enterprise. Such a model of collaborative governance can facilitate discussion between parties seemingly separated by impermeable boundaries of profession and politics. This paper explores the means through which expertise and interest are brought together toward opening policy discussion to a wider field of stakeholders. In this way, it is a case study of an emerging collaborative governance model that hopes to add to this burgeoning area of theoretical development.

The presented data, including interviews with stakeholders and observation of parliamentary meetings, also investigates how a recognised ethnicity-based health inequity can be strategically deployed for specifically professional, political or civic interests; that is, how socially charged notions of race and ethnicity can be mobilised toward potentially beneficent ends (St Louis 2010; Benjamin 2013). Finally, the paper also brings into relief the tenuous position of the ‘expert’ within a widening forum of stakeholders.

**Thursday 11 September 2014 at 08:30 - 09:35**

Pecha Kucha

White Hall 1, CAMS, Main Building

**The Management of Long Term Conditions in Adults with Learning Disabilities in Primary Care**

Wood, K., Macdonald, S., Allan, L., Cooper, S. A.  
(University of Glasgow)

Adults with learning disabilities, as a minority group, have varying health needs and experience poorer health outcomes than the general population. Many suffer long term conditions such as epilepsy and diabetes. As they live longer such conditions can become more chronic, and if left untreated can result in secondary sequelae of disease. Using QOF action points as a measure we recently investigated chronic disease management by primary care for adults with learning disabilities. Amongst 728 adults with learning disabilities, the completion rate of every single required action point was markedly lower than for the general population, often highly statistically significantly so. Building on these findings we aimed to explore the reasons for this trend and establish the scope of future interventions to address this inequality. Phase one, the findings of which we report in this paper, was a mixed methods literature review that identified and synthesised evidence on the management of long term conditions in adults with learning disabilities. We found few intervention studies, and so our focus became a narrative review. A number of studies focused on health screening, and the views and practices of professionals and patients. Our key finding is the under-representation of learning disabilities in literature relating to health and long term conditions in primary care. Phase two involved case studies in primary care. It is hoped this research will inform the development of future interventions for adults with learning disabilities aimed at improving outcomes in long term conditions. This research is in progress.
Strategic Investigative Ethnography: Tracing and Identifying the Amorphous Phenomenon of ‘Developmentally Appropriate Healthcare’

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

In this paper we discuss the challenges and process involved in conducting an ethnographic study to explore the barriers and facilitators to the implementation of ‘Developmentally Appropriate Healthcare (DAH)’ for young people. We examine the difficulties experienced in trying to engage in research which not only spans three different hospital trusts across two different geographical areas, six clinical areas, at both a clinical and managerial levels, but also when there is no accepted working definition of ‘DAH’. As such, the concept of ‘DAH’ for young people is largely elusive within the populations that one is working. This contrasts with most hospital ethnographies, as they usually take place in specific clinical specialities, or discrete settings in hospitals and often focus on a problem or issue that is more clearly defined, identifiable and normalised.

We discuss how we conducted the research, the methods, the demands involved and the strategy that we developed as a way of trying to narrow the focus down by honing in on certain traceable aspects in order to render the research more manageable. We will discuss and make conclusions about the feasibility of our approach and the potential of strategic investigative ethnography for tracing and identifying seemingly broad, less clearly defined and newly emerging developments in healthcare.

How do People with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Experience their Diagnosis as a Process and a Label?

Wotherspoon, N. (University of Sheffield)

Work in Progress - My research will explore how people with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME) experience their diagnosis as a process and a label. It is an attempt to build on the emerging field of the sociology of diagnosis. I will use two methods of research, one will be an historical analysis of chronic fatigue syndrome and the second will be empirical research where at least 30 people with CFS/ME will be interviewed on their experience of the diagnosis of CFS/ME. Underpinning both my historical and empirical work is a Foucauldian theoretical framework.

The historical analysis can be split into three distinct periods; Neurasthenia and moral panics (late Victorian era), the epidemics of ME and poliomyelitis (mid twentieth-century) and lastly, the ME virus and HIV (1980s). My focus will be on the how CFS/ME frames and is framed by the social, historical and cultural context within which it appears. My empirical work will explore how this historical and cultural inheritance potentially affects how people with CFS/ME experience their diagnosis. The aim of the interviews is to also try to understand how people CFS/ME currently experience their diagnosis as a process and a label.