Aasbø, G., Kristvik, E., Werner, A.  

Invisible work: Experiences of family caregivers for chronically ill lung patients

Chronic obstructive pulmonary disease (COPD) is a fatal diagnosis with no effective cure. Recent health care policies emphasise an increasing need for family members to assist health care professionals in the care of chronically ill patients. However, research indicates that family caregivers are already involved in a considerable amount of work related to managing illness and treatment. On the basis of material from an ongoing project, we explore how women and men describe, understand, and manage their role as family caregivers of COPD patients. This in turn will be crucial to the development of an understanding of their relationship to health care professionals. The data material for this project was derived from in-depth interviews with patients’ spouses and health care professionals and observations from home visits with ambulatory pulmonary nurses.

Our preliminary analysis indicates that family caregivers work hard to maintain everyday life as it was before chronic illness interrupted their lives. Although they try not to focus on the illness, it determines the course for their daily life. Indeed, a central issue raised in family caregivers’ accounts is the huge effort expended in order to create normalisation in everyday life. Bury’s notion of biographical disruption offers a relevant perspective for an understanding of this phenomenon. A basis for this analysis is the concepts of emotion work and embodiment of notions of duty and care. It will work in conjunction with further explorations of the significance of gender.

Allan, H. T., De Lacey S., Payne, D.  

The Shaping of Organisational Routines and the Distal Patient in Assisted Reproductive Technologies

In this paper we comment on the changes in the provision of fertility care in Australia, New Zealand and the UK to illustrate how different funding arrangements of assisted reproductive technologies (ART) shape the delivery of patient care and the position of fertility nursing. We suggest that the routinisation of in vitro fertilisation technology has introduced a new way of managing the fertility patient at a distance, the distal fertility patient. This has resulted in new forms of organisational routines in ART which challenge both traditional forms of nursing and advanced nursing roles. We discuss the consequences of this increasingly globalised approach to infertility through the lens of three national contexts, Australia, New Zealand and the UK to unpack the position of nursing within the new forms of organisational routines.
Allen, D. A.  
Cardiff University

Just a typical teenager: normalization, self and other in mothers' accounts of parenting young people with diabetes

Discourses of ‘normal adolescence’ dominate the space in which young people with diabetes, parents and clinicians make sense of health behaviours. In this context adolescence is widely understood as a universal transient phase driven by biological impulses and characterized by emotional turmoil and risk-taking. This view, which has its origins in developmental psychology, has been the subject of considerable criticism in the academic literature, but persists both in formal theory and everyday use. In this paper it is suggested that this anomaly can be understood in part because ‘normal adolescence’ provides a framework of understanding and vocabularies of motive with which to negotiate the other conflicting which shape the moral order at this stage of the life course: normalization, teenage autonomy and adult responsibility. In the diabetes field, these tensions are expressed most powerfully by mothers, reflecting the ambiguity of their status whereby they are expected to encourage their child's independence on the one hand, but feel held to account for their actions on the other. Qualitative interviews generated in a wider study of the transition from child to adult diabetes services are analysed to reveal how discourses of 'normal adolescence' may be enrolled to do two kinds of interactional work: management of mothers' moral credentials and management of the moral credentials of their child. Part of the power of a psychological discourse of 'normal adolescence' is that it furnishes an interpretative frame and discursive resource through which present difficulties can be contained and more optimistic futures constituted.

Alo, O., Gbadebo, B.  
Joseph Ayo Babalola University

Spousal Violence in Southwest Nigeria: Prevalence and Correlates

Spousal violence is increasingly a health issue all over the world, especially in Africa where an unhealthy mix of tradition, inequality and ignorance aggravates the scourge. Despite numerous interventions from human right groups and NGO’s, the problem is still widespread. This study investigates the prevalence of two forms of spousal violence- physical and sexual violence and its correlates among the people of Southwest Nigeria. Data was collected from 300 ever married or cohabiting women through an interview method, and it was processed with SPSS to generate simple percentages and logistic regression analysis. The sample was selected through multistage stratified random sampling technique across all the states of Southwest Nigeria. Spousal violence was measured using a Shorthand and Modified Conflict Tactics Scale. The result indicated spousal violence prevalence rate of 47.3% for ever experience of spousal violence, and 32% for spousal violence prevalence in the 12months preceding the survey. The common forms of physical violence are: kicking/pushing- 31%, slapping-15.5% and arm twisting/throwing things at-14.1%; while the most common form of sexual violence is forced intercourse with 12.7% and 11.5% for ever experience and experience within the 12 months preceding the survey respectively. The experience of spousal violence varied substantially with number of living children, educational levels of women, union status and women's attitude towards wife beating. The paper concluded that there is the need for massive girl child education and the enlistment of social, political, religious and other leaders in speaking out against spousal violence.
Health workers who do not want to have patients

In our society there has been a tremendous increase in commercial merchandises and services related to health issues. In the present paper I discuss how employees in a private, commercialized health resort in Norway, look at their own role within the health field.

"Peace in the forest" is advertised as a health resort or a health hotel both for people with health problems and those who need a break from a stressful everyday life. The resort mainly serves vegetarian food and offer different physical activities. The resort also includes a spa department with massage, chiropractics and different treatments for the body and soul. The employees at the resort are introduced as therapists.

This paper is based on interviews with the "therapists", who have a diverse background from different kind of masseurs, fitness instructors, nursing, and nutrition. Even though these "therapists" have different background they all look upon themselves as health workers and that they treat health problems. However, they all make a distinction between health and disease. They say that their job is not to treat people who are sick. The people that they treat are not patients. They all want to enhance the health, understood as wellbeing. In the present paper I discuss the therapists understanding of their own role in relation to a negative and a positive health concept. I also discuss how they categorize their own activity in relation to the public health service.

Performing Accountability in the Context of Introducing New Technologies

In medical practices accountability is often reduced down to the writing and use of protocols, guidelines and standards in order to standardize practices and hence provide a justification for these actions – what could be termed ‘audited’ accountability (Giri, 2000). In presenting examples from ethnographic field work in two cancer treatment units I will show how accountability is performed in the context of the introduction of new technology and how these performances of accountability can be considered as a means for coping with potential absences of evidence or a lack of confidence surrounding new technologies.

Informed by Science and Technology Studies, I will explore the role of protocols as tools for constructing and performing accountability. I argue that, in separating the processes of ‘giving an account’ from taking responsibility, practitioners are able to work with, or ‘park’, any uncertainty relating to their duties in order to continue to practice. The collective action afforded by introducing protocols therefore can be seen as necessary to enable practitioners, who are also affected by their practices, to continue to work. This parking of uncertainty may be considered unethical or unsafe but I suggest this technique enables practitioners to protect their own role and status within the organisation, in light of the changes associated with introducing new technology.

I conclude that providing accounts, in order to legitimate practices, does not necessarily equate to responsible practice and that justifications for such practices should be based upon a rationale which includes ethical responsibility beyond the legal minimum.
Now You See It; Now You Don’t: The Experience of chronic illness in Six Italian Women Living With Autoimmune Disease.

For those affected, chronic illness is a frightening, often isolating experience. Part of its power lies in its invisibility: to the onlooker, the chronically ill often appears “normal”. In addition, with the passing of time the absence of an immediate threat to life can lead the observer – medical professional or otherwise – to misjudge the true impact of the condition on the sufferer.

This paper draws on an original corpus of interviews with six Italian women living with Rheumatoid Arthritis and Lupus. It is qualitative in nature and is informed by insights gained from Discourse Analysis, Narrative Analysis, and functional approaches to language.

It will show how patients construe and present their experience of chronic illness, whilst shaping a new sense of self. In particular, the paper will highlight the often neglected impact of aggressive pharmacological therapies on sufferers. It will become apparent that for the patient undergoing such therapies, it is often the treatment, rather than the disease, which is construed as having the worst impact on quality of life. As my informants clearly indicate, a better appreciation of this fact by the medical profession would not only be appreciated, but also enhance quality of life, as well as the quality of medical encounters.

How Self-help Shape and Respond to Healthcare Service in a Urban-Rural Divide

Healthcare systems provide a context that shape and respond to the contours of self-help/mutual aid. Norway is a heterogeneous country that allows for variations across the rural/urban divide. We investigated this variation from three angles: 1) the presence of self-help groups, 2) how those working in the support-system perceive self-help, and 3) how self-help groups’ contact persons perceive self-help.

We conducted one telephone survey and two Internet surveys. The support-system survey had a total reply of 380 out of 735, giving a reply rate of 52%. For the contact-persons survey the reply was 54 out of 105 – a reply rate of 51%.

Self-help groups were found to be more frequently available and more viable in urban than in rural areas. In rural areas self-help groups also were more intertwined with public sector and thus more dependent upon professionals and the healthcare-system. Rural respondents were more inclined to see self-help groups as a tool to become more autonomous, while urban respondents were more inclined that self-help groups mainly concern mutual support.

Individuals and communities themselves need to take responsibility for own health and well-being. Thus it becomes natural for public sector to draw upon mutual support to ensure health and well-being prevails in rural areas. This skews the focus of self-help away from mutuality towards individual based benefits.

Understanding the role of professionals is vital if one wants self-help to flourish in rural areas. They influence upon both the functioning and the nature of the self-help groups.
Maternity services for traveller women in South West Wales: risk and blame.

Introduction - Traveller, Gypsy or Roma communities are known to have a significantly reduced life expectancy compared to settled groups. Women of reproductive age have additional challenges to accessing maternity services. Assumptions healthcare providers may have about the ability to travel, the rationale for antenatal care, and women's ability to take time from domestic work can present barriers to uptake of antenatal services.

Method - In a small-scale, ethically approved project in the catchment area of Singleton Hospital, Swansea, 50 women were interviewed in two travellers' sites about attitudes to pregnancy and delivery, and their awareness and perceptions of the available care. In parallel interviews were held with 25 midwives and obstetricians of all grades to examine attitudes and assumptions from the provider's perspective. Grounded theory was applied to the transcripts.

Results - Themes emerged from the women relating to a range of specific health beliefs, perceived lack of understanding and insight of the clinicians of whom they had experience, and a sense of Faith-based predetermined outcomes.

The clinicians' transcripts yielded more consistent themes with cultural stereotyping and essentialism. Solutions to disparities of access focused on assimilation to a perceived cultural norm. There was acknowledgment of personal lack of insight and experience of patients from these communities.

Conclusions - There is little research on the needs of this group of women and larger scale qualitative work would be helpful.

Education should broaden the traditional NHS 'Diversity and Equality' training to improve understanding about potential barriers. Some simple outreach measures are suggested.

Restoring a sense of wellness following colorectal cancer: a grounded theory

Aim: To develop a grounded theory to explain the experience of recovery following surgery for colorectal cancer.

Background: Advanced in diagnostics and treatment have led to many patients experiencing colorectal cancer as an acute episode; where illness is short lasting and resolves through recovery. Existing research has predominantly adopted a biomedical framework where recovery is measured through sequelaes of treatment. Fewer studies have considered the emotional, social and cultural aspects of recovery over time.

Methods: A longitudinal study using grounded theory was conducted with 12 individuals, who had received surgery for colorectal cancer. Semi-structured interviews were conducted at 4 time points over one year. Grounded theory analysis was undertaken using Strauss and Corbin's framework.

Findings: Individual's describe their illness experience in three phases: disrupting the self; repairing the self; restoring the self. The disease and treatment disrupt personal identity. Recovery is a process of body repair and restoring personal identity and control. The core category is Restoring a sense of wellness; fostered through awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. A sense of wellness exists as a duality with a sense of illness, where both perspectives co-exist but one usually takes precedence. A sense of illness pervades when the individual is preoccupied with illness which continues to disrupt their daily life.

Conclusion: This study adds to the conceptual vocabulary of chronic illness by illustrating how social and cultural meanings associated with cancer create an illness experience beyond the immediacy of an acute treatment episode.
Blickem, C., Vassilev, I., Brooks, H., Kapadia, D., Reeves, D., Cheraghi-Sohi, S.  
*University of Manchester*

**Social networks, illness management and different lines of work: an empirical study of the impact of social networks on managing long term health problems**

Healthcare has seen a shift in emphasis from paternalistic models of care to lay-led partnership models of care which promote self-management education programmes as a potentially effective way of addressing chronic disease management (Foster 2007, Lorig 2002). Although a patient-centred perspective is welcome, there is a tension between the vision of patient responsibility for health management (Wanless 2002) and the dominance of biomedical priorities within the discourse of self-care where there remains a focus on the support given by health professionals to people living with long-term conditions (LTCs).

This paper argues for the need to highlight contextual issues in everyday life and the central role played by social networks of support in shaping capabilities to adapt to living with a LTC. This involves sharing the work that is additional to everyday responsibilities, which includes re-negotiating and co-ordinating existing arrangements in everyday practices in a range of contexts (e.g. home, family, work, leisure, etc).

We draw on the notions of illness work, everyday work and biographical work (Corbin and Strauss 1985) and social network analysis (SNA) and propose a conceptual framework for detecting these areas of work in order to understand who should do what, who does what, and what is the process of negotiating and sustaining new practices with and between actors within networks of care in relation to LTCM. These concepts were operationalised in a mixed-method survey conducted with 300 people with vascular conditions in the Greater Manchester area and this paper will report on the findings.

**Thursday 15th September 2011 16:55 - 17:25**

Blows, E., Bird, L., Seymour, J., Cox, K.  
*University of Nottingham*

**The experience of long-term cancer survivorship: a multiple-case study**

Background: Of 2 million people living with cancer in the UK, 1.24 million were diagnosed over 5 years ago. Adopting a biopsychosocial approach - looking beyond ‘disease’ and outcomes to exploring cancer within the context of survivors’ daily lives - this study aimed to explore experiences of long-term survivorship (=5 years post-treatment).

Methods: A multiple-case study, collecting data using narrative interviews, was conducted. Interviews were held with 12 cancer survivors and their ‘significant others’. This paper outlines preliminary findings from the descriptive stage of the analysis: ‘restorying’ of individual narratives, followed by cross-case analysis, to describe experiences of long-term survivorship.

Findings: There appear to be 2 types of ‘survivor’: those for whom cancer is in the past, who would describe themselves as having ‘had’ cancer; and those for whom cancer is in the present, who are ‘living with cancer’. For those that perceive it to be in the past, cancer tends not to affect daily living. Those experiencing ongoing consequences of cancer find it continues to limit daily activities, affecting their identity and relationships. This being said, all survivors describe triggers that remind them they were diagnosed with cancer. In this respect, all survivors oscillate between the past, present and future, in terms of the place cancer has in their lives.

Conclusions: Whilst many long-term survivors adjust well to life post-treatment, some continue to feel the impact of cancer on their daily lives. Explanatory analysis now seeks to further our understanding of why some survivors adjust better than others.
Friday 16th September 2011 09:00 - 09:30
Maternity/Reproduction Westminster Building Room CWE126/1

Bosanquet, A. Kingston University/St Georges University of London

'Follow Nature, trace her footsteps, listen to her voice': writings of pioneering midwives from 17th and 18th century London

Concerns about the on-going medicalisation of childbirth and struggles to sustain 'normality' have been at the forefront of professional and wider societal debates since the 1980s. The achievements of modern medicine and science, with their undeniable benefits, have also introduced a risk of disempowering women by robbing them of physiological ability to give birth naturally, and have given rise to new challenges to midwives in maintaining normality and preventing unnecessary intervention. These contemporary concerns and dilemmas closely resemble those of the conflict ridden 18th century London where female midwives fearlessly contested the new interventionist male midwives. Research presented here looks at the original writings of five 17th and 18th century London midwives who were the only known female authors of midwifery books published in English before 1800– Jane Sharp, Sarah Stone, Elizabeth Nihell, Margaret Stephen and Martha Mears. It focuses on their understanding of the normal birth processes and the arguments used by them for supporting 'nature' and 'normality'. Contrary to widely held views and images of early-modern midwives as uneducated, superstitious and dangerous birth attendants, the emerging picture is that of highly dedicated, skilled, knowledgeable, erudite and inspiring women. Studying the history of midwifery and childbirth opens opportunities for better understanding of the development of clinical knowledge and adds refreshing perspectives to professional debates of today.

Thursday 15th September 2011 11:20 - 11:50
Healthcare Organisation Westminster Building Room CWE125/2

Boudeau, C. University of Reading

Designing the observability of hospital inpatients in single bedroom wards

The proposed paper explores the relationship between the architectural design of healthcare infrastructure and the organisation of healthcare activities. It is based on the examination of architectural drawings produced in the course of the design of a new hospital in the UK, specifically successive drawing studies of single bedroom wards. The objective of these drawings was to find an acceptable architectural solution to the specific problem of achieving 66% visibility of inpatients in each ward by nursing staff. The proposed paper study is informed by the ethnomethodological programme. Hence is concerned with the embodied methods by which architects sought a design that would satisfy this requirement. It therefore addresses the following question: how were nurses' real-world observation and monitoring practices manifested in the architectural design of the single bedroom wards? The central thesis demonstrated is that the design of healthcare infrastructure incorporates and prospectively arranges real-worldly healthcare activities. The objective of this paper is to describe the ethnomethods by which this was accomplished in the drawings of the single bedroom wards. In addressing the relationship between the design of healthcare infrastructure and the delivery of healthcare services, this paper is consequently highly relevant to the sociology of health.
Boulos, M.  
*University of Sydney*

**'Good eggs': ideal donors for stem cell research**

This paper will describe a study into perceptions of eggs provision for stem cell research. Few women have volunteered to provide eggs for SCNT research which has substantially limited the progress made. In an effort to increase the number of eggs available, some jurisdictions, including New York and the United Kingdom, have permitted some form of payment for eggs. These policies have had some success but have attracted criticism from ethicists, sociologists and feminists on the grounds that they are potentially exploitative because paying women exploits vulnerable populations who often have little choice but to use their bodies in instrumental ways.

Scientific egg provision must contend with the established demand of eggs for reproductive purposes. Studies concerning reproductive egg provision contribute to understanding providers’ motivations and the political implications of the practice. However, the provision of eggs to SCNT research is a significant reconfiguration of the relationships that exist in the reproductive paradigm. The new field draws together women, scientists, state and non-state funders, patients, and their families. It shifts the purpose from a baby in the ‘here and now’ to a much less tangible process of scientific knowledge, making explicit issues about property rights.

Drawing on empirical data from fertility patients, reproductive egg donors, and the ‘ideal’ donor – women aged between 18 and 30, this research reports on various factors that contribute to the low provision rates of eggs for SCNT research in Australia.

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Bracher, M.  
*University of Southampton*

**Sense, perception and embodied sociality – exploring identity, place and risk in autistic people’s autobiographies.**

Autism Spectrum Conditions (ASCs) are lifelong neurodevelopmental conditions, currently understood as involving impairments to social, communicative and mentalising/theory of mind operations as well as sensory and perceptual differences affecting the reception, rendering and modulation of sense data. These experiences have profound implications for experiences and negotiations of social life for people with ASCs. Recent social scientific work has indicated that issues of identity, relationships with place, and social risk are configured in particular ways by sensory and perceptual differences; and these are implicated the production of particular patterns of embodied social activity. Relationships between these aspects of experience are at present underexplored in the literature, particularly with regard to their implications for framing and exploring autistic sociality. The presentation will be structured as follows; first, I present a summary of my theoretical approach, which conceptualises autistic sensory and perceptual differences within a wider context of embodied human sociality. This, I argue, helps to mediate the tendency in some of the wider literature on ASCs to ascribe a priori deficits to what are complex multifaceted experiences emerging within disparate biographical, intersubjective and emotional circumstances. Second, I will present a summary of my methodological approach to examining and analysing autobiographical materials, and indicate the manner in which autobiography as an embodied communicative and intersubjective practice is well suited to exploring the experiences of this group. Third, initial findings from my PhD project will be discussed in relation to their role in reframing conceptions of embodied sociality in autism.
Exploring the structure and narrative of general practitioner-community pharmacist networks

The relationship between general practitioners (GPs) and community pharmacists is often described as ‘uneasy’. On the one hand both professions possess a common focus on optimising the benefits and reducing the risks of medication for patients, but on the other, the overlap in both service and skill can lead to competition and tension. It is the norm for both professions to work in isolation from one another with only limited contact regarding routine administrative queries. The patient acts as the lynchpin of the relationship, dictating the connection between the pharmacy and the GP surgery.

It is against this back-drop that recent policy and guidance in the UK has encouraged GPs and pharmacists to work together more collaboratively. Previous evaluations of such attempted collaborations indicate that the relational structures or networks between GPs and pharmacists are either not present or too weak to fully support such initiatives.

The paper presents findings from four case studies of GP-pharmacist interaction using a social network analysis approach. The analysis focused on the structural properties of the networks and individual actor and dyad properties, in addition to the characteristics of ties in terms of reciprocity and multiplicity, and of the actors themselves in relation to homophily. Qualitative interviews have provided narrative to the structural form of the networks, exploring what it means professionally to be situated in different positions in the network (e.g. well connected or isolated), how these positions may have been achieved, and the opportunities or constraints these positions present.

Perceived impact and experience of participating in peer support interventions: a qualitative synthesis

There are several contemporary discourses about the growing burden of chronic illness, resource constraints within health care systems, and self-management in chronic illness. One particular form of self-management is peer support, defined as ‘the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person’ (Dennis, 2003). We conducted a synthesis of qualitative studies, using meta-ethnography, to address the question: What is the impact of formal or informal peer support on improving the health and wellbeing of individuals with chronic disease? Following the usual procedures of literature searching, applying inclusion and exclusion criteria, and quality appraisal, 25 papers were included in the synthesis. Data extraction covered methodological quality, method of peer support, intervention duration, peer training, disease type, severity and duration, co interventions, and demographics. Fourteen key concepts were identified through a process of translation: emotional entanglement; sense of connection; finding meaning; experiential knowledge; reciprocity; helping; role satisfaction; changed behaviour; changed outlook; changed knowledge; sharing; isolation; empowerment; and accepting disease. These concepts have been synthesised in the form of a conceptual model which is intended to explain the experience and impact of participating in peer support interventions. We compare the model with other sociological models of self management, with particular reference to the interplay between experiential and professional knowledge.
They think it's all up to the girls: gender, risk and responsibility for contraception

Introduction - The UK continues to have the highest teenage pregnancy rates in Western Europe, and reducing them remains a priority for the UK Government. There remains a need to understand why unintended conceptions still occur, despite widespread availability of contraception.

Methods - We re-analysed the data from two earlier qualitative studies, with an emphasis on findings related to responsibility. The first study investigated unintended conceptions and in particular, reasons for non-use of contraception amongst 16-20 year old women soon after or prior to termination of pregnancy. Interviews focussed on knowledge of and views on contraception, sex education, and sexual health services. The second study involved focus groups with two groups of 14-18 year old men to explore their views on sex education, sexual health, and knowledge of and responsibility for contraception. The interview and focus group transcripts were analysed using a grounded theory approach.

Results - The issue of gendered responsibility for contraception emerged during the interviews with young women, with interviewees reporting assumptions by young men that women should take responsibility for contraception. Almost all the young women said that young men viewed contraception as "not their job". However, the young men thought that responsibility for contraception should be shared.

Conclusions - There are clear gender differences in assumptions about responsibility for contraception, and in accounting for decisions about use of contraception.

Health professionals’ emphasis on hormonal methods of contraception reinforces gendered assumptions of responsibility; although it may result in fewer unintended conceptions, there are implications for rates of sexually transmitted infections.

Living in the Present Versus Desiring the Past: A Qualitative Analysis of Women’s Experiences of Ovarian Cancer

In recent years, a common socio-cultural discourse has emerged in much literature on cancer experiences. The discourse centres on the notion that cancer brings about a realization that life is more fragile than previously thought, and thus affected individuals feel a greater urgency to enjoy life. This discourse is evident in references to the desire to ‘live in the present’ or ‘seize the day’, among others. This presentation explores this socio-cultural discourse with respect to data generated in a qualitative study of women’s experiences of ovarian cancer carried out in Saskatchewan, Canada. Analysis of face-to-face and e-mail interview data revealed that this discourse was commonly referenced by participants, with several indicating that cancer was a catalyst to live their lives differently. However, a tension also emerged in some participants’ narratives because they also expressed a desire for the reliable nature of life prior to having cancer. In other words, sometimes participants yearned for a return to their pre-illness life when they could go about their daily routines with ease and were able to plan for the future. Thus, while participants often drew upon the ‘living in the present’ discourse, as many individuals affected by cancer in contemporary Western society do, some also communicated a desire for the stability afforded by their pre-illness lives. This presentation contributes to the sociological study of cancer experiences by offering insight into how women affected by ovarian cancer negotiate and give meaning to their experiences with respect to socio-cultural discourse.
### Burr, J. A.  
*University of Sheffield*

**Exploring the role of research ethics committees from the perspective of Luhmann’s social systems theory.**

There have been a number of criticisms about the general efficacy of Research Ethics Committees (RECs) in their different institutional settings. Recently, a number of researchers have raised concerns about ‘ethics creep’; ‘illegitimate generalisation’ from ethical review procedures designed for biomedical research and incompatibility with social science research methodologies.

I aim to present a theoretical explanation for the role and practice of research ethics committees through sociological system theory and specifically the work of Luhmann. The primary starting point for Luhmann is that social relations cannot be successfully analysed on the basis they are humane. RECs are not a social system but used to support and legitimate the social system ‘science’ which has the primary function of producing knowledge and truth (we may argue ‘truths’). I argue that one explanation for the role of RECs can in found in Luhmann’s descriptions of how different systems are functionally differentiated and therefore, systems are not tied to a supreme value, for example, truth or justice.

Through an analysis of the discourse used in RECs, for example ‘dignity’, ‘respect for privacy’, I argue that these fulfil certain functions including that of ‘scientific’ legitimacy. Legitimacy is not produced because we truly believe in these discourses, but through participation in REC proceedings. Therefore, the process of gaining REC approval is nothing to do with issues of ‘ethics’. It is the participation in these procedures that determines the legitimacy of decisions and therefore that of science as a whole.

### Busby, H. W., Julie, K.  
*University of Leicester*

**Risk and Safety in the Blood Supply in the 21st Century: Perspectives from Qualitative Research with Patients, Professionals and Regulators in England**

Blood is a staple of the supply of biological materials that underpin contemporary medical practice across most health systems. The technological, organisational and regulatory dimensions of blood services have changed beyond recognition, and the management of these risks is a complex and changing terrain. The paradox in the long endeavour to supply safe blood - that new risks have emerged or been manufactured, even as progress is achieved- resonates with sociological discussions about the nature of risk in modern societies.

This paper aims to offer a sociological analysis of the transitions in the governance of blood supply in the UK, with respect to the management of risk. It is now proposed that greater openness should characterise public policy in this field, that the precautionary principle should guide policy decisions in this area, and that a more robust approach to informed consent should be taken. The implications of these proposals will be explored through an analysis of policy developments and of a consultation about informed consent in blood services in England. The paper will also draw on the preliminary findings from a qualitative study being conducted with the aim of exploring the framing of risk in this context by patients, professionals, and regulators with an involvement in blood services. Whilst the sociology of risk offers important directions for reflection on these findings, the paper will also draw on an older body of work about lay knowledge, and will be grounded in a recognition of the vulnerability that need for blood entails.
Buse, C., Joynes, V.J.  
University of Leeds

The embodied biographies of carer and cared for: interconnected meanings of illness and identity

There is a burgeoning sociological literature on care and embodiment which has explored the experiences of those receiving care, or the ‘bodywork’ involved in providing paid care (Twigg 2000). However, it has been argued that carer/cared for are often positioned as binary opposites (Chattoo and Ahmad 2008), whereas many unpaid carers are themselves suffering from a serious health condition (Lloyd 2006). This paper explores how biographies of illness are interconnected with the stories and identities of unpaid carers and carers’ own experiences of health and illness, drawing on data from the national evaluation of the ‘National Carers Strategy Demonstrator Sites’. This research used mixed methods including case studies, carers surveys, and documentary analysis. Data illustrates how many providing unpaid care do not identify themselves as ‘carers’, which is often linked to continuity in their embodied biographies and roles (for instance as a loving spouse) and a sense of compassion or moral duty. Carers often focus on the needs of the cared for person and neglect their own health needs, and at the same time health professionals tend to focus on the needs of the service user. Therefore, while the carer may be experiencing illness, the carers’ body often remains ‘absent’ (Leder 1990) although initiatives such as carer health checks help to bring it to the fore. The importance of bringing the body of the unpaid carer ‘back into focus’ therefore has important theoretical, practical and policy implications, and helps to overcome dualisms between carer and cared for.

Byrne, G., Moore, R., Daly, L.  
University College Dublin & Trinity College Dublin

An exploration of Polish migrants perceptions of accessing healthcare in Ireland

Background - The Polish community are one of the largest ethnic groups in Ireland. The Polish embassy estimates that 180,000 Polish continue to live in Ireland in 2011. Their expectations about Irish healthcare are influenced by cultural issues including their previous experiences of healthcare in Poland.

Methods - Participants were recruiting via Polish churches, organisations, schools and medical centres, using purposive sampling. Between January 2010 and April 2011, 12 individual interviews, 3 group interviews and four focus groups were conducted. All interviews were recorded, transcribed and analysed with the aid of NVIVO.

Results - Forty –eight participated in this qualitative study, the majority of whom were female and a minority (n= 11, 22.9%) were unemployed. The major themes from the data analysis included: lack of information about the Irish healthcare system, expectations about the role of the GP (General Practitioner), access to specialist care, English competency of the participants, cost of healthcare and long waiting times. Some participants reported changing pattern of accessing GP care, the longer they lived in Ireland.

Conclusions - Poor access to health care may contribute to health inequalities among ethnic minorities. It is imperative to understand the barriers to health care as perceived by migrants to improve access and to promote integration. An historical review of the developments of the different health care systems in Poland and Ireland will help contribute to an understanding of the Polish migrants’ expectations about healthcare in Ireland.
Carter, P., Jinks, C.  

*Keele University*  

**A case study to evaluate patient and public involvement in musculoskeletal research.**

This paper presents a mixed methods case study of active patient and public involvement (PPI) in research. In 2006 the Arthritis Research UK Primary Care Centre established a “Research Users Group” and supplemented this with a “Virtual Panel” in 2009. In total there are 30 “experts by experience” who have a musculoskeletal condition and are willing to contribute this expertise to academic and clinical research. Support is provided by a paid PPI co-ordinator who shares the experience of having a musculoskeletal condition. An evaluation sought to understand how the groups function and their impact on patients, researchers and the organisation.

The data set comprises documents, semi-structured interviews with patients and researchers and field notes. A theoretically informed abductive approach was used to analyse the data. Emergent findings indicate that experiential knowledge contrasts with the socially privileged form of academic expertise and that respect and recognition are key mediators of successful ongoing relationships. The PPI co-ordinator uses the metaphor of translation to explain how she communicates across different linguistic repertoires. Active involvement of lay people has made some difference to themselves, to research topics, study design and to patient information materials. PPI has also had an impact on the organisation and on research funders. At a key moment in the organisation’s history, a group of patients were “handpicked” to represent the Centre’s approach to involvement and they were described by visiting funding assessors as “inspirational”. The findings will be discussed in relation to sociological theories of participation.

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Castro-Vazquez, G.  

*Nanyang Technological University*  

**Japanese Men, Pride and Circumcision**

This paper reports part of an ethnographic investigation on circumcision, maleness, sexual behaviour and health matters of Japanese men.

The aim is to answer two questions: What are the views of young Japanese men in relation to circumcision? And, what are the implications of male circumcision in terms of gender and sexuality in Japan from a male perspective? To respond, the outcome of interviews with twenty-six Japanese men are examined. Three of them were circumcised, eight were homosexual and one was bisexual. Twelve were under or graduate students at universities in Ibaraki or Nagoya and fourteen were either blue or white-collar workers in Tokyo.

The analysis of interviews suggests an almost complete absence of medical and health concerns. Instead, the connection between genitalia and masculinity was recurrently referred to as the core issue underlying circumcision. At first glance, being able to show the glans was synonymous with adulthood. A deeper analysis indicates, however, that an uncovered penis, circumcised or not, symbolises a bigger sexual organ and a higher position in the hierarchical order of men. In addition, some informants stated that circumcision meant longer sexual intercourse and better control of ejaculation. Nonetheless, talking and/or ‘bragging’ about genitalia could damage the reputation of ‘well-educated’ and seriously working men. In this line, circumcision implies male embodiment contrary to the disembodied, asexual ‘salaryman’ archetype.
Caswell, G., Pollock, K., Walker, W., Harwood, R., Porock, D. University of Nottingham

**Dying with dementia in the acute hospital setting**

Levels of dementia are increasing in the United Kingdom, as well as in the rest of the world. The Alzheimer's Society calculates that the current number of people in the UK with dementia is approximately 750,000, and this is expected to increase to a million by 2021. Dementia is estimated to be a factor in 60,000 UK deaths each year and many of these deaths will take place in an acute hospital ward. Published research about the experience of dying in hospital with dementia is limited, but a number of themes recur across studies. Patients with dementia, it seems, may receive different treatment from their peers who do not have dementia and advanced dementia is not always recognised as a terminal illness. There are also issues reported concerning communication and the processes involved in end of life decision making, which are complex when the patient has dementia. The study reported here aims to add to the current evidence base. It is a qualitative project exploring end of life experiences of people with dementia and their family carers in comparison with end of life experiences of people without dementia. Taking place on five wards in an acute hospital, the study is employing observations, informal and formal interviews with members of staff, interviews with bereaved relatives and a review of nursing and medical notes. This paper reports preliminary findings from this ongoing research project.

Chamba, R. The Open University

**Bio-medical and Social Explanations for Schizophrenia among Black African-Caribbean People**

For several decades, psychiatric epidemiology and other survey data has suggested that, compared to non-Black ethnic groups, Black African Caribbeans are anything between 2-17 times over-represented within psychiatric in-patient mental health facilities, with diagnoses of schizophrenia. Although this over-representation has become established as an epidemiological truism, explanations for why these ethnic disparities occur have remained fraught with controversy, especially among two key groups of professionals: academic psychiatrists, and Black mental health activists.

The principal research question which has informed my Ph.D. research is: How and why do academic psychiatrists and activists award authority and legitimacy to their explanations for these ethnic disparities occur have remained fraught with controversy, especially among two key groups of professionals: academic psychiatrists, and Black mental health activists.

In this presentation I propose to, one, describe the production of authoritative knowledge claims by academic psychiatrists and activists as a reflexive activity; that is, all knowledge claims emerge from situated identities and interests. Two, I describe how knowledge claims are stabilised and awarded technical and moral assent with reference to key issues within science studies. In doing so, my approach addresses enduring themes within medical sociology too – epidemiology, race/ethnicity, class, and the production of medical/psychiatric knowledge and research – using an eclectic disciplinary approach.
Chamberlain, K., Leggatt-Cook, C.

**Blogging for weight-loss: Personal accountability, writing selves, and the weight-loss blogosphere.**

Body weight is a key concern in contemporary society, with large proportions of the population attempting to control their weight. However, losing weight and maintaining weight-loss is notoriously difficult, and new strategies for weight-loss attract significant interest. Writing about experiences of weight-loss in online journals, or blogging, has recently expanded rapidly. Weight-loss bloggers typically write about daily successes and failures, report calorie consumption and exercise output, and post photographs of their changing bodies. Many bloggers openly court the surveillance of blog readers as a motivation for accountability to their weight-loss goals. Drawing from a sample of weight-loss blogs authored by women, we explore three issues arising from this practice of disclosing a conventionally private activity within an online public domain. First, we examine motivations for blogging, focusing on accountability. Second, we consider the online construction of self, exploring how weight-loss bloggers negotiate discourses around fatness, and rework selves as bodies transform. Finally, we consider the communities of interest that form around weight-loss blogs. This ‘blogosphere’ provides mutual support for weight-loss. However, participating in online social spaces is complicated and bloggers must carefully manage issues of privacy and disclosure.

Chapple, A., Evans, J. University of Oxford

**Patients with pancreatic cancer and relatives talk about preferred place of death and what influenced their preferences: a qualitative study**

Objective: To explore reasons why people with pancreatic cancer express a wish to die at home or elsewhere.

Design: Qualitative study using semi-structured interviews collected by maximum variation sampling.

Setting: Respondents recruited from different parts of the UK during 2009/10.

Participants: Eight people with pancreatic cancer and 8 relatives of other people who had recently died of pancreatic cancer talked at some length about place of death (from a total sample of 32 people with pancreatic cancer and eight relatives).

Results: People’s preferences were affected by their perceptions and previous experiences of care available at home, in a hospice or hospital. Preferences were also shaped by fears about possible loss of dignity, or fears of becoming a burden. Place of death had symbolic meaning for some people, who thought that a home death might leave bad memories for other members of the family. People with pancreatic cancer and their relatives were aware that preferences might change (or had changed) over time as death approached.

Conclusions: The NHS End of Life Care Strategy for England seeks to address the needs of people who are dying and promotes enabling more home deaths. More information is needed about why patients and relatives change their minds about place of care and place of death, and what importance patients attach to place of death.
When Boundary Objects are Dispensed with – Implications of Electronic Prescribing in Primary Care

This paper explores the symbolic and boundary object value of the traditional paper prescription in the context of the planned move to using electronic prescribing in primary care in the UK. It is argued that, after Pellegrino, the physicality of the traditional paper prescription represented an important form of closure for the medical encounter; that it represented a boundary object within Star and Griesemer’s typology as a ‘standardised form’ which made sense of the different understanding of the medical encounter and social process of medicine supply (including pharmacy supply); that considering the physical prescription as a boundary object may have had more of an influence than was recognised in the symbolic transformation of (inert) drug to (socially useful) medicine in Harding and Taylor’s nee Dingwall’s critique of the role of pharmacists. It is argued, as a result of this interpretation, that the move to electronic transfer of prescriptions will remove this significant boundary object and introduce uncertainty in the process of prescribing and dispensing. It also raises broader questions as to what happens when boundary objects are lost and whether another boundary object can be used to facilitate this new technology.

The Role of Peer Educators in their Peers’ Negotiation of Sexual Decisions- A Wits University Case Study

“This research investigated “how peer educators assist their peers in negotiating sexual decisions: a Wits University case study”. The research study explored the necessity of explaining peer education in the social context of South Africa given the crisis and concern of young people’s sexual health in the society. The study additionally explained the particular opportunities presented in viewing a cohort of students enrolled at a South African university and the ways in which informal peer education occurs in these social spaces. The theoretical framework underpinning this project incorporated elements of behavioural change, social identity, knowledge dissemination and life-cycle theories. The research study assessed the ways in which socialization sources and agents shift in influence and importance during different phases of social life. The details of the study will be outlined, including the methodology comprising research design, methods, sampling techniques used and ethical considerations involved in conducting this research project. The usefulness of diaries in capturing personal narratives when conducting informal peer education is discussed. The findings arising from the data collection phase of this research project will be presented and analysed into four interrelated themes. These include “The social environment of student life at Wits University”; “Peer educators’ social identity and its influence on informal peer education interactions in different contexts”; “Just Jokes- Icebreakers”
Cooper, J., Kierans, C. The University of Liverpool

The Cultural Anatomy of Decision Making: Ethnicity and the Organ Donation Encounter

Deceased organ donation among the UK’s Black and Minority Ethnic (BME) groups has become a particular issue for renal transplantation. Despite constituting just 8% of the population, BME patients account for 25% of the transplant waiting list, yet only 5% of deceased organ donors (NHSBT 2010). Current transplant practice favours sharing organs between similar ethnic groups, meaning BME patients have a vastly reduced chance of receiving a transplant compared to their White counterparts. Searching for ways to solve this ‘problem’, existing policy, and health and social research has focused upon ‘communities’ to understand the reasons for low donation rates, with findings concentrated upon discrete ‘cultural’ factors like religious beliefs (e.g. Hayward & Madhill 2003). Such insights, however, fail to account for contextualised experiences of the organ donation encounter; where a patient dies in Intensive Care and their relatives are approached about donation. Reporting on findings from a multi-sited, ethnographic study looking at a range of stakeholders’ experiences of donation, this paper will argue that donation decision-making is far from a simple matter of a family saying ‘yes’ or ‘no’. Using observations and narratives, it will show how the ‘issue’ can be mapped through the entire donation trajectory: from the evolving processes of procurement, to the relational, practical, and emotional labour for health professionals involved in organ donation. Bringing these together, the paper will finally argue that understandings of ethnicity become enacted in donation processes; demonstrating that donation disparities are far from a simple problem of ‘community’ ‘culture’.

Corbett, K., Smith, A., Ruston, A.M. Canterbury Christ Church University

The impact of neoliberal political ideology and the reconstruction of health care placement circuits.

Government policy has been politically transformed during the Thatcher, New Labour and Con-Lib Coalition eras by the adoption of neoliberal ideologies. This has led to the deconstruction of the post-war welfare state/public sector and its reconstruction in line with the guiding ideology of laissez-faire. This paper focuses on the impact of this radical approach on the current development of placement circuits for professional healthcare education. Placement circuits are networks of education providers where healthcare students learn competences in order to gain professional registration with UK professional regulatory bodies. The paper draws on the analytic findings from an evaluation of a novel project that aimed to develop new placement capacity for healthcare students inside the private/independent sector. Originating and sustaining new placements by public sector providers inside the private/independent sector was found to require the variable adoption and promotion of neoliberal values such as marketing the benefits of placement provision and the conceptualisation of provider remuneration in both fiscal and non-fiscal terms. Where provider remuneration was once considered in non-fiscal terms, and often conceptualised in terms of professional capital and professional values, these findings showed how such values are now being reconstructed by the market and reconceptualised in neoliberal market terms like cost, performativity and throughput. The various implications of these findings are explored in terms of the contradictions between a laissez-faire marketization of health services and the concomitant effects on reconstructing the placement capacity within higher education programmes that lead to professional healthcare registration.
Sleep, pharmaceuticals and 24 hour living

Pharmaceuticals that can be used to augment all stages of the sleep – wake cycle fuel visions of a 24 hour society in which humans can operate around the clock. Embedded within these technologies is the promise of a pharmaceutical future in which we can remove the corporal constraints of our biological bodies and choose when to be awake and when to sleep, freeing ourselves from the constraints of clock time and blurring the temporal lines between day and night.

This paper will explore discourses around the pharmaceuticalisation of sleep in contemporary Britain using the wake-promoting drug modafinil as a case study. Empirical data were collected via 40 qualitative interviews with leading scientists and clinicians involved in sleep research and management; and two prospective user groups of the drug.

The paper will argue that despite the ‘social arrhythmia’ that exists in today’s world, the idea of pharmacologically controlling sleep and wakefulness by healthy persons is met with a high level of scepticism and ambivalence, by experts and prospective users alike. The data show that there is still a strong cultural tendency to associate drug taking with illness, addiction, dependency and risks to health which may provide a barrier to widespread pharmaceutical use to control and augment sleep patterns outside of medical authority.

Individual budgets in mental health: a narrative turn

Mental health services are challenged to provide recovery focused delivery across all their provision. These services equate to around a quarter of monies spent within the National Health Service. This and previous administrations have supported the development of more personalised, user oriented approaches in meeting clinical and user need. However, without moving towards flexible and person-centred approaches, efforts to create choice may amount to little more than a complicated procedurally neutered process, with services remaining unchanged (Alakeson and Coyle 2011).

This paper will address the narrative turn when user perspectives become equal partners in care processes of commission and delivery. It will focus on the impact of individual budgets for users of mental health services and their journeys of recovery and perceptions of role and change for service providers. The paper will report on two studies undertaken within mental health services that implemented individual budgets in the North West of England, (Eost-Telling 2010, Coyle in press). The narrative methodologies used in these studies will form the basis for a wider discussion of service development and the rise of the consumer’s voice.

References
Toward a critical sociology of men's health

Recent concerns with the health of men have culminated in the emergence of new movements characterised by the pathologisation of masculinity as a gender identity judged to be deleterious to men's health and wellbeing and the promotion of neo-liberal modes of self monitoring and governance. Such movements, it is argued, fail to interrogate more fundamental questions regarding the construction and reification of men and their bodies within late modern cultures. Rather, the male body and the masculine identity which is unproblematically seen to follow from it, is taken as the starting point for understanding inequalities between men and women in late modern industrial societies. The aim of this paper is to interrogate, using established theoretical perspectives, the construction of men and masculinities as universal objects of enquiry, illuminating their historical and cultural specificity and the role of power and knowledge in constructing particular forms of men and their bodies at particular historical junctures. It is argued that the recent men's health movement may only serve to reflect prevailing discourse regarding health, risk, the body and individual responsibility, themselves inextricably linked to dominant modes of social and political organisation.

Women, Self-Harm and the Moral Code of the Prison

Discriminatory attitudes directed at women self-harmers – i.e. women who engage in non-fatal acts of ‘deliberate self-harm’ such as self-poisoning or self-injury – have been well documented in such diverse clinical settings as accident and emergency departments (A&E) and upon psychiatric wards as well as amongst the public at large. These attitudes have been summed up as constituting a particular ‘moral code’ which surrounds the act of self-harm and subjects it to detrimental comparison to experiences such as physical illness or being considered suicidal. Following Foucault, we might call such clinical settings as A&E ‘moral universes’ constituted of discourses which are as much ‘moral’ as they are ‘clinical’. What is less clear, however, are the characteristics of that distinctive ‘moral universe’ which is the prison environment – considered here as simultaneously a clinical and a custodial setting – despite the fact that the prevalence of women’s self-harm in such an environment is now well documented. Deploying the findings of an on-going research project in an English prison – including survey and qualitative data collected from both staff and women who self-harm – this paper, for the first time, identifies some of the chief characteristics of the ‘moral code’ of the prison. It also, following the work of Alison Liebling, assesses the extent to which the ‘moral code’ of the prison, as it specifically pertains to the act of self-harm, reflects more widely upon the prison’s ‘moral performance’.
The Limits of Medicine in Progressive Ataxias

Although it has been identified that medicine may act as both a resource and a constraint in chronic illness, thus far this notion has not been interrogated in any depth. Contingent narrative accounts of people with ataxia are used to highlight the limits of medicine in the context of a rare, untreatable and disabling disorder. These accounts highlight the embodied uncertainties brought by slowly progressive diseases which lie at the boundaries of mainstream medical knowledge. The existential crises faced by people with ataxia are seemingly magnified by sometimes idiopathic aetiologies and uncertainties related to the questionable veracity of information about their condition found on the Internet. Whilst people’s accounts suggested the notion of patient as medical consumer, this construction was problematic in the context of an untreatable condition. People were drawn into a medical system that was focused mainly on attempts to diagnose their condition, with widely varying results. However, when asked, most had rather valued the provision of disability aids and physical therapies. Only one informant reported overcoming the myriad uncertainties of progressive ataxia, and their account supported the notion of ‘biographical repair’ in chronic illness. Clinical uncertainties in ataxia seemingly constrained people’s attempts to deal with their condition.

Innovations and Emotions in funeral rites: cremation, green burial, dissolving bodies.

This paper takes us from a relative familiarity with the shift from traditional burial to cremation on to the innovation of ecological burial and to yet newer possibilities of dissolving bodies. Issues of cultural sets of emotion in relation to such shifts will be discussed, using Geoffrey Gorer’s classic, Death, Grief and Mourning, as a launching pad. The paper will highlight some recent resurgence of interest in the study of emotions in the sociology of religion. It notes the paucity of treatment of death in mainstream sociologies of religion and argues for a wider flow of material between ‘death studies’ and the sociology of religion in general.
Balancing the (sexual) act: towards new conceptualizations of trans-sexuality in healthcare

The sexualisation of transgender is a thorny issue due to the negative associations within sexology and society. The political move from transsexual to transgender was announced to be important as a way of shifting associations surrounding transgender and sexuality generally. However, after years of being either silenced about sexuality or hypersexualised, for fear of being regarded as unworthy of medical interventions or sexual deviants by the medical teams providing healthcare, transsexuals and transgender people have started to explore and produce their “sexual bodies” and represent them in novel ways through prose, poetry and (pornographic) film. These projects of sexual representation rely on transforming spaces and discourses in which transpeople explore their sex lives. These textual productions often speak back to the medical fields various positions on trans-sexuality. I will argue that Queer and camp aesthetics are intrinsic to these explorations and representations. In the words of Kate Bornstein (1994: 163), over a decade ago, an “irreverence for the established order” and the “often dizzying use of paradox” will underpin the analysis. Using empirical and textual data, I will illustrate that transsexualism and transgenderism is not solely about gender, as a core characteristic, and suggest that sexuality informs trans subjectivity too. I will further suggest that new representations of trans-sexuality pose an ideological challenge to the medical policy and practices surrounding transgender medicalisation and the sedated ideas surrounding transexuals as either nonsexual or hyper-sexual. This focus will allow for new conceptualisations of transgender sexuality to enter medical knowledge and point to a more patient centered approach to their healthcare needs.

The Rise and Fall of Essentialist Understandings of Psychological Erectile Dysfunction

The current treatment solutions for psychological erectile dysfunction (psyED) have been developed through a reductionist and essentialist understanding of male sexuality. Pharmaceutical and technological solutions are offered for a complex aetiology which has psycho-sexual trauma at its foundation. These provide a treatment answer to the physiological signs and symptoms (a flaccid penis) rather than acknowledging complex psychological damage. As such, successful penetrative sex is considered the solution to deep rooted psychological problems.

Data is presented through a conceptual analysis of philosophical, psychological and medical literature, such as contemporary interpretations of St Augustine’s City of God to the new ‘Erectile Dysfunction Service’ offered by Boots Pharmacy. This data emphasizes the essentialism at the core of dominant understandings of psyED. Combining this with data from my previous research I illustrate that the normative power of male sexuality is a social determinant of psyED.

Drawing on Wentzell and Salmerón’s research I conclude that the current biomedical treatment is insufficient for understanding the aetiology of psyED and inadequate in providing any meaningful treatment solutions. By consistently relying on physiological cures for the signs and symptoms of psycho-sexual damage, men are simply realigned within the normative power of masculine sexuality. Such realignment may exacerbate the prevalence of psyED through accentuating the social determinant of normative male sexuality. I tentatively argue that solutions should aim to borrow from the nominalist disease concepts that have been developed in medicine rather than follow the essentialist principles so dominant in treating and understanding psyED.
Symbolic Violence, Cultural Capital and Evidenced-Based Dentistry

Low levels of cultural capital have been suggested to be important factors associated with dental caries (tooth decay). Coupled with this it has been suggested that the decline in caries according to the DMFT (decayed, missing and filled teeth) index has been caused by a shift in treatment philosophy from restorative invasive treatment to a preventive treatment of the disease.

Saturation sampling of pertinent cariological literature followed by a counter-conceptual analysis of the two treatment philosophies has discovered that the restorative treatment philosophy has been constructed as a representation through an anti-restorative discourse within dental research. This representation has been achieved through an evidenced-based impetus within dental public health which aligns itself with a preventive treatment philosophy of caries. The repercussion of this is that non-evidenced based knowledge is de-centred and constructed as traditional, obstinate and abject. This allows dental researchers to re-align and re-configure dental knowledge through the “objective” scientific logic of the evidenced-based movement. This objectivity however is normative and politised.

I conclude that this both punishes those who possess limited levels of cultural capital and is a form of symbolic violence (Bourdieu) upon the dental profession. I further argue that this is linked to Wacquant’s notion of the restructuring of the neoliberal state around the logic of the “objective” scientific paradigm of evidenced-based research and the trope of individual responsibility.

Electronic Patient Information Systems and Care Pathways: reconfiguring the delivery of health care in primary care.

This paper reports on efforts being made to integrate care pathways with e-patient information systems within two NHS primary care trusts (PCTs) in England. Our aim here is twofold:

1. To examine the role of care pathways in reshaping the delivery of health and social care.
2. To find out how health professionals and information specialists work together to construct and use these systems.

The research is inter-disciplinary, bringing together socio-technical systems (STS) and social theory. These ‘e-care pathways’ are constructed from human, technical and organisational resources in various heterogeneous configurations (Law 1992; Dent 2003), which reflect their ‘path dependent’ character (Greener 2002) by which we mean that the ‘shape’ of the pathways tend to be adapted to fit the character and history of particular local health (and social) care organisations.

We draw on the research on five care pathways (two from each PCT plus one common one):

1. Frail elderly care
2. Stroke care
3. Diabetic retinopathy screening
4. Intermediate care
5. Unscheduled care in both PCTs

With our main focus on the older patient for they reflects the broader context of health care, with the demographic shift to a longer living citizenry and the challenge to control escalating health costs, for which these pathways are intended to be part of the answer.
Dimond, R.  

**The Ceremonial Order of the Conference**

The Ceremonial Order of the Conference

This presentation explores the public representation of medical work. I discuss my observations of national 'family' conferences to demonstrate the value of approaching the conference as a significant site of social interaction.

The conference offers a unique platform to examine the representation and performance of individual and collective identities. This setting remains relatively unexplored as a site of medical work, particularly when compared to the wealth of research on the hospital and clinic (Becker, 1961; Strong, 1979; Davis, 1982; Atkinson, 1995; Featherstone et al., 2005 amongst many others). Previous research has explored the conference as a place of medical communication but this is more frequently focused on outcome rather than process or located within the context of medical teaching.

The conferences that were observed as part of this multi-site ethnographic PhD project were organised by two national parent-led support groups. The focus of this presentation is to highlight the types of interaction between patients, parents and clinicians that occurs at these events. The structure of these conferences, where the audience are primarily parents or patients and the presenters are mostly health professionals reflects the power inequalities inherent in the 'doctor/patient relationship'. Relationships that exist within the clinic are therefore performed, and transformed on the public stage. Strong's (1979) ‘Ceremonial Order of the Clinic’ is developed and extended to identify a ‘Ceremonial Order of the Conference’ that enables and constrains individual and collective talk and behaviour.

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Duffy, M.  

**Shadows in the Background**

This paper explores the experiences of being a partner of a lesbian woman in Irish health care. In their day to day living lesbian women know how to act, react and behave to exist within society, having developed what Draucker (1999:361) calls “everyday skilful coping”. However these taken-for-granted ways of understanding of being in the world are thrown or brought to the forefront when lesbian women seek health care.

The epistemological and methodological framework used for the study derived from hermeneutic phenomenology utilising Heidegger and Sartre. Heidegger’s (1962) concern with being in the world, offered a theoretical framework whereby lesbian women are constructed in the research as active participants in the world, creating understanding and meaning to their existence. Sartre (1969) offers us a lens through which we can examine how lesbian women experience the self. It is this capturing of life as it is lived, that frames the articulation of understanding and meanings that lesbian women derive from the situations they find themselves in, in this case health care. The ways in which interpretative phenomenology shaped and framed the study will be investigated in this paper. The process of analysing the data will be described to illustrate how a hermeneutical phenomenological study can be useful in seeking an understanding of the lived experience of a minority group that has hitherto remained hidden.

The findings from this study suggest that lesbian women come across various attitudes towards their lesbianism, ranging from negativity to positivity.
Friday 16th September 2011 09:00 - 09:30
Death & Dying Westminster Building Room CWE124/2

Dunn, L., Byrne, P., Lloyd-Williams, M. University of Liverpool

Caring for family members with end stage disease: an exploratory qualitative study examining the biographical impact of caregiving amongst bereaved family caregivers

The impact of chronic illness on the lives of patients and their families is well recognised in today's society. The biographical impact of health and illness first gained academic attention in the 1980s and 1990s, with a focus on the lived experience of patients with chronic illness (Bury 1982, Carricaburu and Pierret 1995, Pound et al. 1998, Williams 1984). Biographical models have since been employed to investigate the impact of caring on informal family caregivers. Findings suggest that these models are indeed useful in aiding our understanding of the experiences of carers (Adamson and Donovan 2005).

This study draws on narrative methodology to explore the lived experiences of bereaved informal caregivers and the biographical impact of caring amongst this population. It seeks to extend the contribution made to the area of biographical theory and contribute to new knowledge by retrospectively exploring this issue with carers of people with end stage disease. The presentation will give an overview of the literature in this area, followed by a discussion of methodology and emerging themes resulting from early PhD findings.

Friday 16th September 2011 10:10 - 10:40
Ethnicity Westminster Building Room CWE125/2

Durey, A., Thompson, S. C. Curtin University

Confronting racism towards indigenous people in health care: An Australian perspective

Health disparities between indigenous and non-indigenous people exist in many developed countries with worse health outcomes for indigenous people. As health researchers, we are ethically bound to address inequalities, not only from the perspective of the disadvantaged but also to offer a critical analysis of those in power. This paper will shine the lens on the privileged to identify how inequitable power relations in health service delivery manifest systemically, institutionally and interpersonally to compromise health in indigenous people and enable health in the advantaged. Using Australia as a case example, we show how Aboriginal ontology, epistemology and axiology are subjugated to white Anglo-Australian cultural dominance in a mainstream health setting. We present findings from discussions between non-Aboriginal medical practitioners experienced in Aboriginal health that highlight frustrations with a health system that discriminates against Aboriginal patients by failing to recognise how cross-cultural misunderstandings compromise the quality of care to Aboriginal patients in hospital. We argue that racism in mainstream health care undermines Aboriginal people's health, yet is often unchallenged and unreported. Recognising that the problem of health inequalities starts with the privileged provides an opportunity to expose, critique and interrupt those processes. Blaming Aboriginal people for their disadvantage, over which they have little control, conveniently shifts the gaze away from government and organisational accountability and reinforces the invisibility of privilege. Accountability requires organisations to go beyond rhetoric or tokenistic Aboriginal employment and effectively address racism to promote health through reformed practices.
Ebenso, B.

**Life course perspectives on experiences of and responses to leprosy-related stigma in Yoruba-land, Western Nigeria**

Drawing on research amongst people affected by leprosy, this paper explores the complexity of health-related stigma by investigating everyday experiences of people affected by leprosy in Yoruba-land, Western Nigeria. Fieldwork combined life-history interviews of those affected by leprosy with semi-structured interviews of non-affected community members and an ethno-linguistic study of the leprosy phenomenon. The study contributes rich understandings of Yoruba ideas of leprosy and illuminates how cultural processes and macro-social events shape experiences and responses to leprosy-related stigma.

Contemporary scholarship on leprosy-related stigma is dominated by epidemiological surveys conducted among health workers and the general public using stigma scales to measure the burden of stigma in diverse global contexts. Whilst epidemiological studies seek evidence-based solutions for improving treatment outcomes and/or ameliorating the impacts of stigma, they ignore the experiences of people affected by leprosy and the influence of culture on stigmatization. This paper theorizes how processes of communal living that normally promote solidarity and admiration of members who contribute to group survival, inadvertently provoke envy and resentment which, on occasion, intersect with deprivation to induce deliberate infliction of a leprosy-like illness on others in order to stigmatize and exclude them from society.

The paper concludes that notions of health-related stigma should incorporate lay perceptions that stigma is shaped by cultural values and dynamics of interpersonal relations. Classifying leprosy merely as an infectious disease overshadows alternative theorization of illness causation and stigmatization that are defined within interpersonal relationships. Insights for improving health policy and practice are discussed.

Ellingham, B.  
Cranfield University

**The origins and salience of healthy behavioural intentions amongst members of weight loss groups in deprived rural England**

Interest amongst policy makers in getting the public to eat more healthily and take exercise continues to grow. People living in deprived areas generally tend to have less healthy lifestyles, putting them more at risk of lifestyle-related disease. Deprived urban areas are most often used as the setting for health promotion interventions, as the actual level of deprivation in rural communities may be less and their populations by definition, more dispersed. However, rural areas may have specific issues that make staying healthy more difficult; for example access to services (Commission for Rural Communities, 2005).

The purpose of this research is; based on a socio-ecological view of health, explain and reveal the salient features that have driven a specific segment of the population to make decisions that have led to positive changes in their health behaviour intentions. It will achieve this through an ethnographic study of members of weight loss groups living in deprived rural areas of Eastern England who have displayed a theoretical precursor to behaviour change – behavioural intention (Ajzen and Driver, 1991).
"Alcohol is a way of life. If we don’t go drinking, you’d never see anybody". Men, masculinities & drinking in early midlife.

Policy and media attention has focused on young ‘binge’ drinkers but substantial numbers of men and women in ‘early mid-life’ also engage in heavy drinking. Our focus group study explored how people in early midlife (30 to 50 years) perceive alcohol consumption and how cultural constructions of gender influence drinking behaviours in the west of Scotland. This paper focuses on how men in early midlife ‘do’ masculinity through drinking using data from 10 focus groups (pre-existing groups of friends and work colleagues; some all-male groups and some mixed-sex). Our data reveal the social contexts in which men in early midlife drink alcohol and some ‘standard procedures’ which govern drinking (e.g. rules of buying rounds, choice of drinks and order in which they are consumed, banter and trading of insults which contribute to male camaraderie). Respondents described the situations in which they drank most alcohol and the strategies they used in order to limit their drinking (e.g. pacing with pints, playing sport, making a sharp exit). Heavy drinking - as a release from tension, an escape from the responsibilities of life, a means of improving mood through laughter with friends - could be seen as part of the process of maintaining good (mental) health. Hegemonic notions of masculinity were firmly aligned with drinking pints, drinking heavily, and drinking at the pub. Exploring how some men, in some contexts, attempted to manoeuvre outside of these behaviours may provide valuable knowledge for social scientists, health promoters and policy makers.

Adopting medical devices: pathways through the healthcare system adoption space

Technology adoption into the NHS has been variously criticised as inappropriate, too slow or too fast. There is limited knowledge about the social and technological processes and determinants of adoption pathways. This study aims to elucidate the factors shaping decision processes in the early-emerging adoption pathways of device technologies, in order to inform policy and practice, and to explore possible criteria for ‘appropriate adoption’. The study uses in-depth, multi-method comparative case studies of eight specific technologies in a wide variety of settings and draws conceptually on Science and Technology Studies approaches including actor-network theory. Initial analysis proposes that adoption can be understood as occurring within a technology-specific ‘adoption space’ - a dynamic network of actors (people, technology, documents, concepts) that transcends organisational and geographical boundaries and the rationalities of ‘evidence-based’ approaches to technology assessment and adoption. The research is developing an empirically grounded model of technology adoption processes applicable in the NHS. We outline this developing adoption space framework, showing how rational factors (policy positions, scientific evidence, evidence reviews) and the marketplace (cost, marketing) are mediated by attributed identities that network participants construct for a technology; by visions and expectations; by the requirements and affordances that technologies themselves exert; and by relational, regulatory, cultural and structural factors. The paper provides data, initial results and developing analysis based on ongoing NIHR SDO-supported research.
'Then it hit me in the stomach' - visceral and affective motivations in autism research.

In this paper, I explore the role of emotions and (bodily) attachment as motivators for doing clinical research, with particular reference to autism. During 2010/11, I interviewed c.30 autism researchers – psychologists and cognitive neuroscientists – about the relationship between autism and the new brain sciences. As an ice-breaker, I asked my interviewees what interested them about autism in the first place. While most replied with a standard litany of courses and books, I was taken aback by a significant minority who narrated their entry into autism research in terms of their emotional attachment, and their visceral commitment, to the area. This paper is an attempt to situate and theorise these unexpected responses.

In particular, drawing on interview data, and building on Shapin's (2010) discussion of the presumed 'moral ordinariness' of the scientist, and the role of 'the personal, the familiar, and even the charismatic' at the heart of technoscience, this paper asks two sets of questions: (1) how, and to what extent, do emotional and bodily commitments mediate research into autism? How do autism researchers unfold such narratives? And how do the narratives relate to the clinical and therapeutic futures that often form the public script of their research motivations? (2) What insight can such commitments give us into the nature of autism itself, and its position as the paradigmatic developmental disorder of the twenty-first century? What relational epistemologies hold our knowledge of autism together? And how, if at all, are these structured by affect and the body?

The role of pleasure in drinking during pregnancy

The dramatic rise in women's alcohol consumption in Scotland has led to an increased interest in the role that alcohol plays in women's lives, with sociological research focussing on issues of gender and identity linked to wider social and economic changes for women such as workforce participation and rising levels of income and borrowing. Clinical and public health researchers have raised concerns about the impact of increased alcohol consumption on women's health, and the reported link between alcohol and Foetal Alcohol Syndrome (FAS) led to the Scottish Government recommending in 2007 that women abstain from alcohol altogether whilst pregnant or whilst trying to conceive. Yet despite this advice and some media awareness of FAS, recent research indicates as many as 1 in 4 women in Scotland report that they continue to consume some alcohol during their pregnancy.

Drawing on in-depth narrative interviews with 21 women from Edinburgh and Inverness who had a child under the age of two years, I explore the ways in which many of the women's narratives fluctuate between notions of guilt and pleasure and go on to examine how some women legitimised their decision to consume alcohol during their pregnancy in terms of the gratification that it gave them, related to their sense of identity and pre-pregnancy 'self'. These often contradictory and conflicted accounts offer meaningful explanations as to why some women continue to drink during pregnancy, and how they believe that (not) drinking alcohol affects their health and the health of their child.
The health identities of young UK men

This paper reports a secondary analysis of qualitative interviews, exploring the health identities of young UK men (18 – 21 years).

Health identities, Fox and Ward (2008) have suggested, manifest from the confluence of the active, engaged, experimenting body with its physical, psychological, emotional, social and conceptual relations. Identity is fundamentally embodied and social, and consequently we need to study body and identity together, as emergent in activity and practice, and located within the totality of a body’s physical, psychological and social relations.

Gender and sexuality, work identities, class and ethnicity, growth, maturation and ageing are all embodied, reflexive and social. Amid these various body identities, health identities are clustering of relations around specific aspects of embodiment, such as sport and exercise, body modification, sexuality, disability or growing old.

Fox and Ward (2008) developed a methodology for the empirical study of health identity, in which data are interrogated in terms of body relations and assemblages, to discover the limits and possibilities of identity and embodiment. This paper reports such an analysis of a dataset.

The research found that body size and shape, fitness, underlying health conditions, sexuality, work, stress, beliefs about embodiment and many other relations contribute to health identity. I focus on three examples of disparate health identities, and use these to assess young men’s health identities and the utility of the approach to understanding health among young men.

Understanding experiences of life following a stroke via Frank’s quest, restitution and chaos narrative genres

How people create and present stories about the experience and impact of having a chronic illness can be examined using narrative analysis. Arthur Frank describes three types of illness narrative – ‘restitution’, ‘chaos’ and ‘quest’ - which can aid listening to the ill. Restitution focuses on a cure for the illness. Chaos narratives show a lack of temporal order, despair, futility, impotence, and vulnerability. Quest and its three sub-types - memoir, manifesto and automythology - focus on acceptance of and gains from the illness experience. Frank’s approach has been applied to chronic illness narratives but not stroke narratives.

This paper explores people’s experiences of life after a stroke - its impact on their lives, sense of self and identity - through their interview narratives, and examines the applicability of Frank’s approach for 9 male and 9 female UK stroke survivors.

For all but three people, we could classify survivors’ accounts to one dominant narrative genre. Quest memoir was the most common dominant genre; there were fewer restitution or chaos narratives, and no dominant quest manifesto or automythology narratives. The severity of stroke and level of subsequent impairment largely explained which genre predominated. Having purpose in life helped people accept the long-term effects of stroke. The cultural and social availability of genres also influenced the genre presented but gender did not appear to.

People who have had a stroke may present a narrative that conforms to a culturally preferred restitution or quest genre, but chaos narratives need to be recognised and acknowledged.
The debate about the funding of Herceptin in New Zealand: a case study of `countervailing powers'

In December 2008 the newly elected Prime Minister of New Zealand overruled the agency that negotiates with manufacturers about the cost of medicines and agreed to fund Herceptin for women with early stage breast cancer for a twelve months course of treatment. This presentation describes the ‘natural history’ of this decision and seeks to explain it in terms of the theory of countervailing powers, which has recently been applied by Busfield to understand the rapid growth of medicines. We explore the role of various actors in the debate about whether Herceptin should be funded, drawing on documentary analysis and a systematic search of journals, web sites and media databases.

The case of Herceptin both confirms and questions the balance of countervailing powers suggested by Busfield. On the one hand the manufacturers of the drug proved to be highly influential in their attempts to get Herceptin funded and were generally supported by consumer groups, along the lines suggested by Busfield. On the other hand some scientists and regulators attempted to challenge the power of the manufacturers, with the latter not showing signs of ‘regulatory capture’ as one might expect. The media, which were ignored by Busfield, did not act as a countervailing force. In the end the government overturned the recommendation of its regulators, thereby undermining the latter’s efforts to act as a countervailing power. The response of the state is as Busfield suggested, although it seemed motivated more by electoral success than by the desire to please the manufacturers.

A History of Deep Brain Stimulation

Deep Brain Stimulation (DBS) has become an accepted treatment for severe Parkinson’s disease, essential tremor, and dystonia in specialist centres in Europe and the United States. It is generally acknowledged that the development of DBS started with a French Team’s 1987 publication on DBS for the treatment of tremor. Yet, DBS and other forms of neurostimulation had been used for almost 20 years prior to this. By exploring the development of DBS, this paper will illustrate how innovative medical technologies are shaped by various interests, and how such technologies prompt particular understandings of the body and disease. Specifically, this paper will argue that commercial interests facilitate the dissemination of quantitative standards for measuring the body and disease. DBS devices were originally produced to treat chronic pain, but after the introduction of FDA regulation, these treatments failed to gain approval. This was attributed to the “subjective” nature of pain. The medical device industry thus lacked a lucrative market for their DBS technology until it was used to treat Parkinson’s disease (PD) in the 1990s. Quantitative standards for measuring the severity of PD were developed, making PD treatments amenable to clinical trials and thus FDA approval. The medical device industry sponsored such trials, and these quantitative standards have disseminated. This paper will suggest that such standards render individuals intelligible according to “difference in degree”, and constitute what Foucault refers to as a disciplinary technology, enabling individuals to become both analysable and manageable. This research has been supported by the Wellcome Trust.
Locating the social in Health Promotion’ – A South African case study

The conceptual framework of ‘health promotion’ is rooted in the critique of the ‘downstream’ approach of the medical curative model with its devotion to ‘saving drowning swimmers’ and the development of an alternative ‘upstream’ approach that aims to ‘tackle the forces that push them into the river’. Thus in the context of this paper ‘Upstream’ – ‘Downstream’ refers to the different paradigms in addressing public health problems as explored in various publications and adopted by the ‘New Public Health’ with its declared emphasis on the ‘Upstream’ approach. Similarly, theories and practices of health promotion from its earliest versions have been advocating a shift from a biological/medical preventive focus to a more social one, from the level of individuals to organisations, communities and broader social policy. However, it seems that a real shift in the desired direction remains an elusive goal in practice despite many achievements in promoting health and changing people’s behaviour in specific areas.

It is against this conceptual framework that this paper explores the HIV/AIDS epidemic in South Africa and critically analyses its health promotion efforts focusing on the traditional dichotomies of: bio-social; individual-society and downstream-upstream in order to draw attention to the associated complexities that should be taken on-board. Using evidence from South Africa (historical and current) the main thesis focuses on the limitation of these dichotomies and argues towards a more comprehensive approach. An attempt is made to add to our understanding of the meaning of the ‘social’ and to demonstrate why a strong and real emphasis on the ‘social’ in all interventions throughout the disease trajectory is an essential condition in successful efforts to reduce HIV/AIDS prevalence. A model based on the critique developed in the paper is presented as a ‘Way Forward’ suggesting solutions along a ‘continuum of options’ that take the ‘social’ on-board. The ideas raised in the paper feed into the discussion about the nature of public health and provide a good example for the deliberations about the myth of a value-free public health.

Conferences as ethnographic sites: the annual medical conference on assisted reproduction as a case study

Biomedical conferences and meetings, lay and professional alike, have received little attention as ethnographic sites. However, as I will argue in this paper, they have proven to be extremely useful when trying to understand the process of knowledge construction, socialisation and normalisation (Dimond, 2011; Gonzalez-Santos, 2011). For example, at patient-oriented conferences attendees see and sometimes interact with others who are facing similar health issues; this can have effects on their illness related identity and on the way they understand their condition. Likewise, at these events they meet physicians outside the consultation setting, facilitating with this a different type of interaction and of information exchange. During professional meetings, attendees debate about new and sometimes controversial diagnostic and treatment procedures and about emerging ethical issues vis a vis everyday practice. All these interactions and discussions influence the direction the field will take.

Drawing on information gathered during four years of ethnographic work within the field of assisted reproduction, in this paper I present two issues: first, a discussion regarding methodological and ethical aspects of conducting ethnographic work in these settings; and second, presented as a case study, the process of knowledge and realm construction that took place within a meeting of biomedical professionals on assisted reproduction. The aim of the paper is to highlight the usefulness of using conferences and meetings as part of an ethnographic methodology when studying current and emerging biomedical areas, specifically when the purpose is to see how fields are transforming and establishing themselves.
What influences prescribing behaviour in general practice? An ethnographic exploration

While the new public health management and audit cultures emphasise the importance of research evidence, the persistence of prescribing variation in general practice suggests some resistance to these control measures. This raises questions about 'what influences prescribing in general practice'.

An ethnographic study, involving participant observation, semi-structured interviews and a review of practice documentation allowed an in-depth comparative study of three different general practices in Scotland. These findings revealed that prescribing decisions were made in two contexts; macro and micro, and were influenced by different factors.

Macro prescribing decisions were collective; population decisions considering the average patient and were influenced by research evidence and clinical governance. Micro prescribing was made during patient consultation and considering their unique circumstances. When making micro prescribing decisions GPs relied on internalised personal formularies and clinical judgement. The macro prescribing analysis drew on Weick et al’s (2001; 2005) work on organisational sensemaking. The micro prescribing analysis drew on Gabbay and le May’s work on knowledge management ‘mindlines’ (2004).

It is argued that practices had an identity, shaped by their practice values, organisational structure and communication channels. Practices engaged with research evidence and clinical governance mechanisms which were aligned with their values and identity. At the micro prescribing level GPs drew on personal formularies and clinical judgement, informed and updated by social networks. Current managerial initiatives seeking to influence prescribing focus on macro prescribing, which limits their effectiveness. Further research is required to understand the complexities of micro prescribing and the mechanisms through which evidence becomes internalised.

Thursday 15th September 2011 14:00 – 14:30

Gender

“IT's sort of more male-dominated ...you're not threatened at all, where most of these slimming things are really more aimed at women” A feasibility study of a gender-sensitised weight management programme delivered through Scottish Premier League football.

The prevalence of obesity in men in the UK is among the highest in Europe, but few engage in traditional weight management programmes designed to deliver the 5-10% weight loss associated with improved health. Despite growing recognition of the potential of professional football clubs to deliver health promotion (including weight management) to men, little research has been done in this area.

Football Fans in Training (FFIT) is a 12-week, gender-sensitised weight management/physical activity group programme delivered by Scottish Premier League (SPL) clubs. A mixed-methods feasibility study, including a pilot randomised trial and participant focus groups, involved 103 men aged 35-65 years with BMI = 27kg/m2 being randomised to intervention (N=51) or waiting-list comparison (N=52) groups in two SPL clubs. Primary outcomes were viability of recruitment procedures and attrition. Secondary outcomes included potential efficacy of the weight loss programme, and changes in self-reported physical activity, eating habits and psychological status. Process outcomes included acceptability of FFIT to participants.

Recruitment targets were achieved in one club (the largest) but not the second, and overall attrition (16.5%) was low. Intervention participants achieved a mean 4.6% (SD 2.8) weight loss at 12 weeks compared with a 0.6% weight gain (SD 2.0) in the comparison group. Intervention (but not comparison) participants reported significant improvements in physical activity, eating habits, self-esteem and SF12 scores. Men were positive about FFIT, and the football setting was a particular draw; many indicated they would not have attended a similar programme elsewhere. Follow-up assessments will examine maintenance of short-term improvements.
How may action research help patients awaiting colorectal cancer surgery regain a sense of control over their lives?

The educational process within the colorectal unit varies widely according to patient diagnosis, proposed surgery, and further treatments, and is provided by diverse healthcare professionals along their care pathway. Relatively few preoperative education services for colorectal patients have been formally evaluated. An action research-based evaluation of a preoperative education service examined whether and how patients and carers might see the service as beneficial and relevant and what they might identify as potential improvements. An action research study was carried out using three cycles of planning, acting, observing and reflecting on changes. Themes relevant to informing changes in education provision were taken to a healthcare staff decision-making meeting to inform the next action cycle.

Themes identified in patient, carer and staff views and suggestions focused on potential ways they could play a more active role in preparing for surgery and enhancing their own recovery to self-manage their lives. These included patient journey timescales, stoma management, normalising bodily changes, dietary changes and resuming normal occupations. Identifying information which was meaningful to their lifeworlds was seen as critical for enabling patients to regain a sense of control after major disruption to their biographies and sense of self following a diagnosis of cancer requiring colorectal surgery. Action research provided ways to represent and integrate these within clinical practice in the innovative development (including through poetic narratives), content, timing and communication of preoperative education.

'This abstract outlines independent research commissioned by the National Institute for Health Research (NIHR) under the RfPB programme Ref: PB-PG-1207-13321. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.'

Hope in Hopelessness. Competing discourses in Motor Neurone Disease and Parkinson’s Disease charity discussions on improved treatment and euthanasia.

In addition to their traditional roles as charities or advocacy groups, patient organisations now have an established role in scientific research, with many funding research teams as well as aiding recruitment for studies on their disease of interest. With this increasing involvement comes an interest in promoting research to charity members, to encourage participation. Yet, charities working for people with rare, incurable diseases, such as Motor Neurone Disease and Parkinson’s Disease, may also wish to host discussion or engage in advocacy around issues affecting members such as death and euthanasia. This raises the question as to how patient organisations reconcile these contrasting roles and take part in such seemingly conflicting discussions. This paper draws on analysis of websites, information materials and public statements from patient organisations and charities working in the field of Motor Neurone Disease and Parkinson’s Disease relating to key themes of clinical trials, palliative care, and euthanasia. Drawing on literature on the sociology of expectations and the sociology of patient organisations it will discuss their engagement in the conflicting discourses of hope and hopelessness. -- the hope of research ventures aimed at finding cures or better treatments, and the absence of hope, or thoughts of death, for many of their members. The analysis focuses on how, if successful, patient organisations seek to balance these discourses, in efforts to maintain relevance in the research sphere without damaging their ability to represent member needs.
Wednesday 14th September 2011  15:20 - 15:50
Health Service Delivery  Westminster Building Room CWE125/1

Haland, E., Toussaint, P.  NTNU

Communication and cooperation; experiences with net-based learning among health personnel in Norwegian municipal care

The need for improved cooperation and coordination in the health care sector is firmly put on the political agenda in Norway, especially with the introduction of the so called Coordination Reform in 2010. The reform implies that more health care services should take place in the local municipalities, in cooperation with regional hospitals, and various ICT-tools are presented as a necessary prerequisite for this cooperation and coordination. In the wake of the reform, the importance of educating competent health personnel is also highlighted.

The region of Fosen in Norway has made efforts to meet the new demands of the Coordination Reform. Fosen has small municipalities and large geographical distances, a fact that requires new modes of cooperation to uphold a stable and reliable health service within the region. As an alternative to physical meetings at courses that imply extensive travelling, net-based competence development for health personnel has been initiated. The participants then meet mainly in net-based discussion forums and through lectures via video conferences.

This paper is based on material from a research project that is evaluating these competence development initiatives. Based on observation and interviews, we investigate how health personnel experienced this type of communication and cooperation, and look into the opportunities and limitations use of technology (video conferences and Internet) offers for cooperation in health care. We explore the relationship between face-to-face interactions and technology-mediated interactions concerning communication, cooperation and the development of professional networks.

Thursday 15th September 2011  09:35 – 10:05
Lay-professional Interface  Westminster Building Room CWE126/1

Hamilton, S.  Rethink

How do doctors and patients perform 'expertise' in a psychiatric consultation?

Background - Shared-decision making is now a well-established concept in health communication. More recently, the notion of 'expert patient' has become popular. However, there is currently little agreement on what patient expertise is, its role in medical consultations and how it is constructed in interaction.

Aims - This study explores how psychiatrists and patients with psychosis evoke and defend their expertise in consultations, and how the other party responds to this. It contrasts how 'expertise' is constructed differently by different participants and how potential conflicts are managed. Finally, it starts to explore whether 'expertise' is a useful concept in this setting, and whether 'expertise by experience' and 'professional expertise' can be meaningfully combined.

Methods - The presentation is based on an analysis of 92 audio recorded consultations between psychiatrists and patients with psychosis. I use a discourse analysis approach drawing heavily on Goffman's theory of interaction as performance and Habermas' distinction between lifeworld and system.

Results - I present a typology of ways in which expertise is 'performed' and negotiated, using examples from the transcribed consultations.
The Translation of Stem cell Research

Stem cell research has been argued to hold great promise for the future of medical therapies although it is often stated that the translation into the clinic is dissatisfactory, seeming to face hurdles that are not yet understood.

Based upon ethnographic research carried out over a period of time in stem cell laboratories and at other venues, this presentation shows the motivations and attitudes of diverse stakeholders working in this field. In my analysis of the regulatory, disciplinary and ethical tensions that influence the process of translation, I use a three-step model of translation such as that presented by Michel Callon, Pierre Lascoumes and Yannick Barthe (2009). Examples of strategies that are employed by differently positioned participants in the field are discussed, as well as how the complexities of translational space in stem cell research are negotiated. Translation is, in a spatial metaphor, a site of on-going deliberation regarding the interface between scientific knowledge and medical practice, a locus of strategic professional adaptations on the part of the actors involved and a forum of conflicts and negotiations of expertise.

This presentation illustrates how and why stem cell research at present largely resides in stage 2 of translation (t2) – the laboratory. I will emphasise the need to scrutinize the practices, networks of interactions and interdisciplinary exchanges that co-produce the deficit in fulfilling the translational imperative.

Self-help as a public health policy strategy and rhetoric in the shape of cults, converts and charisma

This presentation focuses on ideology and design of self-help as a basic methodological principle for approaching health problems in recent Norwegian public health policy. This type of ideology is often surrounded by a special kind of rhetoric that includes the construction of the cult, converts, and the use of charismatic communication and expression. This presentation is presenting data from qualitative analysis of the construction of rhetoric and cult-cultures related to self-help as a topic in Norwegian health policy. Particular focus is on transformation and the use of charismatic communication to regulate patients and users who belong to target groups for self-help methods and self-help groups. The data is obtained from analysis of public documents and web pages about self-help as they are presented using digital tools and web design. The analysis is done by the means of discourse analysis. Focus is at the social forces and networks behind self-help as a new and important strategic measure in Norwegian health policy. Self-help and self-help groups have become more widespread and common in todays Norway, and the self-help movement grows in scope. In the presentation it is explored how this happen in the Norwegian society and also how the growth in interest in self-help is socially ‘constrained’ by certain interests, agents and ideology in the Norwegian society.
Hendrick, R.  University of Strathclyde

**Publishing Ethics: The Political Economy of Medical Communication Companies**

Communication ethics has become a prominent issue in medical and associated journals. The practice of ‘ghostwriting’ (whereby pharmaceutical companies commission professional writers to produce articles, which are then attributed to academics and published) in medical literature has been much debated (Ross et al., 2008; Górski and Letkiewicz, 2010; Sismondo, 2004, 2010), and organisations such as the ICMJE and COPE have provided guidelines on what constitutes authorship. Less understood, however, is the political economy underpinning the medical communications industry, which facilitates ghostwriting.

This paper will examine this large and lucrative industry. Research shows that it is a web filled with conflicts-of-interest. Many medical communication companies (MCCs) are subsidiaries of large advertising conglomerates, which often also have research wings, and which run advertising campaigns on behalf of the pharmaceutical companies for the products they are developing and writing up evidence on. Some MCCs are wings of large journal publishers, whilst others are part of the pharmaceutical companies whose drug trials they are writing up. Unbeknownst to their audience, medical journal articles frequently act as marketing instruments.

Such relationships are unethical, with implications on the way science is portrayed to the outside world. Through a desk-based analysis, and through participation in the European Medical Writers Association conference (May 2011), my research aims to interrogate the political economy of MCCs. What organisations are involved; when and why did they emerge; how widespread are they; what services do they offer; and what are the effects on the medical literature and beyond?

Hilton, S.  Medical Research Council

**Other than counting words: Using content analysis to examine manifest and latent newprint reporting on health**

Content analysis has been defined as a systematic, objective, replicable technique for compressing many words of text into fewer content categories; but it is more than a method which provides category and word count measurements as the only evidence. It is potentially one of the most important research techniques in the social sciences to understand how messages are mediated. Over the past 50 years as mass media technology has advanced, so too has content analysis methodology and the media’s influence in shaping public opinions on health matters. Stories about health are a daily feature of life, telling us what’s important and what risks we should be aware of. Some news reporting has a positive influence and is supportive of public health measures, for example much of the newprint coverage of the swine flu pandemic in the UK. However, news reporting can also have a negative influence and undermine effective public health interventions; sometimes stories are skewed towards the dramatic rather than the scientifically sound as was the case during the MMR vaccine controversy. This presentation describes manifest and latent analysis of newprint reporting on health and highlights how news stories can set the public health agenda and impact on health behaviours.
**Friday 16th September 2011 10:10 - 10:40**
Maternity/Reproduction Westminster Building Room CWE126/1

Hinton, L., Locock, L. University of Oxford

**When childbirth is a “near miss” event: the experiences of women and their families of life-threatening obstetric complications**

Childbirth is a major life event for women and their families. Although safer than ever, women still die during or shortly after pregnancy. Confidential enquiries into every maternal death have been conducted for over 50 years. The most recent report, published in March 2011, provides a detailed analysis of each of the 261 women who died in 2006-2008. Maternal deaths are thus rare, but represent the tip of the iceberg. For every death then there is a large body of women beneath the tip who are experiencing “near miss” events – severe life-threatening obstetric complications during or recently after the birth of their child. The experiences of these women are largely unstudied.

The causes of these “near miss” events are varied but include pre-eclampsia, haemorrhage, thrombosis and sepsis. These events can be life-threatening to mother and baby, and can lead to an emergency hysterectomy or premature birth.

A qualitative study is being conducted to understand the experiences, and long term follow up needs, of these women and their families. Narrative interviews have been recorded with 27 women and 6 men across the UK who have experienced “near miss” events. The analysis has used a qualitative interpretative approach, combining thematic analysis with constant comparison so that that data is explored for anticipated and emergent themes. Initial themes include the shock of emergency childbirth, ongoing physical symptoms and emotional trauma, difficulties in bonding with the new baby, isolation of partners and the value of follow up.

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**Thursday 15th September 2011 15:10 - 15:40**
Preventive Health Westminster Building Room CWE126/1

Hinton, D. University of Liverpool

**Uncertainty and doubt: exploring clinician’s perspectives of delivering secondhand smoke advice to parents in a children’s hospital**

Sociological research exploring the relationships between doctors and patients has consistently indicated that, “…the single most important source of knowledge and meaning for patients is their doctors’ (Moerman, 2002:46). Recent UK public health initiatives have focused on modifying individual lifestyle choices, and clinicians can play a key role in this process by delivering brief interventions that address not only patient’s lifestyle choices but recommend to parents of children attending their clinics that they practise and promote ‘healthy’ lifestyles to protect their children from preventable health risks. Few studies have critically examined clinicians’ views on delivering public health messages to the families of their patients and there is a limited understanding of the factors that may facilitate or hinder health promotion practice.

Drawing on the findings from a pilot study at four specialist out-patient clinics at a NHS children’s hospital, I explore the views of 10 clinicians on their experiences of discussing the health effects of secondhand smoke on children with family members during routine consultations. While clinicians were keen to encourage families to adopt healthier lifestyles, concerns about professional boundaries and responsibilities meant that they were uncertain about the nature of their clinical relationship with the parents (of their patients) and the most suitable way to deliver the intervention. Clinicians doubted their capacity to influence family behaviours outside the ‘public’ setting of the clinic with an underlying reluctance to intrude on the ‘private’ environment of the family home, highlighting the complexities of delivering public health messages in the clinical environment.
**Thursday 15th September 2011**  
*Methods*  
Westminster Building Room CWE125/1

*Hofmann, D., Simpson, C., Scott, D., Wykes, T., Cope, A., Lempp, H.  King's College London*

**Developing a Patient-Generated Outcome Measure to Improve the Identification of New Treatments for Rheumatoid Arthritis.**

**BACKGROUND**

Best Research for Best Health emphasises the partnerships with service users as essential for the development of evidence-based care. This may be one solution to accelerate translation of clinical science into meaningful treatments. Many scales that are routinely used to measure physical and mental health in Rheumatoid Arthritis (RA) lack sensitivity to subjective wellbeing.

**AIM:** to develop a patient-generated outcome measure in RA using a novel participatory methodology, successfully applied in mental health.

**OBJECTIVES:** the new outcome measure, created with involvement of patients with RA and a Patient Researcher, will achieve: (i) a valid reflection of patients’ expectations, (ii) a reliable measure suitable for use in routine clinical practice and (iii) a measure sufficiently sensitive to detect change with new treatments, e.g. biologic therapies.

**METHOD:** a mixed method approach: to start with a participatory methodology (qualitative) and then proceed to psychometric testing through a three stage process – Stage 1: three repeated focus groups and two expert panels for refinement with patients currently receiving treatment with RA, facilitated by patient researcher and patient co-facilitator. Stage 2: feasibility study of new scale for one week with clinic attendees and psychometric testing of instrument against routine clinical measurements with consecutive patients attending an outpatient clinic. Stage 3: additional data will be derived by including the new outcome measure in current clinical trials.

**CONCLUSION:** the development of research partnership between patients and clinical/ academic staff is expected to improve the quality of the evidence-base and to speed up the translation into clinical care.

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**Wednesday 14th September 2011**  
*Autism*  
Westminster Building Room CWE126/2

*Hollin, G.*

**New psychological knowledge, health policy and the reconstruction of human behavioural disorders: the case of Autistic Spectrum Disorders**

Autistic Spectrum Disorders (ASD) are conditions with an early age of onset and a ‘cognitive triad’ of impairments in the form of impaired social interactions, deficits in communication, and repetitive behaviours. There is currently no consensus over the aetiology or treatment of ASD and, since their ‘discovery’ in the mid-1940s, this has been an issue of constant debate. In 1985, Baron-Cohen, Leslie, and Frith utilised the recently developed notion of Theory of Mind (ToM), with its antecedents in cognitive and biological psychology, to explain ASD as a disorder of sociality. In line with broader shifts detected within medical sociology towards the biologicalisation and medicalisation of behaviour, ToM has been joined by a number of intrapersonal models of ASD that straddle cognitive and biological psychology.

This paper will therefore seek to examine the extent to which these changes in psychological theories of ASD in the last thirty years have been reflected in UK health policy, specifically in the recommended diagnostic and treatment regimes and services developed in the NHS, and how this might have shaped the biologicalisation or medicalisation of ASD. The paper will present analysis of various documentary sources in order to map any changes which may have occurred. In conclusion, reflections will be offered about the way in which new psychological knowledge is translated into policy and practice, and the extent to which human behaviour is being increasingly seen in somatic terms.
Holman, D.  
*University of Essex*

**Understanding the underuse of talking treatments by the lower social classes with reference to cultural dispositions**

In the UK today, talking treatments are underused by those from the lower social classes: they have higher rates of common mental disorders (CMDs), but are no more likely to use talking treatments, and are more likely to drop out of them prematurely. They are also more likely to be prescribed medication. Given that overall, talking treatments are useful in helping to ameliorate CMDs, understanding why the lower social classes underuse them is important. My research is concerned with cultural explanations for underuse. At a surface level, one might suppose that the lower social classes have less knowledge of talking treatments and hold more negative attitudes towards them, which survey data generally indicate is the case. But data from semi-structured interviews reveal that concepts like ‘knowledge’ and ‘attitudes’ are much more richly understood with reference to culturally rooted dispositions. My research explores these dispositions, using Bourdieu’s concept of habitus, which helps to explain how they are grounded in the life situations of the lower social classes. I build upon Hollingshead and Redlich’s classic 1958 work, which proposed that the lower classes were less aware of psychological conflicts and frustrations than their middle class counterparts, and less able to verbalise and symbolise them. Far from taking a position that there is some of ‘cultural incompatibility’ between lower social class dispositions and talking treatments, I argue that taking them into account allows for a more thorough consideration of interventions to tackle the underuse of talking treatments by the lower social classes.

Holme, I., Fenwick, A.  
*University of Southampton*

**Forming norms and practices in genetic testing of children: the role of professional guidelines.**

A genetic test can predict the likely onset of a disease many years in the future. In families, where there is a disease with an inherited cause, parent may wish to know whether their children have inherited the condition. However, when the onset of the disease is not expected for many years, professional guidelines (1994 and updated in 2010) state that such testing should be delayed unless there is a medical benefit (e.g. screening or treatment) to testing or until the child can make a decision about testing for themselves. This paper explores the historical development of professional guidelines in the UK and how they are shaped, focusing on the interplay between actors from different settings including academic, medical and patient support groups. Drawing upon the perspectives of these stakeholder groups as well as families who have requested testing of their children, we interrogate the role of professional norms and practices in genetic services. This illuminates various tensions; for example do professional guidance serve as a paternalistic tool for medicine or are they a vehicle to protect the rights of future adults to make decisions for themselves?
Contracts in the English NHS: markets and social embeddedness

This paper argues that there is a parallel between market reforms in the English NHS and Karl Polanyi’s (1944) account of how the rise of markets provokes a self-protective counter-reaction that re-embeds economic relations in social relations. While Polanyian scholarship analyses this ‘double movement’ at the macro-level of the social system, the paper discusses a similar interplay between market-oriented innovations and relational norms at the organisational level. We report findings from a qualitative study of NHS contracting, which examines the recent move to harder-edged contracts with greater use of financial penalties and incentives. In practice, use of these techniques tended to be confined to nationally-mandated sections of the contract rather than emerging from local bilateral agreements, and when things went wrong the parties relied more on co-operative behaviour than on the provisions of the contract to find solutions. Making the new contracting system work depended more on existing relational networks than on the incentive structures created by top-down initiatives, but the inability of the market to evolve as expected has led policy makers to plan further radical reforms. The reforms now being introduced in England are likely to abolish SHAs and PCTs, and risk sweeping away the relational networks that have been crucial to keeping the system working.

Exploring the health and religious beliefs of British South Asians with epilepsy

Background

It has been acknowledged that religious and complementary therapies are commonly used among South Asian communities in the UK. However, little is known about their religious beliefs in relation to epilepsy and the type of South Asian therapies that they use to treat the condition.

Aim - To explore the influences of spiritual and religious beliefs on explanation of the cause of epilepsy, and the choice of treatment in people of South Asian origin who have epilepsy.

Design of study - Qualitative study using interviews with patients, carers, health professionals, and focus groups of people from minority ethnic communities.

Method - Semi-structured individual interviews with 20 Muslims, six Sikhs, and four Hindus with epilepsy; 16 nominated carers (family members, friends); 10 health professionals (specialist GPs, neurologists, specialists nurses, social workers, community GPs); and two focus groups with a total of 16 South Asians without epilepsy.

Results - It was found that over half of responders attributed their illness to fate and the will of God, or as punishment for sins of a past life. Some patients had experienced prejudice from people who believed that their epilepsy was contagious. A strong network of traditional healers was found, providing a parallel system of health care in the UK and on the Indian subcontinent. People turned to religiospiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine. Such treatments were viewed as complementary rather than as an alternative to Western medication. Younger people in particular expressed considerable scepticism about the effectiveness of these traditional South Asian treatments.

Conclusions - In this study’s South Asian sample, patients commonly turned to traditional healers in search of better health. Health professionals should be aware of the belief systems of these patients and understand the types of treatments in common use. Although these treatments might potentially compete with Western health care, they are used as an adjunct rather than a substitute. Patients have a ‘healthy’ scepticism about the effectiveness of such treatments, and adherence to medical therapy does not appear to be affected.

Keywords - beliefs; epilepsy; medicine, traditional; Southern Asia; spirituality.
Iversen, T. B., Melby, L., Toussaint, P. Norwegian University of Science and Technology

Variations in surgical work and their influences in information need

Due to the fragmented and specialized nature of modern health care, collaboration and coordination of work are important characteristics of the work of health professions. In order to coordinate and collaborate health professions need a representation of what has happened and what will happen to the patient. The concept of patient trajectory, introduced by Strauss and others is a good framework for analyzing such representations. In this paper we examine variations in clinical work due to unexpected or unplanned events. We have spent in total over 150 hours observing work, 30 hours observing surgical patient trajectories and conducted over 22 hours of interviews over approximately 50 interviews. Based on interviews with nurses at two inpatient wards in a university hospital we firstly describe three frequently occurring variations from the planned patient trajectory. We argue that the trajectory representation required changes due to the occurrence of variations. In order to cope with these variations, health professions need to be more thoroughly informed about what has happened to the patient in the context of his care process. The representation of a patient trajectory (whether in an information system or on paper) is not a static representation but a dynamic representation, determined by the clinical context.

Jackson, C., Tarrant, C., Dixon-Woods, M. University of Leicester

Paediatric trial recruitment: perspectives of families and clinicians

This paper reports on an ongoing NIHR doctoral research fellowship which examines recruitment to childhood cancer trials.

Background: Recent policy and regulatory changes are encouraging a massive increase in the quantity of research involving children. However, there are many current and emerging challenges of recruiting children in to clinical trials, and much of the evidence-base to ensure that the process is optimised from the perspective of families is lacking. There is little European or UK research to inform how best to enable families to engaged as partners and make choices about trial participation that are consistent with their values and preferences. In order to ensure that the recruitment process functions well from the perspective of families it is essential that their priorities for the recruitment process are identified and addressed and the views of clinicians involved considered.

Methods: A qualitative study design has been used, involving semi-structured interviews with purposively sampled families and clinicians. The emerging data was analysed using a systematic and iterative method of analysis based on the constant comparative method.

Results: In this paper I offer a preliminary report on the views and experiences of families asked to participate in childhood cancer trials alongside those of professionals involved in their recruitment. I consider emerging themes, including the structural and emotional aspects of decision making, and reflect on the unintended consequences of a rights based approach.

Conclusions: Good quality evidence is required on the needs and priorities of families to better inform regulatory processes and procedures.
Jamie, K.  
**University of York**

**Implementing Pharmacogenetics into Pharmacy Practice: A (Re)professionalising Project?**

Pharmacogenetics is concerned with genetically determined variations in drug response and has been constructed as a 'revolution' in drug production, medical practice and patient experience. Despite being hailed as a potentially significant development for pharmacy practice, the ways in which this new genetic paradigm will impact on the profession of pharmacy has not been extensively explored. This paper traces the history of the professional development of pharmacy and draws on interview data with hospital and community pharmacists, pharmacy stakeholders, general practitioners and pharmacogeneticists to argue that pharmacogenetic technology has the potential to (re)professionalise pharmacy by drawing pharmacists further into the clinical team and making them a more centralised and normalised feature of the patient experience. Running concurrent to this (re)professionalising potential, however, are concerns about the implementation of a novel and, potentially, ethically questionable technology which this paper locates within wider anxieties about pharmacogenetics more generally. While the profession of pharmacy has been relatively neglected by sociologists, the implementation of new genetic technologies generally, and pharmacogenetics specifically, is likely to create greater demands of pharmacists which will require extended educational curricula, new working practices and strengthened communication networks, which will drive an increased sociological interest in this area of medical practice.

Jenkins, N., Lawton, J., Douglas, M., Hallowell, N.

**‘We just used to think my dad had funny eyes’: Exploring inter-embodiment in patients’ accounts of discovering high cholesterol and undergoing genetic testing for familial hypercholesterolemia (FH)**

Many of the explanatory concepts which characterise the sociology of health and illness have been developed through empirical studies of illness biography and of patients' experiences of genetic medicine; biographical disruption and biological subjectivity being prime examples. In this paper, we explore the concept of inter-embodiment - as developed by Gail Weiss and Stephanie Springgay - and its potential for advancing research into illness biography and into lay experiences of genetic medicine. Inter-embodiment views body knowledge as the product of relations between bodies, as opposed to originating from within the body, or as the product of relations between dis-embodied selves. Drawing on our qualitative study, in which we explored 38 patients' experiences of discovering high cholesterol and of undertaking genetic testing for familial hypercholesterolemia (FH), we discuss how our interviewees' accounts may be understood from an inter-embodiment perspective. In contrast to previous research, we found that participants frequently talked at length about their family histories of high cholesterol and/or of cardiovascular disease. In exploring their accounts, we develop the concept of the family corpus in order to highlight the role body-networks play in shaping lay constructions of genetic identity and of familial disease biographies. We argue that, understanding participants' constructions of the family corpus helps contextualise their experiences of FH genetic testing as either biographical disruption or as biographical re-enforcement. We conclude by arguing that inter-embodiment can provide new insights into lay constructions of disease biography and of biological subjectivity.
Exploring the professional identity of health and social care staff via experiences of interprofessional education and working

This paper will present some initial findings from a PhD study exploring debates around professional identity formation, and more specifically how these debates apply to health and social care (H&SC) staff. The study itself aims to explore these concepts via the ‘lens’ of interprofessional education (IPE), that is where more than one profession is either working and learning with and from each other (Hammick et al 2007, CAIPE). Where the majority of existing work on IPE focuses on students – either on their ‘readiness’ to engage with IPE or the impact upon their learning, this study focuses on staff because the drive towards successful IPE requires a change in working culture, and such a change will not be possible without the acceptance of the staff who are required to work together, and who are often responsible for the socialisation of students and new professionals in to their chosen profession (Carlisle et al 2004). Using a mixed method approach of an online survey and face to face interviews, phase one of the research (to be presented here) has involved asking practicing H&SC staff about their perceptions of their own professional identity, and to describe their experiences of IPE. This paper will question if it is possible to see a relationship between experiences of IPE and the formation of professional identity and will consider debates around whether IPE initiatives do more to enhance ‘ stereotypes’ of professions than to dismiss them.

The (un)caring logic of field work: the limits of witnessing in health research

The widespread use of ethnographic methods in health research has called for the critical enquiry into the nature of ethnographic work and the role of the researcher in the process of studying medical settings. The methodological literature addresses these issues variously by recalling the principles of neutrality and rationality characteristic for the classical, ‘realist’ approaches to fieldwork, or the postulates of reflexivity and involvement inspired by the advocacy and action research. This paper contributes to these debates examining the tensions between these conflicting values in the lived experience of doing fieldwork in a medical setting.

Drawing on the experiences of conducting an ethnographic study of communication between urological cancer patients and urology and oncology health professionals, this paper explores the concept of the researcher as a ‘witness’ recalling different meanings and levels of ‘witnessing’ inherent in the fieldwork involving chronically ill. Acknowledging the inherently emotional character of the research process, it gives account of the difficulties in reconciling the contradictory expectations of analytical neutrality and caring involvement experienced by the researcher while witnessing interactions between cancer patients and health professionals.

Drawing on Mol's (2008) concept of ‘the logic of care’ and Kleinman’s (1988) notion of ‘empathic witnessing’, this paper explores the tensions arising from the contrast between the caring context of the hospital setting and the researcher’s powerlessness to demonstrate care for the suffering research participants. At the same time it questions the limits of the researcher’s (un)involvedment in the world that she studies, and its ethical and methodological implications.
Kennedy, P.  
Glasgow Caledonian University

‘Complimentary and Alternative Medicines and the State: a Tail of Contradictory Narratives’

The popularity of CAM’s arose partially as a rejection of biomedicine for person-centred treatments and therapies. Reflexive modernity articulates this as the erosion of traditional structures and opening of new possibilities for a critically informed cliental (Giddens, 1991). The narrative of ‘life’ and ‘system’ worlds Habermas (1987), suggests another reading. The growing popularity of CAMs saves biomedicine from relative unpopularity – its tendency to function within a systems world uncoupled from a life world – is thwarted by its re-coupling with the values and practices associated with the life world of CAMs. Both narratives are far from fictions, hence CAMs relationships with biomedicine is one of contradiction, tension and partial resolution, revealed most clearly in state policy towards regulating medicines.

This paper addresses these contradictory narratives. It argues that when system imperatives of cost-cutting, efficiency drives and administration are uppermost, the state leans towards attempting to impose abstract managerial discourses upon and across CAMs, taking less account of the particularities of their individual practices and skill sets and more account of the need to mirror the administrative contours of biomedicine. However, this process is attenuated by ‘life world’ imperatives that also compel the state in genuinely searching for professional codes of conduct and training that are sensitive to the specifics of CAMs they are designed to regulate and so sensitive to recognising the underpinning philosophy that comes with CAMs, rather than expunging its holistic philosophy for a reworked Cartesian dualism.

Kerr, E. A.  
University of Leeds

The ethos of practice in assisted conception: access, protocols and outcomes in NHS and private settings

The work of contemporary health professionals involves a range of practices which go well beyond traditional conceptions of healing. Professionals are involved in managing patients’ and their families’ expectations, choices and rights as well as meeting requisite standards of ethics, safety and efficacy in an increasingly complex regulatory and funding environment. This involves a range of partnerships with patients and their families as well as other health professionals, managers, administrators and regulators. In this paper I explore the ways in which professionals working in NHS and private assisted conception clinics manage these different aspects of their work. Drawing on an ethnographic study, I explore their practice ethos, in particular the construction of gateways to treatment, the use of protocols and narratives of success and failure. I argue that, in NHS settings, professionals were predominantly oriented towards appropriate care of the patient population. In private settings the ethos was more concerned with tailored individual patient care. I conclude by exploring the implications of my analysis for professional practice in other sectors of medicine.
Growing up with Congenital Heart Disease

Despite improvements in foetal diagnosis and prenatal care, Congenital Heart Disease (CHD) continues to be the most frequently occurring congenital condition. Advances in paediatric cardiology and cardiothoracic surgery have resulted in children born with CHD now surviving well into adulthood. Thus, this 'new' population of young people with CHD are faced with the task of potentially living with ill health over a longer period of time, which can have significant impact on many of the 'normal' rites of childhood associated with growing up. Moreover, coping with CHD in such a transitional period as adolescence may pose a threat to an individual's sense of identity and may transform values, expectations, and life priorities. Despite this, research into the childhood and adolescent experiences of living with chronic illness has long omitted this group.

Drawing on narrative data collected for this PhD study from a cohort of young people living with CHD, this paper aims to explore, within the sociological framework for understanding the experience of chronic illness, both the notion of 'biographical disruption', and the 'narrative reconstruction' of this disruption posited by Gareth Williams (1984). Personal narratives have been described by Arthur Frank (1998) as the means by which the links between body, self and society are articulated and thus the narratives obtained have afforded the opportunity to explore the ways in which an individual makes sense of an illness, and how their identities are constructed as part of that process. Close attention will be paid to the notion of biographical disruption in this context and the extent to which it may or may not account for a range of possibilities in which illness may already be central to an individual's biography, either from birth, or early childhood, as in the case of CHD.

The space of access to primary mental health care

Guided by theoretical perspectives of relational social science, this paper draws on re-analyses of multiple qualitative data-sets generated from 2008 to 2010 in an urban, multi-ethnic, economically disadvantaged area in UK, with the aim of advancing understanding of access to primary mental health care and its equity, whilst using the local Somali ethnic minority as an exemplary focus.

The findings formulate a novel concept of the space of access. The shape and dynamics of the space of access are determined by at least four lines of tension: understandings of area and community; cognitive mapping of mental wellbeing, illness and care; positioning of primary care services and resources; and dynamics of resources beyond the medical ‘zone’ of care.

The conclusions indicate a need for de-centring and re-connecting the role of medical professionals within primary care, which itself needs to be transformed by endorsement of multiple avenues of access to mental health support, and by development of conditions for intrepid communication amongst all involved actors.

This work contributes to theoretical discussions on access to health care, and more specifically on access to help for people suffering from common mental illness, belonging to marginalised groups, and living in multi-ethnic urban areas. It also demonstrates the importance of medical sociology in applied health research.
Deinstitutionalisation in mental health care in Japan

Since the 1950s, a shift ‘from hospital to community care’, namely deinstitutionalisation, in health care has occurred in many Western countries. In the sociology of health and illness, deinstitutionalisation has been studied with a focus on mental health services, and reasons for the shift towards community have been associated with various factors, such as developments in pharmacotherapy, economic factors, and reconceptualisation of the medical model.

In this study, I shall give an overview of the current situation of deinstitutionalisation in mental health care in Japan, where the deinstitutionalisation process only began from the beginning of the 21st century. Japan has the largest number of psychiatric beds among OECD countries, and there are arguments that it would be difficult to shift towards community care because the medical costs of psychiatric services are much cheaper than in Western countries and therefore there is little economic incentive for deinstitutionalisation, especially when over 90% of psychiatric hospitals are privately run.

However, in 2004 the Japanese government implemented a policy that aims at the discharge of approximately 70,000 ‘social hospitalisation’ patients with mental disorders by 2014. This study examines the effects of the deinstitutionalisation policy through analysis of transformation in mental health care. It is based on statistical data, such as the number of patients who were hospitalised or discharged, and rates of use of community care services. In addition, this study adds a new finding to existing accounts of deinstitutionalisation in Western countries by considering the uniqueness of the Japanese health care system.

Medical and social constructions of ‘Hope’ in relation to older people with cancer

This paper presents findings from a qualitative study of patients’ and professionals’ perspectives and experiences of cancer care for the older person. The research design (using focus groups and interviews) involves comparison of a medical and a specialist ward in one hospital – exploring challenges, depending on whether the focus is on the older person or the disease. It also highlights the tensions that may arise – both for patients and professional carers, as they negotiate the potentially contradictory demands of the ‘social’ and ‘clinical’ aspects of their care.

Ideas about ‘hope’ were frequently invoked by both patients and professionals attempting to understand and manage the experience of illness. The concept had salience for all patients, with some relating this to the need to remain positive, focussing on expectations for the future, whilst others stressed the importance of acceptance. Rather than falling into two distinct ‘camps’ there was evidence that patients vacillated between these two approaches. ‘Hope’ was an issue that really exercised professionals and their responses are more complex than they first appear. Professionals seemed to ‘pussy foot’ around the issue of hope with patients: gauging the right time to talk and engaging in a ‘balancing act’

Integrating analysis of original study transcripts and data generated in dissemination sessions also allows for further interrogation of the theoretical frameworks that have been developed in order to provide greater understanding of ‘hope’ and elaborates the processes involved in the intersection of the older person, professional carers and the cancer experience.
Laverty, L. University of Liverpool

**Being at risk, doing risk: How young people conceptualise and interpret health behaviours in neighbourhoods in Liverpool**

Youth studies and public health research and policy are increasingly influenced by discourses surrounding risk and the concept of a “risk society”. Within youth studies the dominant focus on “problem youth” and “delinquency” has shifted to discuss youth “at risk”. While offered as a progressive view of young people the concept of risk still suggests prevention, management and outcomes which are conceptually no different in describing and understanding the lives of young people. In the field of public health the population based concerns such as infection and disease have largely been replaced with problems in individual lifestyle behaviours such as smoking and drinking. These individual lifestyle behaviours are dominated by risk related research in the psycho-social and medical fields into prevention, risk factors and consequences.

Drawing on a recent study looking at exploring perceptions of alcohol within neighbourhoods in Liverpool, England I will focus on how young people view and act upon the local cultures and norms surrounding alcohol. I discuss how narrative interviews with parents and focus groups with young people and teachers in schools revealed the divergent ways in which alcohol use is perceived and acted towards in neighbourhoods, forming only a small part of everyday experiences in relation to health and space. I will go on to critically explore the difficulties in relating concepts of risks when talking to young people or about young people, and in particular how living within certain communities may have particular meanings and interpretations of what it means to perform risk.

Lee, J. Y.

**Construction of Dual Health Citizenship: Foucauldian Understanding of Korean Migrant Women's Health-Seeking Behaviours**

This presentation examines the techniques that Korean migrant women living in the UK employ in order to maintain their health and their family's health. More precisely, it investigates both the medical and non-medical (lifestyle-oriented) practices that Korean women utilise in such a way as to maximise their sense of agency. The Foucauldian framework is useful for understanding the processes that Korean women undergo as immigrant women, as they vacillate between the two very different forms of medical subjectivity of the good patient and the active patient. However, this also makes it difficult to grasp the subtleties of their experiences, inasmuch as their personal narratives often reflect a sense of empowerment and agency as they challenge medical expertise in both their host and home countries. Through their reflexive narratives, they reconstruct their own selves and subjectivity in fluid and flexible ways, contributing to the constitution of a nomadic identity as dual health citizens.
‘What’s the point in that…?’ Reflections on teaching ethnography as an approach in qualitative health research

Janice Morse has suggested qualitative health research become a sub-discipline (2010). She argues that the “outsider” – the non-clinically trained researcher – is unable to conduct themselves appropriately in a clinical setting, be aware of the rules of engagement, or be able to control their emotional response to trauma. She notes the ‘value’ assigned to the naïve perspective in ethnography (op.cit.: 1461) and confines her argument to hospital settings, but her paper raises concerns about how qualitative health research, and ethnography in particular, is perceived and taught. Does ethnography remain a valid approach?

I consider what is happening to ethnography as it sits alongside fellow methodologies in qualitative health research methods curricula. Faced with texts that present qualitative research methodologies as having clear boundaries, can we discuss the permeability of the sociocultural worlds that students will find themselves studying? Find opportunities to ground students’ learning in powerful concepts like ‘being there’? Ask if the ethnographer can and should occupy the space symbolised by the backslash between insider/outsider?

If ethnography is to flourish in the pantheon of qualitative health research methods – our own experience has demonstrated strong demand for ethnographic approaches in public health (Lewis and Russell, forthcoming) – and not become something unrecognisable in the process, how can its fundamental principles and debates survive and be communicated effectively?

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Men behaving well? Journeys towards constructive engagement with well-being through meditation

Research suggests that men may experience distress in ways that go undetected. Many commentators argue that hegemonic forms of masculinity can render men unable or unwilling to deal constructively with distress, leading to maladaptive responses including avoidant behaviour and emotional numbing. However, there are indications in the research that men are also able to constructively engage with their well-being, although little research exists exploring how they do so. The present study sought to find men who currently appear to self-manage their well-being in order to examine issues around how men adopt a constructive approach. In-depth narrative interviews were conducted with 30 male meditators in the UK, selected using principles of maximum variation sampling. Using a modified grounded theory approach, the analysis suggests that while these men took up meditation for varying reasons, they have discovered strategies to better manage their wellbeing. However, the journey towards meditation was fraught with difficulties. Men described crossing a threshold from boyhood into ‘manhood’, and most had tried in the past to be emotionally tough and/or disconnect from difficult emotions. Many had experienced internal conflict, and sought relief in a variety of ineffectual coping responses. Exploring varying pathways toward meditation, this study sheds light on the ways men deal with distress and find constructive ways of coping. Here, resisting dominant norms of masculinity is a difficult struggle for men. Moving away from the ‘masculinity as deficit’ model, we discuss implications for helping men to better understand, engage with, and manage their feelings of distress.
**College drinking behaviour: a social network analysis**

Excessive alcohol consumption accounts for an important share of morbidity and mortality among teenagers and adult population. Such behaviour is to a large extent learnt at the University where an increasing percentage of young adult are heading after secondary school. So far, however, most studies on college students relied on cross-sectional survey disregarding the ties between individuals. Yet, college students are socially connected so that it is very likely that their alcohol consumption behaviour is also socially connected. We aimed to analyse how much alcohol behaviour spread among peers networks. In particular, we hypothesized that individual social position within a network of social ties predict drinking behaviour depending on the overall level of drinking within a network.

We carried a social network analysis (SNA), with a complete network approach with first-graders of two faculties (n=487), engineering and psychology, two faculties, respectively predominantly male and female. All students had to fill-out a social network questionnaire tapping their social ties (friendship, working with, partying with and room-mate-) as well as their drinking behaviours.

We found that drinking behaviours is socially patterned: being close to a heavy drinker increased the risk of being a heavy drinker. Being socially central in the engineering faculty increases the risk of heavy drinking but not in the faculty of psychology. We conclude that peer-effect is an important factor drinking behaviours but depends on the local social norms within a network.

**The Hermeneutics of Care and The Support of the Self: A New Pastorate in Complementary Healthcare**

This paper draws on fieldwork with cancer patients who use complementary healthcare and self-help (‘complementary self-health’) and an analysis of several ‘self health’ books. The aim of this paper is to explore the critique that self-health is a disciplining framework that inculcates the individual into a regime of health, or what can be described as governance through ethics. I argue that whilst under an ethopolitical analysis (Rose, 2007), an analysis of strategies of governance might be necessary, it is not sufficient to examine the claim that those using self-health are being subjugated through ethics. I argue that self-health needs to be conceptualised within an ethopolitics that gives room to the ‘double game in play’ in Foucault. One way to do this is through contrasting an analysis of the ‘care of the self’ (Foucault, 1988; [1982] 2005) with an understanding of what I have come to call the ‘support of the self’. In doing so it is possible to move beyond an analysis of discourse, disciplining and self-governance, to explore the possibilities of subjectification and the formation of one’s self as a subject in one’s subjectivity. This paper argues that techniques and practices of care are increasingly orientated towards systems of knowing the self and are forming a new hermeneutics of care. Two key examples include Gilligan (1982) and Mol (2008). In contrast, the paper suggests the possibility that the ‘support of the self’ in complementary self-health opens up new possibilities for the self.
MacBride-Stewart, S.  
Cardiff University

The Effort to Control Time in the ‘New’ General Practice

Since the 1980s and 1990 GPs have reported a lack of time, and this has persisted despite the reorganisation of GP work through various contracts and regulatory mechanisms (Donald, 1985; Pritchard, 1992). I draw on interviews with 30 GPs in Wales focusing on accounts about the limited nature of their time, and the possibilities that they offer for its transcendence. Following work by Adam (2004) I explore the ways in which time is a conduit through which new forms of doctoring in general practice are organised. I pay particular attention to the control and commodification of time and the tensions that it generates for GPs between traditional and new ways of doctoring.

Macdonald, S. Macleod, U.  
University of Glasgow

You’ve got to die of something: the importance of age in cancer narratives

Introduction - Cancer is arguably is often thought of as the most feared of diseases. ‘Illness as Metaphor’, published first in 1978, highlighted the importance of the cultural representation of illness. Studies since Sontag have shown that, in spite of medical advances, cancer continues to illicit fear in the public psyche. A recent Cancer Research UK survey showed that cancer was the greatest fear pointing to the links between cancer and tragedy. Cancer is most commonly a disease of older people. Yet awareness of the links between cancer and age as a risk factor amongst the general public is variable. This paper presents findings from a larger study on lay epidemiology and cancer. It questions whether, to the lay public, cancer means something different when the sufferer is an older adult.

Methods - A series of in-depth semi-structured interviews, with members of the lay public in two communities in Glasgow, one affluent and one deprived.

Findings - Participants provided evidence for their beliefs about cancer introducing narratives of people known to them. Typically, cancer meant tragedy which was often coupled with a quick and unexpected demise. Often the cancer event was a shock because the sufferer was thought to be healthy. Yet, such tragedy was not associated with cancer in older people. Rather than being an illness associated with fear and dread, cancer in older people was accepted and more palatable.

Conclusion - Cancer affects a different cultural resonance in older adults.
MacLean, A., Hunt, K., Sweeting, H., Egan, M. & Adamson, J. Medical Research Council

How robust is the evidence of an emerging or increasing female excess in physical morbidity rates between childhood and adolescence? Results of a systematic literature review.

It is widely acknowledged that higher rates of psychological morbidity among males in childhood are replaced by higher rates in females during adolescence. This pattern has also been reported for asthma prevalence. We conducted a systematic review to investigate evidence of an emerging/increasing female excess in relation to a range of physical symptoms (headache, stomach ache and others) and chronic illnesses (diabetes and epilepsy). Identifying and appraising evidence for this pattern is important for understanding the apparent deterioration in female health which begins in adolescence and continues into adulthood.

Five databases (Medline, Embase, CINAHL, PsycINFO, and ERIC) were searched for studies presenting physical morbidity prevalence data for both males and females for at least two age-groups within the 4 to 17 age-range. Three screening stages (initial sifting; detailed inspection; full extraction) were performed, followed by study quality appraisals. Multiple reviewers quality-checked decisions. Data were synthesised by calculating odds ratios (OR), then graphically representing and tabulating findings.

Of 11,245 identified studies, 48 met the inclusion criteria. Results suggest that evidence of an emerging/increasing female excess is more robust for some measures of physical morbidity than others. For example, only one of six diabetes studies showed clear evidence of an emerging/increasing female excess. Stronger evidence of this pattern was apparent for headache, with eleven of thirteen studies showing an emerging/increasing female excess. Our findings raise questions about whether symptom/condition specific or more generalised social or biological explanations may explain the patterns of an emerging/increasing female excess where these are seen.

Madden, M.

Evidence based medicine meets medical device marketing: Ethnographic observations of a UK Wounds Conference.

Aging populations living with chronic conditions and those living with various degrees of immobility present a growing market for pharmaceuticals and medical devices. Wound care management is one of the largest segments of the UK medical technology sector with a turnover exceeding £1bn in 2009. Most treatments for chronic, complex wounds, such as leg ulcers, pressure ulcers and diabetic foot ulcers are classified as medical devices and are subject to less stringent requirements for testing than pharmaceuticals. The evidence-base that informs clinical decision making is therefore very limited.

This paper presents an ethnographic enquiry into one of the spaces in which wound care clinicians make up their minds about wound care evidence and innovation. It is conducted and analysed in the context of the trend towards increasing marketisation and privatisation in the UK National Health Service (NHS).

The conference positions evidence based medicine in opposition to clinical knowledge, as an obstacle to innovation and as a remover of solutions rather than a provider of them. Advanced wound care promises profitable higher technological solutions which will enhance the professional status of wound care without an accompanying rise in the quality of evidence of effectiveness. However, the extent to which the commodification of medical technologies in wound care is providing innovations that lead to better health outcomes for patients remains uncertain. The conflation of education and research with marketing in this sector, and the problems that wound care clinicians face in attempting to operate in a research-informed fashion require further research.
Donated Blood: towards a hierarchy of Self

The aim of this paper is to present data about how blood donors view their Gift in relation to their body. It also examines what is now understood to be blood, with the emergence of what I call ‘manmade’ blood being added to ‘natural blood’.

The chapter introduces new ideas about the Self in relation to body part donation related to blood. Fieldwork produced data which alluded to what I came to describe as an internal mental process that the donors experienced when thinking about whether blood was part of the Self. I theorised this as evidence of what I termed ‘an emerging hierarchy of the Self’. During the fieldwork donors relayed information as to their solid organ donor status. It is from these statements and discussions that this part of my thesis emerged. By this I mean that set against the contemporary background of the further medicalisation of blood and its components, the narratives from the donors interviewed seemed to develop the notion that the body has been made hierarchical to create a ranking order of parts of the Self, both solid or liquid. The ranking represents which parts would be missed or which parts were ‘too special to give away’, the most special being related more closely with the concept of the Self rather than the body.

This area of the fieldwork data led to theorising that a hierarchy of the Self had been created to deal with the moral and ethical demands on the person as a result of the medical need for all body parts, and increasingly blood part donors felt that they ‘have to give something’, so they give what they think of as not being a part of them, rather than electing to give away something else more central to their Self. It introduces the concepts of hierarchy of the Self, the inner Self and the liquid Self.

Problem Solvers: Lay Evaluation of the Working Practice of Sports Physiotherapists

This paper examines the recent and significant development of sports physiotherapy and, in particular, lay evaluations of the working practices of sports physiotherapists. The paper is premised on the belief that a striking feature of elite sports healthcare is the strength of physiotherapy’s challenge to medical dominance. However, the paper extends existing work by further arguing that the basis of this hierarchical challenge is rooted in lay evaluations of the treatment practice and philosophical traditions of physiotherapy. Close physical contact and experiential learning fosters physiotherapist-patient mutuality, defines the physiotherapist as an inherent part of the recovery process, and leads to trusting and collaborative healthcare relations which patients see as qualitatively different to those they experience with doctors. Crucially, physiotherapists are seen to solve the problems of patients, rather than ‘simply’ identifying them through diagnosis. While it is recognised that there are limits to the degree to which physiotherapy can challenge medicine, such is the extent of physiotherapy’s challenge that the accepted philosophy of healthcare practice in sports contexts is largely in line with, and thus seemingly determined by, the practice traditions of physiotherapy. The paper therefore develops our understanding of the lay-professional interface, the specificities and specialism of physiotherapy treatment, and professional boundary work in healthcare professions.
Mallick, S.  
*University of London / University of Campinas, Brazil*

**Medical Pluralism at the crossroads: Critically looking into the state promotion of ayurveda in Delhi Health Institutions**

In late 1960s, mainstreaming of alternative systems of medicine, also known as Indian Systems of Medicine(ISM) in India is promoted as a part of decolonization and medical pluralism. In which, the market and the state are seen as the intermediaries in the promotion of these medical systems. The postcolonial Indian state has sponsored promotion of alternative systems of medicine in terms of developing a broad institutional framework to carry out the regulatory and developmental activities in the field of ayurveda and other alternative systems of medicine, mainly through AYUSH (an acronym for Ayurveda, Yoga, Unani, Siddha and Homeopathy), Ministry of Health.

The efforts of AYUSH has resulted in the remarkable growth of ayurvedic health care infrastructure in the form of hospitals, dispensaries, bed strength, registered practitioners and so on so that ayurveda can be made available and accessible for the people. However, the attempt to mainstream ayurveda has also resulted in the standardization and scientification of this medical system on the line of allopathy/western science. It has also carefully maintained the dominance of the dominant medical systems. The paper is based on the field interactions with the patients, doctors and other para-medical staffs in the government ayurvedic dispensaries in Delhi during 2010-11.

The attempt is to critically analyse mainstreaming of ayurveda and medical pluralism by the Indian government, broadly its success and failures in the level of actual implementation and the future direction. The paper will be based on the findings of my study in two institutions.

Key-words: ayurveda, AYUSH, decolonization, medical pluralism, mainstreaming.

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Mansnerus, E.  
*London School of Economics and Political Science*

**Governance of public health risks through vaccinations**

Vaccinations form a major group of preventive actions in public health. By vaccinating a majority of population, the transmission of an infection is stopped and a potential outbreak of life-threatening disease is prevented. To prevent transmission of endemic infections, we need a continuous uptake of vaccinations, whereas, at the time of a pandemic outbreak, an immediate mass campaign is required.

This study explores how governance of risk from infectious diseases emerges and is maintained through preventive actions (i.e. vaccination campaigns). I will argue that the perception of risk varies across the different groups who manage, recommend or are expected to follow particular vaccination strategies. What counts as a population-level risk for a public health official, may not be regarded as equally threatening on an individual level, which suggests that there are multiple interpretations of public health risks related to infectious diseases. These risks are increasingly governed by model-based predictions. I will show how epidemiological modelling functions as a form of ‘risk calculation’ and how these calculations help direct and design vaccination programmes. This study analyses how modelling is used in the governance of risks in two case studies. I will compare two vaccination programmes in the UK: the prevention of endemic rubella outbreaks by implementing the MMR triple vaccine as a part of a mass vaccination scheme in 1987 and the pandemic (H1N1)v vaccinations targeted to the risk groups in 2009.
Mao, A., Robinson, J., Bristow, K. The University of Liverpool

**The impact of one-child policy on indoor smoking restrictions before, during, and after pregnancy—a qualitative study in rural China**

Scientific evidence has established that tobacco smoke has effects on every stage of children’s growth. Knowledge on how the mothers of young children in Chinese rural areas deal with indoor smoking is scarce. The aims of the study are to explore the experiences of the mothers of the young children in their management of indoor smoking with the growth course of their children. In-depth interviews were carried out in rural area of East China’s Jiangsu Province. 44 interviews and one focus group happened with 29 mothers and other family members of young children aged 6 or younger. It is found that China’s one child policy has profound effects on protective actions of the family members for their children’s health. Restrictions on smoking begin from the time when young couples get married throughout the early stage of the children to minimize the impacts of smoke on the children. However, with the growth of the children, restrictions on smoking at home are loosing under the perceptions among the participants that their children are becoming more resistant to tobacco smoke over time. Future tobacco control programs aiming to protect children’s health should provide support to the family members in a repeated way so that the smokers can sustain their reduced smoking. Such programs should fully take use of the high status of the only child of the family so that the whole family resources can be mobilized.

Martin, P., Wllaims, S. University of Nottingham

**Cognitive Enhancement, Pharmaceuticalisation and the Making of Neurofutures**

Many commentators argue that we are entering an era of cognitive enhancement. This discourse presents a future in which human attributes can be modified by neurotechnologies to improve competitiveness, enable people to work longer and harder, and make us ‘better than well’. Leading bioethicists and scientists claim that such developments are both inevitable and desirable, and pose few social or ethical problems. In contrast, critics point to a dystopian future in which cognitive enhancement would become the norm, pose major risks to health and further entrench social inequalities. In both visions neuroscience is seen as having the power to transform society. This paper will critically analyse both the current state of cognitive enhancing drugs and the discourses that surround them. Conceptually it will draw on work in the sociology of expectations to explore how particular ‘neurofutures’ are being created and mobilised. Empirically it will review the extent to which we are seeing the introduction and development of cognitive enhancing drugs, focusing on the field of memory and Mild Cognitive Impairment. It will be argued that progress in developing such drugs has been greatly overstated. The creation of these hopes, promises and fears is therefore better understood in terms of a confluence between transhumanist utopian thinking and the dynamics of pharmaceuticalisation in which the very future of social life is bound-up with the increasing use of drugs for non-therapeutic purposes. Such neurofutures play an important performative role in mobilising support for research, expanding drug markets and framing social problems in medical terms.
**Leading from the middle: the constrained reality of clinical leadership in healthcare organisations**

In many developed-world countries, there have been concerted efforts to increase the leadership capacity of healthcare professionals, particularly among lower-status staff without formal managerial power. Creating new frontline ‘leaders’ is seen as a key way of improving the responsiveness and quality of healthcare, but such efforts face considerable challenges in practice, including the institutionalised nature of existing professional accountabilities, boundaries and practices. This paper reports on a qualitative, interview-based study of 29 staff in two operating theatre departments in the United Kingdom, mostly nurses by professional background, who were given formal leadership responsibilities by their hospitals and redesignated as ‘team leaders’ and ‘team co-ordinators’. We find that while participants were familiar with leadership theory and could offer clear accounts of good leadership in practice, they were often limited in the degree to which they could enact their leadership roles. Professional and managerial hierarchies constrained leadership capacity, and consequently in practice the exercise of leadership rested on alignment with a variety of managerial relationships and mandates. The findings highlight difficulties with academic and policy accounts of leadership as a role that can be distributed across organisations; in professional bureaucracies such as health services, established institutional structures and norms render this approach problematic. Rather, we suggest that if fostering leadership capacity is to have the transformational effect that policy makers hope for, it needs to be accompanied by other, wider changes that pay attention to organisational and professional context.

**Sticks and stones: experiencing facial difference and/or 'dis-ability' in modern Britain**

Faces are a significant aspect of human sociality. Yet, very little social science research has been completed exploring the relationship between individuals and their faces and its impact.

Research indicates that those who are considered to be beautiful have more life chances, more friends and better paid jobs (Van Leeuwen & Macrae:2004). Meanwhile those whose faces do not meet expected norms, for example, as a result of illness or accident can have fewer friends, face social disabilities and become isolated (Rumsey:1996). However, most of the research exploring the relationship between an individual and their face has been conducted using un-contextualised, quantitative methods, with bio-medical understandings of disability. Such findings make it difficult to understand how the people experiencing facial difference make sense of it, or to consider whether they see themselves as needing to be surgically ‘fixed’ and/or psychologically supported (which most research suggests).

This presentation will start with an overview of social structures and normative cultural narratives in relation to facial beauty, ‘difference’ and disability. The body of the talk will involve a report of my early PhD fieldwork findings. The PhD aims to explore how damage to the face may disrupt and recreate notions of identity and social agency (using narrative interviews with approximately 20 adults with an acquired facial difference of 2 years+).

The presentation will conclude with a call for further qualitative research in this area, to de-stigmatise facial difference and promote the acceptance of facial diversity.
Mazanderani, F., Powell, J., Locock, L. University of Oxford

**Biographical value: exploring the economics, epistemics and ethics of patients' narratives**

The study of illness narrative is one of the cornerstones of medical sociology. In the rich body of research that examines different aspects of illness narratives it has been argued that rather than simply being a means of giving expression to a prior ‘experience’, narrative work plays a crucial role in shaping the subjectivities, identities and experiences of illness. Yet, in spite of the diversity of this work, relatively little attention has been paid to examining the economic implications of the creation and circulation of patients’ experiential narratives. Drawing on Catherine Waldby's notion of ‘biovalue’, in this paper we propose the concept of ‘biographical value’ as a means of thinking through the interdependency of economics, epistemics and ethics at play in the public sharing of illness experiences through books, websites, blogs, promotional material, and other media. The concept of ‘biographical value’ is developed through a secondary analysis of in-depth interviews conducted with people across a range of different health conditions. Particular attention is paid to sketching out the different types of value people attributed to the sharing their experiences, ranging from a sense of personal achievement, to the founding of charitable organisations and fundraising for biomedical research. This analysis is integrated with themes from three strands of research: 1) experiences of health and illness; 2) research on health and the media; 3) health social movements, patient activism and biopolitics, and we suggest that increased dialogue between these areas provides opportunities for enhancing our understanding of the ‘value’ of illness narratives.

McDonald, R. University of Nottingham

**Restratification, path dependence and control of medical professionals: the case of ‘Pay for Performance’ in English and Californian primary care.**

Recent reforms, which link rewards to the achievement of quality targets in English primary care, have been seen as enabling greater control to be exercised over medical professionals. The popularity of such initiatives amongst policy makers in countries outside of the UK may be based on an assumption that ‘copying and pasting’ such policies will lead to similar results. This paper draws on interviews with 40 doctors in England and California and highlights how reforms with similar intent and timescales have played out differently in each of these contexts. In particular it describes how reforms appear to have had much greater impact in England. Using concepts from the sociology of the professions, path dependency theory and policy transfer literature, it suggests that the path dependent nature of reforms needs to be clearly understood in any attempt at policy transfer from one country to another. One criticism of path dependency theory is its weakness in relation to explaining non-incremental change. However, the findings also suggest that an understanding of the history and context relating to policy implementation may lead to a reconceptualisation of ‘radical’ reform as somewhat more incremental in nature.

Human secondary sex ratio change, alterations in the proportion of live born males to total live births, is not only a subject of developmental biological curiosity but also a useful epidemiological marker for reproductive health. Various hypotheses have been theorised, ranging from medical anthropological theory, and evidence-based health and environmental science perspectives, in attempting to explain this phenomenon. The research objective is to explore some of these hypotheses by undertaking statistical analysis of recent public health, socio-economic and environmental data in Scotland. Data were sourced from governmental agency web portals and included the following five relevant indicators:

- Multiple Deprivation levels (2006)
- Number of Under 19 mothers (2001-2009)
- Number of Over 35 mothers (2001-2009)
- Number of Pregnant Women smoking at first ante-natal appointment (2001 to 2009)
- Nitrogen Dioxide concentrations (2001-2003), a proxy indicator of endocrine disruptor pollution in air.

The data was tabulated geographically, and for the purposes of the research at the smallest level, 6,550 ‘datazones’ in Scotland (pop. levels between 600-1000 persons).

No associations were established and the null hypothesis holds; that sex ratio in small areas is not influenced by any of, or combination of, the above factors. A forward regression model however established smoking and nitrogen dioxide concentrations as the two most significant variables for predicting increasing low weight births in small areas (Adjusted R squared 0.317 and p<0.001). Further research will be an exposure assessment of endocrine disruptor pollution, health status and sex ratio in Scotland using Geographical Information Systems, together with analysis of the Scottish Longitudinal Survey.

Health and Family Data in Understanding Society - An Illustration about Baby Boomers in the UK

The initial data release of data from Understanding Society – the new UK Household Longitudinal Survey, was in December 2010. The interim release (Wave 1, year 1 data) had 9,718 persons aged 50 or older and 4,385 persons aged 65 or more. The full wave 1 data released in Autumn 2011 will have at least double the number of older persons. The purpose of this paper is to summarize health and family data frequently used by social gerontologists. Several varieties of health data are collected in main or self-completed surveys, annually or in rotating modules. Nurse collection of objective biomasures was recently introduced for adults successfully interviewed in Wave 2. The battery of biosocial measures includes anthropometric measures, blood pressure, lung function, and the collection of whole blood through venipuncture. Data linkage will be used for direct measures of health care use, diagnoses, and mortality. With respect to family information, the household grid has substantial information about household composition. Adult respondents report on family background when young, family networks, caring involvement, and quality of relationship with spouse or partner. In Wave 2 there is information about the domestic division of labour and social support. Understanding Society permits examination of health in connection to multiple social environments—family, community and the larger social structure. The utility of the data are illustrated by contrasting health and family relationships of baby boomer and adjacent cohorts.
McGoey, L.  
*University of Essex*

**Transparent secrets: reframing the politics of disclosure within pharmaceutical cultures**

Drawing on interviews with current and former staff members at the Food and Drug Administration (FDA), I explore the politics of disclosure and dissent in drug licensing and post-market surveillance, examining the personal repercussions of insider attempts to draw attention to failed regulatory policies at the FDA. Through a focus on the case of Ketek, I suggest that efforts to understand a drug’s risk-benefit profile often result in personal risks to reputation and job security for FDA officials. The high number of FDA insiders reprimanded for calling attention to regulatory failures suggests a truism that is both obvious and yet strangely neglected within social studies of organizational life. Within large organizations, individuals often have more to lose than to gain by calling attention to dysfunction within organizations which, by necessity, tend to thrive on not articulating or resolving their own weaknesses. Drawing on work by Jacques Rancière, I then contrast the penalization of individual FDA officials who called to drug risks with the tendency for drug manufacturers to flourish financially even when faced with proof of their own fraudulent activity, and suggest that work by Rancière helps to theorize the paradoxes of liability within corporate and bureaucratic life.

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Mead, R. Thuston, M., Bloyce, D.  
*University of Chester*

**Working strategically to improve health and reduce health inequalities: a sociological study of one public health system**

Partnership working has been a central feature of public policy since 1997 and has endured as one of the key policy implementation mechanisms that is advocated for achieving local solutions to local problems. It has led to the development of an increasingly complex local infrastructure involving a network of statutory, voluntary and private sector organisations. This paper focuses on the implementation of public health policy aspirations relating to improving population health and reducing health inequalities as an aspect of the work of local partnerships. To date, there has been little research that has studied public health policy implementation through partnerships, particularly from a sociological perspective. There is, however, some indication that partnerships are not effective in achieving public health outcomes.

The paper presents some of the emerging findings from a research project examining public health policy implementation processes in one local partnership in the North West of England. It will examine how local actors make sense of public health and work within their established networks to realise public health policy aspirations. Data collected from non-participant observations, interviews and documentary analysis will be used to demonstrate how a sociological approach can be beneficial to understanding public health policy implementation processes through partnerships at the local level. The early findings indicate that policy implementation through partnership working can more adequately be understood if it is viewed as a process of managed social change in which there are a number of intended and unintended consequences and, moreover, if partnership processes are placed in their wider social, political and historical context.
Melby, L.  
Norwegian University of Science & Technology

**Coordinators of care: hospital nurses’ shaping of patient trajectories**

Modern hospitals are complex organisations characterised by highly specialized units and a strong division of labour. They are also fragmented organisations, which implies a need for extensive collaboration between staff and hence mechanisms for coordination of resources (personnel, patients, information etc.) and planning across the hospital site. In this paper I look closer at hospital nurses’ ‘coordination work’, and more specifically on how they through this work enact and shape patient trajectories.

A. Strauss et al.’s ideas about illness trajectories and the organisation of these are used as analytical framework in the analysis.

Our study took place in a university hospital in Norway. We conducted semi-structured interviews with nurses in the operating department (13 persons) and with nurses and physicians in two surgical in-patient wards (14 persons). In addition, we conducted participant observation in the operating department (approx 50 hours) and one day’s observation in an in patient-ward.

The trajectory schemes (plans) are the designated responsibility of physicians. The schemes prescribe a specific course of action – and a specific trajectory. However, nurses shape the actual trajectory by coordinating the work to be done in order to enact a trajectory scheme. I divide nurses in (i) the invisible architect, (ii) the constructive doer, and (iii) the passive observer and discuss how different approaches to coordination work affect care work and the accomplishment of patient trajectories. I argue for that coordination work is an important – and often underestimated - part of nursing work that should be given more attention.

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Menchik, D.  
University of Chicago

**Do Pharmaceutical Companies Persuade Physicians to Adopt their Products?**

The degree and form through which physicians are influenced by private industry is a source of controversy in the public. Only in recent years, however, has the subject received attention by sociologists of health and medicine. To understand how medical technology companies manage the skepticism of potential clients, I compare failed and successful continuing medical education (CME) meetings organized by two different companies for cardiac electrophysiologists. Drawing on ethnographic observations, interviews, and documentary evidence from two out of six meetings analyzed, I relate the success of certain meetings directly to the quality of interpersonal interactions over features of the technology being discussed. At these events, physicians are put into small groups to learn and practice using new technologies. Doctors are more likely to adopt a company’s products when elites in the field are involved in these group interactions. These leaders bring a company credibility by displaying various linguistic qualities that index their commitment to Mertonian scientific norms such as skepticism and disinterestedness. I call these individuals “modulators.” This concept, I argue, more accurately describes the practices of these elite physicians than that of the more commonly-used concept, “broker.” Physicians’ experiences in CME meetings yield insight into the etiology of their long term relationships with economic actors, offering an empirical case study for how companies gain legitimacy among professionals for whom the profit motive is antithetical to their craft.
Healthcare Professionals and Productivity – A Case of Borrowed Technology

The UK’s National Health Service (NHS) is facing one of the greatest financial crises of its history (Nuffield Trust, 2009). This paper focuses on the quest for improved productivity that has been apparent since the earliest days of the NHS. The contested productivity gap is discussed and a historical perspective on the efficiency agenda offered, with emphasis on process improvement technologies ‘borrowed’ from industry: Total Quality Management; Continuous Quality Improvement; Rapid Cycle Change; Business Process Re-engineering and Lean/Six Sigma. These highly successful technologies have frequently appeared to lose momentum once introduced to the NHS (Powell et al, 2009), and it is suggested here that this is because they have conceptualised professional work in a way that may not be commensurate with the view of healthcare professionals. Consequently, this paper seeks to problematise these process improvement technologies from a ‘Sociology of the Professions’ perspective, aiming to reveal a priori reasons why implementation of these technologies may be flawed or inherently problematic.

Furthermore, the literature reveals a dearth of evidence concerning healthcare professionals’ notions of productivity and its amelioration. This subject is perceived to be significant as evidence suggests that the way in which workers deal with a phenomenon such as productivity, is related to how they understand it (Sandberg, 2000). Therefore, this paper will also outline planned research that aims to address this lacuna. It is anticipated that the findings will inform future healthcare productivity improvement policies, and contribute to contemporary understanding of healthcare professionals’ notions of productivity.

Pushing Against The Hill': A Study of Irish Traveller Health in the 21st Century

This paper presents findings from the All-Ireland Traveller Health Study Conducted in Northern and Southern Ireland. The study consisted of a Census, vital Statistics, Demography and Birth cohort study and a series of qualitative investigations including interviews and focus groups of Travellers and Health Care Professionals around Ireland.

Participatory methodology ensured that the Traveller community were consulted throughout the research process.

Key thematic issues emerged from the data. These (non comprehensively) included: Rapid historical changes in the economic, cultural and policy arenas have impacted on the traditional lived experience of Travellers; Nomadism has decreased whilst accommodation problems have increased marginalisation and isolation; A recognised sense of loss of Traveller culture, sense of identity and self esteem but a resilience and determination to seek new forms of meaning; New cultural conditions impacting directly on the quality of life and health chances influencing social and institutional opportunities and barriers; High rates of perceived discrimination; Major concerns regarding the increase in drug culture; Education as a continuing source of concern during the educational process and beyond to employment; New mass communication technology embraced by some (younger/literate) Travellers as an important source of information, exchange and sociability.

Conclusion: Based on their own account, Travellers face multiple health challenges that impact directly upon their physical and mental health. Travellers have interpreted these experiences as ‘pushing against the hill.’
"I'm down to bare bones": imag(in)ing pathophysiology and orientations towards intracorporeal landscapes

Understanding lay interpretations of the ageing body in health and illness is essential to understanding people’s health behaviour as they grow older. This presentation draws on a larger study exploring how older people can best be helped as they age in the presence of musculoskeletal pain. Semi-structured interviews were conducted with 60 adults aged 55-80+. The interviews focused on peoples’ experiences, perceptions and self-management of painful conditions, as part of which they gave a ‘lay diagnosis’ of their condition, utilising visual language, unsolicited physical demonstrations, illustrative drawing and obtained medical x-rays.

This combination of narratives and visual data, together with a perceived increase in media representations of the body in health and illness and advances in medical technology has led us to theorise about peoples’ urge to ‘see’ inside their body and to imag(in)e their pathophysiology as they seek to orientate themselves towards what we term an ‘intracorporeal landscape’. This seeking is manifest in the visual language and actions of the informants as they talk about and ‘show’ their pathophysiology.

We consider the possible advantages and disadvantages of using medical images (x-rays, athroscopic images, scans) during consultations and suggest that these may serve to orientate patients towards their own body and hence a better understanding and management of their condition. This sheds further light on lay interpretations of disease and embodiment theory and we consider how these ideas may contribute further to a sociology of the body.

How do practitioners in community teams conceptualise mental distress? Developing a theoretical framework for analysing discourse and action

The contemporary reconfiguration of UK statutory mental health services involves significant changes including new professional roles, an increasing profile for user involvement, and a shift from medical to more holistic concepts of mental health. Based on findings from nine months ethnographic fieldwork within a community mental health team, this paper examines the effects of this new service landscape on the way conceptualisations of mental distress are utilised and articulated.

Drawing on and extending the work of Rhodes (1993), a conceptual framework for understanding contemporary mental health practice is outlined utilising notions of strata and gesture. It is argued that practitioners and service users navigate a field of contradictions defined by five strata: confinement, biomedicine, systemic/community approaches, commodification of care and risk discourse. These are conceptualised as ideological positions that co-exist within practitioners as alternative modes of thinking and operate in a relationship of mutual tension. Practice should be understood as a process involving movement between these overlapping and co-existing layers of historically sedimented meaning. The term gesture describes the strategic use of concepts-in-action that arises from the tension between formal accounts of mental health work and the practical orientation of staff within services.

The paper goes on to explore methodological challenges encountered in adapting this framework. It explicates the way in which critical realist epistemology has provided a means to address tensions between realist and constructivist elements to produce a situated understanding of the field which captures the dynamic relationships between concepts, actors and the systemic context of action.
The Family Factor: The role of the family in influencing women's decision-making about taking part in breast cancer clinical trials

Many clinical trials recruit fewer participants than the original recruitment target and so interest in patient's perspectives on trial recruitment is increasing as efforts to improve trial participation continue. Studies looking at factors that can influence cancer trial participation have raised several issues including patient's views about trial interventions, extra time required to attend additional appointments, and fears of randomisation. However many of these used quantitative survey methods developed from health professionals’ perspective with little sociological research addressing the patient's perspective.

Qualitative interviews with nine women, (three included their husband) were carried out, in order to discover what key factors influenced their decision. All interviews were transcribed and analysed using a grounded theory approach.

The results show that the most important factor that influenced a woman's decision about trial participation was her family members' views and opinions. For some women their relatives' view of whether or not they should participate in the trial was more important than their own. Key motivations for trial participation were altruistic and there was a belief that taking part would help future treatments, although this was balanced by the need to avoid personal harm when taking part.

This study shows that a major factor unexposed before is the influence of family, and raises the issue of the importance of the family members in cancer trial decision-making and the need to explore this further to meet patients’ needs. This appears to be moving away from physician patient shared decision making, into the social arena of the patient and their everyday life, involving the key family members better reflects a patients needs and women’s decision making about breast cancer trials enrolment.

Population Biobanks: science, translation, promise

The promise of science lies in expectations of its benefits to societies and is matched by expectations of the realisation of significant public investment in that science. The transformation of bioscience into societal benefit is described in terms of research translation. Part of global and local endeavours to translate raw biomedical evidence into practice, biobanks aim to provide a platform that can later provide a firm foundation for generating new scientific knowledge to inform development of new policies, systems and interventions to enhance the public's health. Effectively translating scientific knowledge into routine practice, however, involves more than good science.

Demonstrating the shift from regimes of truth to regimes of hope translational research has become a defining feature of big science and its funding. Called T1 and T2, we can think of translational research endeavours as transforming data into knowledge and knowledge into practice respectively. There is recognition within the bioscience community that translational research presents challenges and that the dyadic model based on drug discovery and treatment implementation does not adequately account for the range of activity within bioscience or for its embeddedness in and with other disciplines, professions and publics. Though less well recognised is the relational, spatial, temporal and, necessarily, transdisciplinary character of translation. The potentiating ontology of biobanks – that their outputs are perpetually a promise of scientific knowledge generation – renders translation even less straightforward. Biobanking science therefore provides a perfect counterpoint against which to test the bounds of thinking in terms of knowledge generation and its translation.
**Professions**

Friday 16th September 2011 10:10 - 10:40

Westminster Building Room CWE218

*Nascimento, R., Nascimento, R., Corrigan, O.* Peninsula College of Medicine & Dentistry

**An exploration of contemporary working life and professionalism of general practitioners (GPs)**

Inspired by Berger’s (1967) collaborative ethnographic account of a general practitioner’s (GP) everyday working life, his values and relations with patients and community in which he worked, this project aims to explore how GPs view the situations they face, regard those they interact with, the values that underpin their work, and how they see themselves as doctors.

Issues of professionalism are increasingly important and ethical norms underpinning it are currently being reviewed in the UK and elsewhere. Moral theories articulate vocational aspirations drawn largely from notions of a ‘good doctor’. Social theories either support a professional ethical predisposition to public service, or critique medical power and self-serving interest, or question the moral status of medical dominance. These theoretical frameworks have been challenged by a perceived ‘proletarianization’ or ‘deprofessionalization’ in medical practice. GPs’ role and work have been subject to organizational change, managerial dictate (EBM emphasis, QOF contract, PHCT) and demands by transforming societal values (consumers movement).

This presentation will explore conceptual and methodological aspects of some attempts to bridge this ethics/sociology divide. To which extent the theoretical models of medical professionalism are based on, or apply to, primary care? Which challenges arise in articulating ‘sociology of the everyday’ and ‘ethics of the ordinary’? What are the limits of ‘the ethnographic’ in approaching the processes that inform the development of these perspectives on professionalism? How is temporality - implicit in the notion of ‘contemporary’ - accounted for? Which are the justifications for taking the ‘daily experience’ as a reference for sociological and ethical reasoning? At the early stages of fieldwork, this study provides some provisional responses.

**Inequalities**

Thursday 15th September 2011 17:30 - 18:00

Westminster Building Room CWE218

*Nazroo, J., Amanda Connolly, Nitin Purandare* University of Manchester

**The impact of retirement on cognitive function and wellbeing: who benefits?**

There are inevitable concerns over the impact on health, economic and social systems of growing numbers of older people; and a desire to maximise the opportunities afforded by healthy, engaged older people – so-called third agers. A broad approach to ageing, however, ignores the significance of marked socioeconomic inequalities at older ages, which extend to cultural, social and civic activities. Of importance here are the uneven, and unequal, routes that are taken into retirement and the implications of this for a rewarding post-retirement life. In this study we have set out to understand the impact of retirement on cognitive function and wellbeing, and how this relates to socioeconomic position, route through retirement, and post-retirement activity.

The study uses three waves of the multidisciplinary English Longitudinal Study of Ageing. We observe the retirement of 600 respondents aged 56 to 70 over a four year period and contrast changes in cognitive function and wellbeing for this group with 670 respondents in the same age group who remained working over this period. Findings show that route into retirement (routine, voluntary and involuntary) is an important determinant of outcomes, as are socioeconomic position and participation in social, cultural and civic activities post-retirement. We show how these factors operate jointly to impact on post-retirement outcomes.

We use these findings to illustrate how social inequalities play out over the retirement process and discuss the need to consider inequalities within the older population, rather than considering outcomes to be a simple consequence of age-related transitions, such as retirement.
Participants’ Perspectives of a Randomised Controlled Trial (RCT) of Supported Socialisation for Persons with Serious Mental Illness

Supported socialisation is a befriending approach that facilitates caring, reciprocal relationships, structured opportunities and supports for people who have a serious mental illness in order to facilitate their participation in community life and to help them to realise that they have something of value to offer others. This paper will report the demographic and qualitative findings of “A Randomised Controlled Trial (RCT) of Supported Socialisation for Persons with Serious Mental Illness” which was conducted in the Republic of Ireland. The purpose of this RCT was to address issues that pose challenges for community integration for persons who have a SMI, e.g. social isolation and loneliness. In the context of this RCT, supported socialisation involved providing people who have serious mental illness (SMI) with a small amount of funding and matching them with a volunteer partner with similar interests in order to facilitate engagement in social and leisure activities in the community, as this was an RCT study, there was also a control group in which members also received the same amount of funding but were not matched with a volunteer partner. The qualitative findings are based on observations, diary entries and group interviews of participants and volunteers who were involved in the project. The diaries were a means of recording activities and reporting one’s feelings about these activities. The group interviews provided an opportunity for the participants and volunteers to reflect and comment on their experiences in the project retrospectively.

The Mental Healthcare System Reform in Belgium: Assessing Network Outcomes and Inter-Organisational Effectiveness

Despite a phase of deinstitutionalisation, the mental healthcare system in Belgium has remained fragmented, uncoordinated, and rather hospital-centred. In 2010, a new phase of reform, ‘Title 107’ was initiated to implement inter-organisational networks of mental health and social care services coordinated from psychiatric hospitals. However, the policy blueprint of the reform lists 18 goals which, as the theory suggests, cannot all be met simultaneously. Moreover, there is no consensus on how to assess the effectiveness of such inter-organisational networks.

Our study maps the goals of this reform and identifies the most relevant indicators to assess inter-organisational network outcomes and effectiveness in mental health. A quantitative stakeholders web survey (n=110: policymakers, professional groups, users and family groups) was combined with focus groups (n=4). Indicators were selected according to the Rosenblatt’s model while reform goals were extracted from the policy blueprint.

Globally, the most supported goals aim at improving the quality of life of the users and their social inclusion. A clash was identified between two groups of goals, the first aiming the increase of the network density of links, the second aiming at the increase of the network centralisation and service coordination. Goals and indicators related to clinical status and hospitalisation were considered as less important, although priorities differ according to stakeholders groups.

This study indicates how nation-wide mental healthcare reforms may be challenging to assess. It gives important indications on network outcomes that such a reform should rely on, and how inter-organisational effectiveness in mental health can be assessed.
**Innovative Culture in Long-Term Care Settings: The Influence of Organizational Characteristics**

**Objective.** To identify organizational characteristics that explain innovative culture in the (long-term) care sector.

**Design.** Large cross-sectional study.

**Setting.** Dutch long-term care: nursing homes and/or elderly homes, care organizations for the handicapped and long-term mental health care organizations.

**Participants.** A total of 432 managers and care professionals in 37 organizations.

**Measures.** The Group Innovation Inventory was used to measure innovative culture in long-term care organizations. Structural characteristics of the organization were centralization and formalization, environmental dynamism and competitiveness, internal and external exchange of information, leadership style, commitment to quality improvement, and organization’s innovative strategy.

**Results.** The determinants of an innovative culture were estimated with a two-level random-intercepts and fixed slopes model. Multilevel regression models were used to account for the organizational clustering of individuals within the 37 care organizations. Environmental dynamism, job codification, formal external exchange of information, transformational leadership, commitment to quality, and an exploratory and exploitative innovation strategy were all significantly correlated with an innovative culture in the multivariate multilevel analysis; the other characteristics were not. The explained organizational-level variance was 13.5% and 35.5% at the individual level.

**Conclusions.** The results pointed to substantial differences in innovative cultures between and within care organizations that can in part be explained by organizational characteristics. Efforts must be made to ensure that organizational characteristics such as environmental dynamism do not hamper the development of innovative cultures in long-term care organizations. Organizations’ human resource practices and knowledge management are particularly promising in strengthening innovative cultures.

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**Am I my brother’s keeper?: household interactions around medication-taking**

Previous research on how people take medications has largely taken the perspective of health professionals, and ‘non-compliance’ has been seen as deviant and requiring explanation. Research has also had an individual focus, studying individuals in isolation from their families or households. In the study reported here, we explore how and why people take their medications, assuming that “compliant” medication-taking requires as much explanation as “non-compliant” medication-taking, and using households as our unit of data-gathering and analysis. We explore how interactions between household members affect medications-taking practices.

Study participants supported other household members’ medication-taking by ensuring a supply of medications was available, administering medications to them, sharing values that supported medication-taking, reminding them to take their medications, sharing medication-taking routines, and checking that they had taken their medications. For some people this was a significant part of their workload of caring for family members, and some participants’ ability to take medications regularly depended heavily on the help and support of others in the household.

Relationships within households could also undermine medication-taking. For example, some participants worried about the effect their medication-taking had on other household members. Carers’ own concerns about morality, risk, and safety of medications reduced their inclination to administer medications to others. Some medication-taking regimes were unrealistic for care-giving household members to adhere to.

Shifting the focus of research from individuals to households allows us to see how previously under-researched relationships and day-to-day interactions within households affect medications-taking practices.
Norvoll, R.

The continuous struggle of overcoming custodial practices: Experiences from acute psychiatric wards in Norway

Mental health and psychiatric institutions were of great interest to sociologists during the 1950s and 70s, both internationally and in Norway. Some of the main topics were the total custodial institutions and institutional tensions between treatment and control. This research, in combination with other factors, led to health reforms with emphasis on decentralized mental health services in combination with a rise in acute care wards. Based on two recent qualitative research projects, current trends in the institutional tensions and some implications of the studies for further research will be discussed. The first project studied use of seclusion ("skjerming") by way of an ethnographic study carried out in two acute wards. The second project explored alternatives to coercion through trailing research on development projects in acute wards at six hospitals. Both studies show continuity of tensions between treatment and control practices as was found in the old asylums. A consistent struggle with custodial practices within the wards was observed despite recent health reforms. The total institution takes different forms however, due to reduced length in hospitalization, and new ideologies. Patients have different views of hospital stay. The tensions in psychiatric institutions are therefore still evident, but take both old and new forms due to stability and changes in the structural and ideological conditions in the hospitals. Inclusion of patient’s views gives new understanding of how these tensions are experienced, and underline the need for developing new sociological perspectives on treatment in further research.

Oliver, K., Everett, M., De Vocht, F. University of Manchester

Public Health Policy Making in the UK: a Social Network Analysis

Introduction

Public health policy-making (PM) activities are currently split between local authority and NHS organisations. Previous research has ignored the ‘human element’ in PM and rarely focused on decision-making processes. Social network analysis (SNA) techniques are increasingly important in the health sector, and have been used in policy analysis elsewhere. This paper describes an innovative study giving a fresh perspective on PM processes in public health.

Methods

- A social network analysis of public health PM networks in Greater Manchester based on publicly available data (documents, websites and meeting papers), an electronic survey, and semi-structured interviews of national, regional and local policy-makers.
- Observation of local authority and NHS key policy meetings (2010-11) in Greater Manchester

Results

Social network analysis captures previously ignored aspects of PM processes and contexts. The structure of policy networks indicates the importance of bridging organisations and individuals, acting as intermediaries between NHS and local authorities cultures. Some overlap between formal governance and informal networks was identified, through analysing networks of perceived power, influence, and being a source of information/evidence. Key individuals were associated with characteristics such as “likeability”, and “charisma”. Personal relationships were frequently identified as central to PM and evidence-seeking/using behaviours. These data indicate the importance of collaboration and good relationships between researchers and policy-makers, but few academics were identified within the networks. Future work may focus on how networks relate to the impact of academic research on health policy, institutions, and practices.
**The tension between professional autonomy and health care as cooperative work**

Health care work, especially in the context of the hospital, is characterized by the need for cooperation. That is, the work cannot be carried out wholly on an individual basis. The complexities involved in modern diagnostic and therapeutic practices require highly specialized services, as well as the collective efforts of health professionals with an array of different competencies. The interdependencies that arise from the cooperative nature of modern health service delivery gives rise to some hard to solve social tensions however. One such tension is between individual autonomy, the hallmark of professionalism, and the need for relational coordination and shared decision making in local contexts. Based on an ethnographic study of everyday work in 4 hospital wards, this paper describes how working within the confines of individual professional priorities undermine the relational and cross-functional work practices necessary for delivering safe and timely patient care.

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**'So, it's my body, I'll look after it': Patients' views of the role of health professionals in self-management**

Self-management has been a central part of many western governments’ health policy over the last few years. We use the definition of self-management as ‘those actions individuals and others take to mitigate the effects of a long term condition (or LTCs) and to maintain the best possible quality of life’. The role of health professionals has been seen as important in stimulating and supporting patients to self-manage. Health professionals are asked by society and policy makers to inhabit the world of evidence and science, while at the same time individual patients also want them to show humanity and compassion. This tension is exemplified in consultations where self-management arises, because scientific medicine has to be applied within an individual and subjective life-world.

We will present an analysis of interviews with 22 people who suffer from chronic knee pain. The interviews included discussion of people’s self-management approaches and their views of the role of health professionals in providing advice and support. The participants made distinctions between GPs, physiotherapists, practice nurses and CAM practitioners. Particularly the role of GPs was defined in different ways, ranging from expert advisor to someone who “should not be bothered with trivial issues (such as self-management)”. Our findings point to a selective use of health professionals, and the difficult balance between maintaining the therapeutic relationship and using evidence-based self-management advice. We will discuss the implications for policy and practice.
Otto, L., Lassen, A. J., Bønnelycke, J. University of Copenhagen

Involving elderly people as users/patients in a public-private health innovation partnership

How are elderly people configured as users and/or patients in public-private partnerships? The paper focuses on different and contesting ideas of elderly people in the Danish, public-private, interdisciplinary, innovation partnership No Age, whose purpose is to create social-technological solutions to better the quality of life for self-reliant elderly people.

The authors are social scientists at the Centre for Healthy Ageing at the University of Copenhagen (http://healthyaging.ku.dk/), and are expected to ensure the involvement of the user perspective in the innovation process in No Age.

The different disciplines within the partnership affect the conceptualization and configuration (Woolgar 1990) of the elderly people: Notions of users, patients, citizens and healthy ageing are contested, as the focus on market profitability clashes with issues of health promotion, prevention and general popular well-being.

We argue that there is an inherent tension in the way the elderly are conceptualised in No Age, as they are articulated as independent and resourceful, at the same time as, according to prevalent public discourse, they tend to be perceived as high-risk, patients-to-be. Our hypothesis is, that the configurations of the elderly people as users and not-yet-ill risk leading to patientialisation and homogenisation.

How can we involve an ageing perspective without categorising citizens as patients-to-be? How to innovate to a group defined by age rather than common practice? What are the medical sociological implications of introducing risk factors to a ‘not-yet-ill’ target group? How does scientific research change when it becomes entangled in market-oriented user-studies?

Owen-Pugh, Valerie. Allen, J. University of Leicester

'I'm doing everything positive now'. Six abstinent alcoholic men review their drinking careers

Few published studies to date have explored the biographical accounts of alcoholics, and these have tended to privilege the female experience. A qualitative study was carried out to explore the male experience of alcoholism and recovery. Six male alcoholics in recovery took part in semi-structured interviews. The transcripts were subject to a grounded theory analysis, and the resulting themes compared with those identified in a comparable study of female alcoholics by Lillie (2002). Thematic analysis elicited five core categories, Beginning to Drink, Paying for Gain With Pain, Reaching Rock Bottom, Struggling to Recover and Leading an Abstinent Life. Though expressed indirectly, low self-esteem appeared to be a notable feature of our participants’ accounts. While Lillie’s female participants had expressed themselves in highly emotional terms, readily acknowledging their shame, and the stigma associated with alcohol abuse, our male participants’ stories were couched in detached and unemotional language, their interpretations often appearing to echo those of support services that they had had contact with, for example, interpretations offered by AA sponsors or counsellors. Lillie’s participants adopted a passive stance – they were ‘done to’ by others – whereas ours portrayed themselves as active rather than passive – they ‘did to’ others. These findings are consistent with socialisation models of alcoholism. They highlight the need to distinguish between male and female perspectives when researching the condition.
Reconstructing professional identities: HIV service providers and confidentiality in the UK

Social and medical conceptualisations of HIV as a stigmatised terminal illness established strict confidentiality as a significant aspect in relation to which HIV service providers construct their professional identities in the UK. This manifests strongly in the distinctive technological practices that restrict information sharing between specialist HIV outpatient centres and other hospital departments within the same NHS Trust. As HIV is becoming redefined as a chronic illness, HIV professionals shift the way they articulate their identities to advocate wider sharing within primary and secondary care.

Drawing on relevant theory (Ibarra, 1999), this paper examines the mechanisms through which professional identity adaptation occurs in two HIV centres in east London. Research methods include semi-structured, in-depth interviews with 46 service providers from HIV centres and other departments in two east London Trusts. These are supplemented by an analysis of organisational documents and observation of work practices.

In these cases inter- and intra-professional negotiations over the integration of stand-alone HIV systems to centralised hospital Electronic Patient Records allow professionals to experiment with ‘provisional selves’. Conflicting identities emerge in this process, since the effort to normalise HIV by increasing its visibility competes with the need to protect individual patients from stigmatisation. Furthermore, interpretations of critical patient incidents invoke diametrically different responses, driving identity development to opposite directions. This analysis highlights how such professional identity transitions in relation to stigma and disease entail complications for the design and use of technological systems and the effectiveness of shared HIV care.

'I love bread, but it doesn’t love me': an exploration of emotional and gendered responses to questions of food choice.

I have been collecting food stories using asynchronous online interviewing techniques and an auto/biographical research approach for my PhD on ‘food choice and identity; beyond a gender binary’. My respondents have been asked to reflect upon their own food histories, their likes and dislikes, how these might have developed and how and why their diets might have changed over time. What is emerging is that whilst some of the male respondents replies have been brief, they are not without emotion, especially when reflecting upon their early food preferences, home lives and inter-generational relationships. However, whilst some of the men have expressed a strong affinity with a ‘foodie’ identity, the performance in the kitchen is often linked to issues of sex rather than nurture. Some of the women’s narratives on the other hand have tended to be more detailed and emotionally complex. For many, food is significant if not ‘the biggest issue in life’. It has the potential to offer comfort, but is also fraught with anxiety. It is also strongly associated with issues of ‘love’ and many women discuss their ‘love-hate’ relationship with food on many levels. What is emerging is that contrary to the idea of food choice as a weak marker of identity, for some it is the means through which they express themselves completely.
A Gendered Analysis of Trauma as a Determinant of Mental Health and Substance Use Among Lower Prestige Service Workers

This paper examines the role of trauma as a determinant of mental health and substance use among a comparative sample of lower prestige service workers, including men and women working in food and beverage service, hairstyling and sex work. There is a substantial body of social science literature highlighting the linkages between female gender, sex work, trauma, and substance use. One limitation of this scholarship is that it typically relies on small samples of data drawn from female sex workers who are in contact with downtown social services for the most vulnerable of citizens. Drawing on closed and open-ended data from a more diverse sample of sex workers in Canada and the US, and a comparative sample of service workers in structurally comparable yet less stigmatized occupations, we present findings regarding the impact of trauma on mental health and substance use, while controlling for other social determinants of health including gender, education, occupation, and income. We conclude with suggestions for intervention and prevention of trauma and related health outcomes.

Living on the ‘virtual’ edge: Young LGBT people, deliberate self-harm and online forums

Youth suicide and self-harm have received widespread research attention but the influence of sexuality and gender identity on these practices has been marginalised. International studies show that young lesbian, gay, bisexual and transgender (LGBT) people's rates of suicide attempts can be at least four times those of their heterosexual peers. Unfortunately, there is very little UK research, making it difficult to develop appropriate health policies and service provision. In addition, the existing research tends to be quantitative; there is a paucity of qualitative investigations which could provide answers why the risk of suicide and self-harm is so dramatically higher in young LGBT people.

This paper addresses the methodology and results of a qualitative study which focused on explaining why young LGBT people are more likely to engage in deliberate self-harm (DSH), and suicide attempting, than their heterosexual peers. It discusses the methodological dilemmas of utilising online forums for investigating the virtual environments in which young people talk about their sexuality, gender identity, and emotional distress. It also considers ethical challenges related to using transcripts of online conversations held by members of a vulnerable group. The paper seeks to build understanding of reasons why some young LGBT people harm their bodies. Specific attention is paid to young people's discussions of everyday lives and spaces (e.g. school, family), and the way social norms may regulate gender and sexuality in young people.
“This is just a probability”: The interactional management of uncertainty in conveying ‘positive’ results in an antenatal screening clinic.

Over the last 20 years, antenatal screening has been the target of considerable sociological scrutiny (Reid et al, 2009). This work is largely interview-based, and uncertainty is a key theme arising from women’s accounts. Given the limitations of current screening tests (Meier et al 2002), pregnant women and clinic personnel potentially face a double uncertainty: not only do screening tests produce uncertain answers, but those results themselves are also of uncertain reliability. However, little is known about how these issues are raised, discussed and negotiated in actual consultations. In this paper we use conversation analysis to examine 18 consultations collected from one public hospital in Hong Kong. The women in these consultations have previously undergone screening tests for fetal abnormalities, and their results fall outside of the ‘normal’ range set by the clinic, so that in official terms they have all ‘screened positive’. The purpose of the consultations examined here is to convey these results and offer options for further diagnostic testing. We examine the ways in which the ‘positive’ test results are conveyed to the women. We demonstrate that results are both quantitatively constructed through use of numeric probabilities and risk factors, but also qualitatively described through use of terms such as ‘high risk’, or ‘not so serious’, and show how these latter descriptions are not always objectively derivable from the results themselves. We also consider the ways in which uncertainty -both in relation to the results and in relation to the tests themselves- is formulated and discussed.

Negotiating action roles for an action research team: developing pre-operative patient education in colorectal surgery

Action research studies seek to develop service provision by generating evidence which participants see reflecting their concerns within practice settings. However, participants’ scope to realise actions for change will be constrained by existing power differentials between groups with differing expectations, and by the resources available to service providers and the researchers themselves. Roles to be taken by those engaging in action research therefore require careful negotiation, expectations of development moderated. These are examined in the context of a three-cycle action research study to develop preoperative patient education awaiting colorectal surgery, drawing on observations, patient evaluation questionnaires; interviews, focus groups; and documentary analysis of educational interactions.

Points of negotiation were encountered as multiple assumptions had to be managed about study actions, reflecting power differentials within the multi-disciplinary, academic/ clinical research team to influence wider organisational changes and shape outcomes of staff-researcher decision-making meetings. These entailed compromises for different participants’ contributions at each stage, including the selective presentation of patient views to staff and to take into the next cycle of action. The action research process itself could be seen at some points to offer individual participants opportunities to voice “different world” thinking for preoperative education, at others to be constrained by organisational dynamics, the discourse of decision-making meetings on what was manageable collective change. These set limits on action research team roles and practice for realising patient-responsive developments.

This abstract outlines independent research commissioned by the National Institute for Health Research (NIHR) under the RfPB programme Ref: PB-PG-1207-13321. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
Porter, J.  
Brunel University

The Making of A ‘Good’ Scientist in an Ethically Contentious Field

In the wake of the Hwang scandal, when most stem cell researchers kept their heads down, a small group of UK scientists made headlines when they called for regulations to be changed to allow the creation of interspecies embryos - that is, animal eggs whose genetic material has been removed and replaced with a human somatic cell. Institutional-political as well as religious opposition became a major obstacle, as critics sought to ban the work. Building on previous debates, a core set of scientists mounted a two-year campaign via the media and parliament, using creative flurries of ‘hope and fear’ to legitimise the research as ‘good science’; to redefine critics as irrational; and to mobilise socio-ethical and political-technical expectations about the necessity of the work. Following a ‘successful’ campaign, which led to regulatory change, three labs obtained licenses to carry out interspecies research, but funding was ultimately declined. The question is, why did these scientists seemingly succeed yet fail? Drawing on interviews with the core set of scientists involved, and documentary evidence from parliamentary debates, this paper argues that to win over the public and politicians, the scientists invested considerable energy in courting the media, yet in so doing, some damaged their professional standing in the eyes of the stem cell community, who in turn, sought to distance themselves and police the boundaries around what they believed constitutes a ‘good ethical scientist’. Key to the findings is a tension between the necessity and danger of campaigning for science.

Power, R.  
Open University

RAISING THE PROFILE OF ‘ELDER ABUSE’ AS SOCIOLOGISTS

Title: ‘It’s not going to bring her back’. Sociological imagination as a source of strength in the process of alerting and complaining: a case study in ‘elder abuse’.

Abstract:

‘Elder abuse’ is challenging to define and to identify, and parallels have been drawn between its current state of recognition and that of child abuse and domestic violence thirty or forty years ago. Naming the problem and getting it recognised by statutory services is a developmental process in which only a handful of sociologists have so far been involved. Yet sociology has much to contribute to popular and professional understandings and thence to policy making and remaking in this area. Using the case study of her deceased mother, Power outlines some of the sociological insights and connections that have inspired her through a long process of complaint, considered at national level through the Parliamentary and Health Service Ombudsman and the Local Government Ombudsman.

Sociologies of the family, domestic violence, mental health and the law provide illumination, as well as an appreciation of the sociology of work and the professions for an understanding of the possibility of any intervention.
‘It just seemed the most natural thing to do, but it was such hard work’: Decision-making surrounding breast/bottle feeding among parents living in a deprived area where breastfeeding rates remain low

It is well established that breastfeeding reduces child mortality and promotes child health and development. The World Health Organisation recommends exclusive breastfeeding for the first six months of life. Women in low socioeconomic status (SES) groups are less likely to initiate and continue breastfeeding. Increasing the take-up and duration of breastfeeding is a key priority for tackling health inequalities.

This study aimed to gain a better understanding of the decision-making processes underlying infant feeding choices among parents of new babies living in a deprived area in England where breastfeeding rates remain low. Purposive sampling was used to select mothers who: were currently breastfeeding; were formula feeding and had never breastfed; breastfed initially but ceased by 8 weeks. Semi-structured interviews, conducted with 38 mothers and 25 fathers, explored parents’ rationales for their feeding choice and the facilitating and constraining factors for breastfeeding initiation and continuation.

While findings suggest positive attitudes towards breastfeeding, irrespective of infant feeding practice, decision-making around infant feeding was the outcome of a multifaceted negotiation occupying factors internal to the individual, socio-cultural knowledge, organisational and structural factors, the external environment and mothers’ sense of agency and control. While it is clear that there is a need to confront social norms and societal attitudes towards breastfeeding, a key message for local service commissioners and providers, is that the decision to breastfeed (both to initiate and to continue) is strongly influenced by parents’ interactions with health services and health professionals at key sites and times along the antenatal/postnatal pathway.

Snakes & Ladders: Delay in access to diagnosis and appropriate care for patients with Juvenile Idiopathic Arthritis

Juvenile Idiopathic Arthritis (JIA) is a heterogeneous group of diseases with a spectrum of clinical features, disease course and prognosis that affects both children and adolescents. The management of JIA is multi-disciplinary and referral to an experienced team is essential as soon as the diagnosis is suspected to facilitate access to effective treatments now available. Sadly delay in access to care is common and likely to adversely affect long term outcomes as the longer the period of active disease the greater risk of impairment. The reasons for delay are multifactorial and we report findings of our study of patients’ trajectories from initial symptoms to referral to paediatric rheumatology services.

We have undertaken one-to-one and joint qualitative interviews with the families of newly-diagnosed patients with JIA (n=16), families of patients with an established diagnosis of JIA (n=20) and a range of health professionals (n=10) and a teacher (n=1) involved in the care pathway of JIA patients. We show the variety and complexity of the routes to appropriate care that patients travel. Three factors are central to receiving appropriate care: the sheer persistance of parents help-seeking actions; the persistance and timeliness of (public) manifestations of the disease; (lack of) knowledge of health professionals in both diagnosis and delivering appropriate care. All three factors need to align in order for patients to receive a diagnosis of JIA and appropriate care, and this often only happens through what can be best described as ‘luck’ or ‘chance’.
(Re) producing the fetal image: exploring the use of magnetic resonance imaging (MRI) in fetal medicine

From its first reported use in the mid 20th century fetal ultrasound rapidly became a key aspect of routine prenatal screening within the UK. Now, fetal MRI is emerging but has not yet been established as routine. Fetal MRI offers information to back up, contradict or confound information obtained in obstetric ultrasound, particularly regarding brain anomalies. Still only offered to a minority of women, this technology is viewed by some as offering a panacea to identification of medical problems. However, the cultural, historical and social context in which MRI has evolved and adapted to the fetus remains unknown. This paper draws on an examination of technical, medical and sociological literature, along with preliminary findings from interviews with professionals working in fetal medicine. It offers an analysis of the development and use of fetal MRI as an emergent prenatal technology. It will address questions such as: how has MRI technology been adopted and adapted within the obstetric world? How do professionals understand and interact with the fetal image and what implications follow? We aim to contribute to a better understanding of the production and uses of fetal MRI, enhancing existing debates on fetal surveillance and management.

The perceived importance of lifecourse factors in ageing well with chronic musculoskeletal pain

Research shows that chronic musculoskeletal pain impacts on older people's health and well-being, and is associated with increased use of health services and decline in quality of life. Minimising the disabling effects of chronic pain as people age is therefore a major public health priority. Consequently, our research explores how older people can best be helped as they age in the presence of musculoskeletal pain.

We used data from an ongoing cohort study of older people to create three groups: (1) individuals who were free of pain in old age: 'no pain', (2) individuals whose pain did not seemingly interfere with their lives: ‘pain with no interference’, and (3) individuals whose pain did interfere: ‘pain with interference’. We conducted sixty in-depth lifegrid interviews with individuals in these three groups and across three age bands: pre-retirement (55–64 years); post-retirement (65–79 years); and the oldest old (80+ years).

Findings suggest that ‘pain with no interference’ can be a long-term state, characterised by high levels of pain medication and frequently involving widespread pain, but participants appeared to be able to control its effects. This paper will therefore explore the lifestyle factors described in participants’ accounts that appear to be important in reducing interference, including lifestage, financial issues, social activity and involvement. Participants’ accounts of how they live now with chronic pain draw on a range of lifecourse issues, including early life and upbringing, and current lifestage, with continuities across the lifecourse being seen as important.
Feeling ‘part of it’: Improving social wellbeing through reading literature aloud

While arts and health have achieved some status within the wider health environment, the potential for shared reading to positively influence people’s health and wellbeing represents a less established field of inquiry. Early research into the reported experiences of people taking part in reading projects run by The Reader Organisation suggest that the act of people reading together a literary text acted as a socially coalescing presence, allowing the readers a sense of subjective and shared experience at the same time. To explore how reading aloud works of literature can positively influence people’s social wellbeing, I reflect on the findings from a year long study of two reading groups, set up for people diagnosed as suffering from depression in two disadvantaged areas of Liverpool. Guided by thinking around ‘inter-subjectivity’ I critically assess how the focus group data and observations of the reading groups relate to the participants’ view that reading and talking about literature had increased their personal confidence and self-esteem and had reduced their sense of social isolation by fostering a sense of community. The development of verbal and non-verbal communication skills not only facilitated the interaction between all participants, but also between the participants and the spoken text, which they said helped them to relax, put any personal thoughts aside, while encouraging them to increase their levels of concentration and their attention to the text being read and others’ responses to it.

The Preceptorship of the Novice Nurse

The retention of new nurses has remained problematic (Baillie et al, 2003, Francis and Humphries, 1998) leading to complaints of “fumbling along” during early professional roles (Gerrish 2001, P.473), more errors and near-miss accidents (Department of health, 2010). This may be influenced by the historical changes and education of the nursing profession, principally, the introduction of Project 2000 diplomas (Gerrish, 2001) and the institutional changes since the Griffith’s report (1983, in Allen, 2001). These have impacted onto the organisational, temporal and technical requirements of nursing. Consequently, the policy of preceptorship is a strategic, structured transition programme aiming to enhance the confidence and competencies of novice nurses and argued to improve productivity, innovation and the patient experience (Department of Health, 2010). Although preceptorship a driver of quality in the NHS (Darzi, 2008), it may also be a form of normative isomorphism (Powell and Di Maggio, 1991) as the nursing profession tries to establish a cognitive base for their occupational autonomy. Preceptorship is little understood (Robinson and Griffiths, 2009); therefore NHS programmes are largely experimental. Based in an NHS Trust, this early stage ethnographic case study, adopts a critical situated learning approach (Lave and Wenger, 1991), to understand the political and turbulent process of learning and transformation of an identity in ‘real-time’ practice as nurses actively integrate with the context. Socialization is understood as practice, both locally and in relation to wider institutions (Antonacopolu and Pesqueux, 2010) and associated spatial and temporal conditions of agentic decision making (Bourdieu, 2004).
Harm reduction and the increasing medicalisation of tobacco use

The message of the tobacco control community has, for some time, focused on abstinence from all types of tobacco use as the only solution to the problem of smoking related death and disease, and harm reduction ideas have proved to be controversial. The most recent two tobacco strategies published by the Department of Health in 2010 have incorporated harm reduction ideas in the form of new ‘routes’ or ‘approaches’ to quitting smoking that encourage those who cannot quit to use safer sources of nicotine. This move away, at least in a limited fashion, from a focus on abstinence can be seen as the result of gradual shifts over the last fifty years in the way that the problem of smoking is understood and the solutions that are offered. These shifts have involved increasingly seeing tobacco use as a medical problem of addiction to nicotine. This paper uses conceptual tools developed within science and technology studies to examine developments over the last decade in England, primarily the increasing importance of the idea of harm reduction in tobacco control. It draws on twenty semi-structured qualitative interviews with key stakeholders in the tobacco control community, as well as analysis of various documents, such as official reports and journal articles. I suggest that the shape harm reduction has taken in English tobacco control policy has been another shift towards the medicalisation of tobacco use, but that this process has occurred in ways that provide a contrast to commonly outlined ‘drivers’ of medicalisation.

Patient experiences of involuntary psychiatric treatment in the community

With deinstitutionalisation of psychiatric services, forms for involuntary community treatment have emerged internationally. Community Treatment Orders (CTOs) were introduced in England and Wales in 2008 and permit patients to be treated against their will in the community following involuntary hospitalisation. Aimed at the most unwell, ‘revolving door’ patients, the intention behind was to improve treatment adherence. Research has failed to show the effectiveness of CTOs and to date, few qualitative studies of patients’ experiences of Community Treatment Orders have been published, none pertaining to England and Wales. This paper reports from in-depth qualitative interviews with a purposive sample of 40 patients from a range of Mental Health Trusts in England. Participants were recruited from a large RCT of CTOs (OCTET). Patients from both arms of the trial were interviewed to provide an opportunity to compare experiences of being on a CTO with its closest comparator in the English mental health system, Section 17 leave. Findings suggest that participants have diverse and mixed experiences of being on the order, and some reported that their views had changed over time. Many participants found it difficult to pinpoint the impact that the CTOs had on their lives, and some felt they lacked information about what they could expect.

Adding to the currently limited understanding of community coercion, this paper provides a patient perspective on issues of impact and effectiveness of CTOs and through that a new dimension to the sociological study of coercion in mental health.
Cigarettes, snus and status: Differences in life-style between user groups of different tobacco products

The article describes differences in broadly defined life-styles between different tobacco user groups. Drawing from Bourdieu’s cultural sociology, I demonstrate that differences in cultural practices (including tobacco use) is manifested in a structured “space of life-styles”, homologous to the structure in the objective “space of social positions”. The first dimension identified in the adult Norwegian population expresses life-style differences in levels of activity and technology use. In terms of social position, this life-style dimension is an expression of age and income. The second dimension expresses life-style differences in cultural consumption and health. In terms of social position, this dimension is an expression of education level. Furthermore, distinct life-styles can be identified based on the four quadrants of the plot. The passive-entertainment life-style is the life-style of daily smoking, the passive-serious life-style is largely constituted by non-smoking, the active life-style is where occasional smoking is located, while snus (occasionally in combination with cigarettes) is the favored tobacco product in the youthful life-style. Looking at tobacco users only, we find that the same differences in life-style distinguish between roll-your-own use (passive-entertainment), pipe smoking (passive-serious), cigar and light cigarettes (active) and manufactured cigarettes and snus (youthful) respectively. These homologies between the structure of life-styles and the structure of social positions is an empirical demonstration of differences in habitus in the Norwegian social space, i.e. the existence of systematic class-based variations in dispositions, which expresses itself in systematical differences between lifestyle components – including those of tobacco use.

Osteoporosis, fracture risk and the biomedicalisation of a new population.

This presentation reports on findings from interviews with older women recently screened for osteoporosis and informed that they are at a higher than average risk of breaking a bone in the next 10 years, but not formally diagnosed with osteoporosis. Data was gathered by the Adherence to Osteoporosis Medicine (ATOM) study using in-depth interviews with 30 older women between the ages of 73 – 85 years in their own homes in Norfolk & Suffolk, UK in 2009-2010.

We will explore the illness experience associated with being at risk of a long term chronic condition and will analyse and discuss the significance participants give to their new fracture risk status. We will suggest that this new category of being at risk of fracture contributes to a ‘new source of social identity’ (Novas & Rose, 2000) that is potential rather than actual and created by risk status rather than illness status. This largely symptomless pre-disease state places the individual in a ‘liminal world betwixt health and illness’ (Scott et al., 2005).

We will argue that screening for osteoporosis and assessment of fracture risk can be understood as a process of biomedicalisation of ageing and bone health. By expanding the population of older women labelled at risk and increasing demand for biomedical tests and prescribed medication for the prevention of disease this process has significance and consequence at both the individual and the societal level.
Samuel, G.  

**Media representations of the use of functional Magnetic Resonance Imaging (fMRI) for individuals bedside defined as being in a vegetative state**

Recent investigative studies which have used functional Magnetic Resonance Imaging (fMRI) in an attempt to diagnose and communicate with individuals bedside defined as being in a vegetative state (VS) raise the possibility that fMRI will become a powerful diagnostic, and possibly therapeutic, tool. A number of social and ethical concerns are associated with the use of this technology in this area. These include: issues relating to the cost and accessibility of the technology; informed consent and clinical utility; and issues relating to end-of-life decision-making, personhood (what defines a person), patient care, and access to proper treatment and therapy.

The social, ethical and legal contentiousness of fMRI for individuals bedside defined as vegetative has prompted us to take a closer look at how public knowledge about fMRI develops and how the public engages with this knowledge. Media portrayal of the use of fMRI for such individuals provides a good platform from which to study these issues because it is well documented that the media is a major source of public information about science and technology. It has also been documented that the media can colour public perception and have a strong influence on what, and how, things come to be constructed socially, and defined as public matters, which can, in turn, influence policy.

We present an in-depth analysis of the media portrayal of two studies, conducted by Owen and colleagues, which used fMRI to diagnose and communicate with individuals bedside defined as vegetative.

Sanchez-Taylor, J., Holiday, R.  

**Sun, Sea, Sutures and Sterostrip: Cosmetic Surgery Tourism from the UK and Australia**

Cosmetic Surgery Tourism is a significant and growing area of medical tourism. The global economic crisis may have slowed demand for cosmetic surgery in some countries but conversely demand for Cosmetic Surgery Tourism appears to be increasing as consumers seek out low-cost procedures abroad. The gendered discourse of cosmetic surgery is striking, however, it does not always operate in the ways we might assume. In addition the experience of cosmetic surgery tourism may be defined more in terms of characteristics like class and race rather than gender, despite the gendered nature of some surgical procedures. This paper explores the gendered construction of Cosmetic Surgery Tourism from the UK to Spain and the Czech Republic, and from Australia to Thailand and Singapore through an analysis of destination websites. In particular we examine the ways in which gender, race, class and sexuality intersect with notions of space, place and travel to construct particular locations and cosmetic surgery tourist experiences. We explore the ways in which place marketing often invokes gendered national identity through holiday scenery, representations of ‘caring’ or ‘serving’ national subjects and medical expertise. In addition we explore the connection between the representation of the surgical subject, neoliberalism and make-over culture.
**Thursday 15th September 2011**  
16:20 - 16:50  
Randomised Controlled Trials & Patient Public Health Westminster Building Room CWE126/2

*Scalabrini, S.  Swansea University*  

**Between strangers- Negotiating Fieldwork within local PPI arenas in England and Wales**  

This paper provides a first-hand account on how fieldwork developed in my ethnographic study of citizen-engagement organisations – Local Involvement Networks (LINks) and Community Health Councils (CHCs) - that form part of the health care systems of England and Wales. This is the main component of my doctoral research project on the social construction of Patient and Public Involvement (PPI) by the actors and agencies involved in this work. The aim is to illuminate the process of data collection with a focus on certain problems encountered over 15 months of observations and interviews. The paper explores issues concerned with gaining research ethics approval and negotiating access, and goes on to reflect on how these preoccupations affected my entry to the field. It discusses the personal strategies I developed to manage field relationships and some of the difficult issues and events that impacted on my sense of self and my construction of a researcher identity. The paper thus offers insights and reflections on the dynamics of fieldwork experience that I hope will be helpful to other neophyte qualitative researchers.

**Friday 16th September 2011**  
09:35 - 10:05  
Maternity/Reproduction Westminster Building Room CWE126/1

*Scamell, M.  Kings College London*  

**‘If it isn’t documented, you never done it.’ Midwifery work at the margins of risk.**

It is well established that the efficacy of clinical governance policies within the NHS depends upon the interpretative work done by practitioners delivering care. How practitioners go about translating organisational risk management policy into meaningful action, however, is far from straightforward.

Using ethnographic evidence, collected during an ESRC funded project set up to investigate midwifery talk and practice, this presentation will explore the interpretative work midwives do when making sense of risk management within the maternity care sector of the NHS. Using both the theoretical and methodological approach taken by Goffman in his analysis of ‘total institutions’, the proposition that midwives, can and do, devise covert manoeuvres through which they can subterfuge the standardised trajectories set by the risk management of clinical governance will be introduced. In particular, I will be looking at the notion of what one of my participants described as ‘If it isn’t documented, you never done it.’

This notion will be analysed to explore the opportunities it presents for midwives to, on the one hand, deliver women centred care, and on the other, protect and preserve the necessary space for women to achieve spontaneous birth. The presentation will show how, in their efforts to normalise birth and deliver effective care, several of the midwives involved in this study came up with innovative devices through which they were able to compensate for the constraints set by the organisation’s privileging of clinical governance and risk management.
Scott, J. Dawson, P., Jones, A., Evans, Y. Northumbria University

The impact of reforms to health and social care on a small-scale organisational development study aimed at increasing patient involvement in the reporting of patient safety incidents.

Punctuated equilibrium theory states that organisations go through periods of stability punctuated by revolutionary periods of change, which within the NHS are often the result of political ideologies. During these revolutionary periods, prioritisation is given to changes in deep structures, impacting upon small-scale organisational development projects. The impact of recent reforms to deep structures in health and social care services are explored in relation to the development of a reporting mechanism for patients to report safety when going through organisational care transfers. Action Research methodology was utilised to develop and pilot the reporting mechanism, providing a collaborative partnership between NHS community care teams, social care homes, private nursing homes and an ambulance trust. Two rounds of piloting were conducted; the first in a period of stability and the second in a period of revolution. During piloting 6 health care professionals acted as co-researchers in the distribution of the mechanism to 20 patients each and provided feedback to the researcher. 89 out of 120 mechanisms were distributed to patients during the period of stability, whereas 62 out of 120 were distributed during the period of revolution. Health care professionals reported a shift in prioritisation away from small-scale service improvements as a result of reforms to NHS and social care systems, with one social care home closing due to service cuts. Reforms to health and social care systems have impacted upon the prioritisations of health care professionals toward small-scale organisational developments, subsequently impacting upon patient and public involvement in their safety.

Shaw, S., Porter, A., Smith, J., Mays, N., Rosen, R. The Nuffield Trust

What is ‘commissioning’?

The term ‘commissioning’ has emerged within the English NHS to denote ‘health planning and purchasing’. This follows a series of reforms which have sought to separate commissioners and providers, the intention being to improve efficiency, challenge sectional interests and shift away from traditional patterns of resource allocation. Those tasked with ‘commissioning’ are encouraged to follow a cyclical model of healthcare planning that incorporates five ‘stages’ of needs assessment, planning, contracting, monitoring and review. To-date, little empirical work has been undertaken with commissioners to understand how they perceive their role and how this may – or may not – shape the processes allied to it. Our paper seeks to address this. We draw on ethnographic data from a two-year study investigating the process of commissioning high quality care for people with long-term conditions. We describe participant perspectives on commissioning from three ‘commissioning communities’ in England. Findings indicate that there is no ‘one size fits all’ solution to healthcare commissioning. Rather, the commissioning cycle operates as a heuristic device which some, but not all, use to shape and enact their work. Whilst some engage with and systematically work through the prescribed ‘stages’ of commissioning, others adopt a more pragmatic and selective approach. Either way, commissioners go beyond the cycle to further incorporate technical and relational aspects of commissioning, shape what is offered by health providers and redesign services, and defy prescribed timelines. Such accounts challenge persistent faith in the apparent simplicity of a commissioner-provider split in the NHS in England.
Pathologists’ perceptions of trust relationships in the aftermath of the ‘organ retention scandal’ and the implementation of the Human Tissue (Scotland) Act (2006).

The necessity of trust for effective health care, which through the embodiment of prized social norms and values also enhances societal well-being, has been convincingly argued (Gilson 2003). Contemporary research on trust and health care seeks to explore how organizational changes in the NHS and in society as a whole have impacted on the nature of trust and trust relationships in a variety of settings (Brown 2008, Rowe and Calnan 2006). Alongside the challenge of conceptualising trust (Brownlie and Howson 2008), theorists also grapple with a number of troubling dichotomies, including that between interpersonal or institutional trust (Giddens 1991, Luhmann 1988) and trust and control (Möllering 2005). Drawing on a thematic analysis of data generated through semi structured interviews with pathologists in Scotland, this paper explores trust relationships post the so called ‘organ retention scandal’ (Sheach Leith 2007). As such it offers the opportunity to explore perceptions of trust in a setting where trust was perceived to have been lost and legislation introduced to regulate practice and ostensibly rebuild trust. Addressing the above theoretical dichotomies the paper explores the nature and bases of trust (Möllering 2001), the tensions perceived in efforts to rebuild trust through tighter regulation, and the changing face of professionalism in the new NHS.

Pleasure meets STI/HIV risk governance: A love story?

Traditionally, sexual pleasure does not feature prominently in discourses on HIV risk governance. The expurgation of pleasure is particularly notable regarding young people’s HIV risk. But, as HIV inequities grow, arguments to put ‘the sexy back into safer sex’ are (re)emerging, with advocates positioning pleasure and safety as mutually reinforcing concepts. However, the notion of pleasure also could be conceived of as a risk governance technique, reflecting normative conceptualizations of the connections between pleasure and risk management; and, thus, I offer a rubric through which to interrogate the potentially problematic aspects of employing sexual pleasure in this way.

The presentation will examine how HIV prevention research relies primarily on theoretical orientations that perpetuate unrealistic and ideological assumptions about the level of agency and control that is afforded to many young people and, furthermore, how those assumptions are reflected in risk governance practices that primarily aim to modify young people’s lifestyle ‘choices’. Drawing on the works of Michel Foucault and others, I begin to elucidate the potential effects of the eradication of ‘pure’ pleasure and the inscription of more utilitarian forms of pleasure (e.g., regulatory, disciplinary, panoptic) within unrelenting, normative discourses on HIV risk. The idea of ‘ideal conduct’ is broken open in order to argue that diversities of pleasure(s) ought to be examined. And, I surface complexities that might arise for those who wish to put pleasure back into practice for risk governance purposes. Finally, I suggest how instrumentalization of pleasure might benefit (or harm) social institutions (e.g., public health).
Transformations: Transcripts to Poetic Representations

When faced with pages of interview transcripts, the researcher is entitled to feel both excited and daunted by their project; excited by the potentialities of the data but dismayed because the process of transforming that data into something ‘readable’ can seem challenging, even overwhelming. This paper shows how I transformed interview transcripts into poetic representations which helped me understand and analyse a group of older women’s stories of leaving home through British WWII evacuation and Australian postwar immigration. Analysis of the data begins with the transformative act itself because this mode of representing stories highlights salient points, showing up repetitions, hesitations and emphases. Poetic representation provides a particularly pleasing aesthetic structure as it parcs the work back, removing extraneous words and clunky phrasing that can inhibit flow.

While much of the narrative literature confirms the usefulness of poetic representation as a sociological tool of analysis, there is little which attends to the processes of that transformation. Devising my own ‘rules’, this paper shows how I produced the poetic representations and how this enabled me to commence the analytical process. I take a piece of transcript and show how it became a poem, a process which I find particularly creative, enlightening and powerful. Undertaking the construction of poems to analyse one’s data might also appeal to other qualitative researchers in the sociological and health and ageing fields who are feeling overwhelmed with the weight of their data or who might simply be seeking an attractive and alternative method of data representation.

Should adults with learning disabilities be encouraged to drink?

A review of research on alcohol and learning disability published in 1998 (Simpson) highlighted three key findings. First, there was a paucity of research on the subject. Second, such research as did exist pointed to very low levels of alcohol consumption compared with the general population, and extremely high levels of total abstinence. And, third, it revealed that this research was invariably orientated towards the statistically very small incidence of problem drinking. That paper concluded that there was an absence of attention to the questions of why the non/low consumption of alcohol was not regarded as problematic, i.e. insofar as it was an indication of failure of cultural inclusion.

Bringing the earlier review up to date, the current paper will show a growth in the size but not the direction of the field. Whilst there is much more, and much better, information available, it still concerns itself only with alcohol misuse. This paper will show how alcohol use can serve as a proxy indicator of the cultural inclusion of adults with learning disabilities; giving rise to the central question ‘Should adults with learning disabilities be encouraged to drink?’ The paper will also give an outline of a planned research project that would redress the current problems of the field.
Smidova, I.  
Faculty of Social Studies, Masaryk University

**Childbirth: masculine and professional hegemonies**

The presentation focuses on a work-in-progress research study analyzing biomedical and alternative approaches to practices surrounding childbirth, especially but not exclusively limited to the context of the Czech Republic.

On the descriptive level, the Czech Republic is catching up in lay men presence in the birthing room, these are esp. spouses of labouring women, establishing a new standard and sets of normative expectations for becoming parents (an empirical study by the author will be referred to). At the same time, dominant biomedical approach to childbirth (delivery - in their terminology) still tends to be stereotypically interpreted as appropriated by the “boys in white” (Becker) and equipped with “toys for the boys” (Cahill), despite the fact that growing numbers of women professionals are entering the ob-gyn specializations of medicine (statistical evidence will be provided to document the trends). On the analytical level, the presentation aims to confront these factual, descriptive changes and trends of the presence of female doctors (professionals) and supporting men (private actors representing a heterosexual family) with structural potential or hindrance for change of the symbolic (gender and power) relations in the birthing room. With reference to rich contemporary thematic research (Annandale, Bradby, Davis-Floyd & Davis, Jordan, Martin, Stacey, Campbell & Poter etc.) and more theoretical literature (Foucault, Illich, Rabinow), the aim is to apply them to the Czech data as well as to enrich the current theoretical frames by examples from the specific Czech context.

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Smith, M., Letherby, G., Stenhouse, E.  
University of Plymouth

**Intergenerational Inter/dependency Relationships between Daughters’ and Mothers’ from Britain and Australia**

In this paper we explore some of the ways inter/dependency offers a fertile analysis of a technology of political power in liberal democracies (Fraser 1989). Sociologists argue (Fraser & Gordon 1991, Watson et al 2004 and Holdsworth 2007) inter/dependency in the West is framed through binary understandings of care, individualised responsibility, work and autonomy. Such dominant discourses may operate to obscure the reciprocity and mutability of human relationships and the multiplicity of subjectivity (Morris 1993). We consider how this impacts on the relationships of mothers and adult daughters from England and Australia who took part in two different qualitative studies. The English study explored the life histories of women with type 1 and 2 diabetes during pregnancy and their family support needs (Letherby and Stenhouse 2010) and the Australian study focused on the experiences of professional women as they negotiated their fertility, family and work life (Smith 2008). We found across both studies that when attempting to articulate the inter/dependent nature of their caring relationships, women were prone to take up the position (and sometimes mimic the voice) of either their mother or daughter (Hollway & Jefferson 2000). These reflexive accounts demonstrate the complex ways in which women are compelled to negotiate dominant socio-cultural discourses that frame care and dependency in predominately negative ways today. However by framing their own experiences of intergenerational inter/dependency as always complex, relational and reciprocal, women found ways to disrupt dominant care binaries and distance themselves from a pervasive ‘culture of blame’ (Holdsworth 2007).
Solbjør, M.  Norwegian University of Science & Technology

User involvement between evidence-based medicine and managerialism? A qualitative study from a mental health hospital in Norway

Traditionally, health services have been the domain of health professionals. During the last decades, medicine and other health care professions have been under scrutiny from new trends such as evidence-based medicine and managerialization. There is a strong philosophical link between clinical governance and “evidence-based medicine”. These trends are not the only “new” perspectives in health care services. Policy trends highlight user involvement and the importance of service users’ perspectives into decision making in patient care and service development. However, the focus on user perspectives may be in opposition to discourses of scientific evidence. The question is how these different trends influence practices of health care services. The present study is from a mental health hospital in Norway which focused on user involvement while carrying out an organisational restructuring. We ask whether discourses of user involvement were intertwined with discourses of evidence-based medicine and managerialism during the re-organisation process. The analysis looks into strategic documents and compares it with observational data from meetings in the group responsible for implementing the strategy for user involvement at the mental health hospital.

Spadacio, C. Gabe, J., Barros, N.F. University of London / University of Campinas, Brazil

The use of Traditional Medicine and Complementary and Alternative Medicine by type 2 diabetes patients as a marker of social distinction in Brazil

Drawing on Pierre Bourdieu’s theory of cultural capital and social distinction, this paper will analyse patterns of social differentiation and cultural distinction in Brazil’s health care system. The paper is based on research which seeks to understand the extent to which the use of Traditional Medicine (TM) and Complementary and Alternative Medicine (CAM) by type 2 diabetes patients is related to social distinction. The data come from in depth interviews conducted with eighty type 2 diabetes patients in public (40) and private (40) diabetes clinics in Brazil. Interview transcripts were analysed to explore how patients’ social class location shaped their perceptions of heterodox treatments. It was found that the choice of heterodox treatments appears to be related to social class. For instance, middle and upper class patients tend to choose TM and CAM mainly within the private health service while working class patients tend to use TM within the public health service. It will be argued that class differences in the use of TM and CAM can be analysed as markers of social distinction in Brazil. According to Bourdieu’s theory of class distinction, taste (in this case, choices of TM/CAM treatments) is one of the key signifiers and elements of social identity. This research attempts to contribute to the much needed understanding of the relationship between cultural practices and social class position in medical sociology.
Spencer, I. H., Wood, V., Curtis, S., Gesler, W., Mason, J., Close, H., Reilly, J. Durham University

**HOW DOES THE DESIGN OF NEW PFI FUNDED PSYCHIATRIC HOSPITALS EMBODY SOCIAL RELATIONS?**

The number of NHS psychiatric beds has been in decline since the 1950s. Since the closure of the asylums, there has been an urgent need to recreate in-patient facilities. In recent years, the Private Finance Initiative (PFI) has supported the design and construction of new hospitals across the UK.

This paper is based on overt ethnographic observation, focus groups and structured interviews with patients and staff in the transition from St. Luke's Hospital to a new PFI hospital (Roseberry Park) in the North East of England.

Drawing on the history of psychiatry, we argue that the form taken by the physical space of the hospital is shaped by the social relations of the wider society. Just as the Poor Law gave us the Asylum, so economic decline and recent rising inequality shapes the form taken by new hospitals. We analyse how the physical structure of the hospital embodies social and professional relations between staff, between staff and patients, carers and relatives.

The new hospitals offer greater privacy and comfort but they are also more physically restrictive, with more locked wards and unprecedented opportunity to monitor patients' activity, usually justified by reference to 'risk'. We examine the abstraction of 'risk' in the concrete forms taken by, for example, the fear of litigation by staff in the event that a patient should abscond or self-harm. We question of whether 'risk' is used to protect the patient, the public or the institution and whether these are more therapeutic spaces than the asylums.

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Steinberg, D. L. University of Warwick

**The Bad Patient: Imperative Subjectivities in the Cancer Culture**

Cancer has long been a cultural touchstone, a metaphor of devastation and a spectre of social as well as bodily anomie and loss. Yet recent years have witnessed significant transformations in perceptions of cancer, particularly in perceptions of the cancer patient. This paper is interested in what might be termed the ‘struggles of subjectivity’ emergent in this transvalued cancer culture. Explored from the standpoint of the ‘bad patient’ and drawing on autobiographical and cultural methodologies, the paper focuses on the convergence of medicine, morality and popular iconography, and on the patient, as liminal figure, caught between clinical imperative and cultural phantasy. Taking medical advertising as a case study, and drawing in part on Frank Mort’s analysis of medico-moral discourse, the paper will pursue several interlinked arguments: (i) that contemporary cancer culture involves a potent articulation of popular, biocultural and medico-commercial discourse; (ii) that the cancer patient has become a primary object of transference, typically represented as edifying subject of the neoliberal age and of neoliberal values; and (iii) that, more specifically, the phantasmatic ‘good patient’ embodies a distinctive array of neoliberal body-affective imperatives — imperatives of will, affect and action — that constitute cancer as an imperative field and in which an imperative of estrangement is a core dimension. The paper aims to integrate and extend analytic debates in the context of bioethics, biopolitics, cancer and popular cultural studies to consider cancer as a site of institutional, cultural, and discursive convergence and in particular to consider the affective, seductive, and spectacular dimensions of cancer’s imperative subjectivities.
Stevenson, F. A., Higgs, P.  
*University College London Medical School*  

**'Ageing well': Competing discourses and tensions in the management of knee pain**

Age and ill-health have long been identified as being intrinsically intertwined, however, in contemporary affluent societies like the UK, USA and Australia the inevitability of the relationship is now challenged. In part this is a result of people living longer without a limiting condition or chronic illness but it is arguably also influenced by the development of strategies of health maintenance rather than chronic conditions always being viewed as an indication of decline and incapacity. The boundary between the discourses of ageing and ill health is not easy to demarcate given that most conditions vary between individuals as well as differ in intensity. It is possible, however, to shed some light on the interplay between the ageing body and chronic illness by considering how differing cultures of ageing play a key role in articulating a dichotomy between seeing chronic illness as an aspect of health or of ill-health. By doing this we hope to show how individual experiences of living with a chronic condition, and we use knee pain as an example, can be interpreted as either signs of 'ageing well' or as signs of impending decline and physical dependency.

Sumathipala, Kethakie. McKevitt, C.  
*King’s College London*  

**The organisation of long-term stroke care: findings from an ongoing study**

The complex nature of stroke requires that stroke rehabilitation takes a multidisciplinary approach and, it is now argued that care should be delivered by staff specialising in stroke management, in collaboration with patients and caregivers. Recent policy documents and guidelines suggest key areas that should be addressed and detailed stroke care pathways have been mapped. Here we discuss preliminary findings from an on-going study of the organisation of stroke care in London. 16 stroke survivors were recruited from an acute stroke unit and are being followed through their trajectory of care up to one year post-discharge. An ethnographic approach is used that includes: prospective formal and informal interviews with stroke survivors and family members; interviews with care providers; and observations of acute and community multi-disciplinary meetings. Trajectories of care were shaped by pre-morbid functioning, “rehabilitation potential”, family support, home and social environment, the availability of resources, integrated working and communication between care providers within the acute setting and between acute and community settings, as well as individual champions. Findings will be discussed using Strauss’ notion of negotiated order. Decisions on discharge destinations and on-going rehabilitation were based on the different perspectives and priorities of care providers, within a set of flexible formal rules and procedures and subject to negotiations within multi-disciplinary teams. Needs and priorities of patients were often taken into account in determining on-going care, particularly at discharge from acute care, highlighting the role of service users in giving rise to different service possibilities.
Sutcliffe, K.  
Social Science Research Unit, Institute of Education, London University

The good, the bad and the amazing: Children’s and parents’ appraisals of care delivered by healthcare practitioners for type 1 diabetes

Qualitative interviews were conducted with 11 children with type 1 diabetes and their parents to explore their views about working with each other and with health practitioners in managing their condition. This presentation will focus on families’ appraisals of the care delivered by practitioners. The research was informed by a ‘sociology of childhood’ approach, which sees children as ‘highly informed experts’ on their own lives.

Children and parents had strong opinions about what constitutes good and bad care. Their perception of the quality of care was influenced by three factors: the services delivered; the manner of delivery and the personal qualities of practitioners. Desirable services included individualised support, adequate consultation time and competent practitioners. Delivery of care was judged as good when practitioners were friendly and approachable, respected children’s and families’ opinions and values and communicated in an appropriate manner. However, families also felt that there was a certain ‘je ne sais quoi’ about excellent practitioners that makes them special – intrinsic qualities that render them exceptional, such as an ability to intuitively know families’ needs or ‘having a magic touch’.

These three factors were found to have a significant impact on families’ satisfaction with healthcare services but also to impact on how they engage with practitioners and ultimately on how they manage their condition. Enabling children’s and families’ perspectives to feed into the delivery of healthcare services is likely improve their experience of healthcare services, but may also improve practitioner-patient relationships and children’s health.

Taplin, S.  
University of Nottingham

A DISCUSSION OF PROPOSED HEALTH AND SOCIAL CARE RESPONSES TO THE NEEDS OF PEOPLE LIVING WITH CANCER AS A LONG-TERM CONDITION

A few decades ago, cancer was a topic shrouded in social silence. Today, stories...of cancer illness have found a place in our culture... the emergence of this discourse means that those who become ill with cancer can expect some degree of acceptance and understanding. The same cannot be said, however, about all those who survive cancer. Despite the interest that is often generated by stories of survival...there still remain unresolved tensions for those who have lived beyond the acute phase of extreme experience. (Little et al, 2002). My interest in this topic originates from my practice as a social worker in the field of palliative care, as I sought to uncover and explore some of these ‘unresolved tensions'in the lives of those who are experiencing cancer as a long-term condition.

I aimed to give individuals who were living 'with and beyond cancer' the opportunity to talk about their experiences, both during the treatment phase and beyond, in order to identify the meaning of this experience for these individuals, and therefore to increase the body of public and professional knowledge in this field.

I conducted 18 semi-structured interviews with people who were living with cancer as a long-term condition, simultaneously analysing these narratives by means of a grounded theory approach.

My findings from this study were that, in the main, individuals experienced cancer as life-changing, not only in terms of their own personal and emotional development, but also in how they related to the people around them, including health and social care professionals.

This session would provide the opportunity for delegates to explore together the findings of the research, and to discuss the possible psychosocial needs of people living with cancer, with a view to providing recommendations to those involved in developing policies in this significant area and to enhance future care.
“At the time I never thought that I was taking a risk”: the impact of feedback about adverse trial outcomes on views about trial participation.

Despite frequent calls to regard feedback of clinical trial results to participants as an ethical obligation, the question of how to provide results remains poorly addressed. We provide an account of participants’ responses to receiving carefully designed feedback about a trial that made a potentially distressing discovery.

We conducted semi-structured interviews with 38 women who took part in a trial of antibiotics in suspected pre-term labour (the ORACLE trial). A long-term follow up study of children born to these women, at 7 years of age, had identified an increased risk of cerebral palsy and functioning problems in some groups. We explore how women interpret, reflect upon and reconstruct their decision to take part, in the light of these results.

Earlier qualitative work with ORACLE participants, conducted before these long-term outcomes were known, found that women’s decisions to participate were motivated primarily by the possibility of an improved outcome for their pregnancy. Women relied on trust in health professionals and in medical research to assure them that they would not be exposed to risk. In the light of these new findings, some women felt that they had been misled about the possibility of harm, and questioned whether their trust had been misplaced. Some women also questioned the extent to which they had been able to give ‘informed’ consent given their vulnerability at the time of recruitment. The implications of these findings for the recruitment of trial participants to trials will be discussed.

The Impact of New Public Management Approaches on Working Relationships within an NHS Hospital in Scotland

Western governments face increasing demands to achieve both cost efficiency and responsiveness in their public services leading to radical and challenging transformations. Following the imposition of New Public Management (NPM) approaches within England, it is argued that similar elements of NPM can be also seen within Scottish healthcare, despite policy divergences following devolution. This paper considers the influence of NPM on Scottish frontline nursing staff in their work. It explores the ways in which managerial practices have shaped the working relationships, interactions, and knowledge-exchange between managers, staff and patients and the ability of staff to carry out nursing duties.

Based on thirty-one qualitative interviews with front-line nursing staff in an inner city hospital in Scotland, this paper presents initial findings in relation to nurses’ views of management and management structures. It suggests that the nurses believe management have little awareness of how policies affect nursing care. Nursing staff emphasise that the deluge of policies, audits and targets are removing them from their core tasks and that regulation and accountability are leading to defensive practice. Further to this, the findings highlight high levels of micro-management, self-surveillance, control and the regulation of the frontline nursing staff which has lead to tensions both between nursing staff and managers, but also with patients. Staff are increasingly frustrated with their working conditions and this does not look set to change any time soon.
Thackray, L.  University of Sussex

“Life’s as hard as you want to make it” – exploring conflict in Special Educational Needs

The Special Education Needs (SEN) system is a major provider of support to children and young people with SEN and/or disability. Although SEN policy focuses on partnership, the system is described as adversarial in many recent government documents. The use of militaristic language and the metaphor of fight/struggle is reported in the academic literature and found in publications aimed at more general audiences. Despite the frequency of this terminology, there appear to be few attempts to explain why a system developed around a policy of partnership is so pugilistic.

My doctoral research focuses on the meaning and usage of the struggle/fight metaphor in a sub-set of the SEN domain, that concerned with children and young people diagnosed with Aspergers Syndrome (AS) or High Functioning Autism (HFA). Although AS and HFA are sometimes referred to as milder forms of autism, it has been suggested that they should be regarded as different ways of functioning rather than as disabilities. However children with these conditions can experience difficulty in daily living and often require a formal medical diagnosis in order to access support.

This presentation uses a case study approach to explore the experience of navigating the SEN system for families with children with AS or HFA. The fight/struggle metaphor is discussed in relation to accessing health, education and social care services. It is suggested that the system is adversarial, not only in practice, but in the way it is structured and the foundations it is built on.

Timmons, S., Hobson-West, P. University of Nottingham

The sociology of the veterinary medicine profession: Exploring the similarities and differences with human healthcare

The study of veterinary medicine presents a variety of interesting challenges to the sociology of health care professions. To date, it has largely been neglected by sociologists, despite being a high-status profession with extremely competitive entry, and a major role in protecting animals and humans through bio-security. Vets themselves see medicine as the profession closest to their own, and model many of their activities on medicine. Unlike most of the health care professions vets appear to have little in the way of threats from competing occupational groups. A high degree of occupational closure has been in place in the UK since 1881, with, for instance, veterinary nurses being completely under the control of the Royal College of Veterinary Surgeons, the regulatory body for vets.

Perhaps the most intriguing issue is veterinary medicine’s relationship with the state. While all other professions, especially in health care, have seen greater regulation and control in the last 40 years, the vets appear to have been left alone. The fact that the current legislation governing vets dates back to 1966 is evidence of this, with a review of this Act being considered, but rejected by the government recently. In this paper we will present an analysis of why veterinary medicine appears to have been able to survive in this ‘unreformed’ position for so long. We will also draw conclusions about what this means for the sociology of the health care professions more generally, and for our understanding of the relationship between medicine and the state.
Trusson, D.  University of Nottingham

On the Borderline: Women’s Experiences After Treatment for ESBC/DCIS

It is well-known that illness can disrupt lives and identities but less is known about the period when active treatment has ended and yet patients cannot be said to be ‘cured’. Taking as its starting point Bury’s (1982) concept of illness as a biographical disruption, this paper argues that disruption does not end with the completion of acute treatment. I will describe my ongoing research which considers the transition from patient to a liminal state, on the borderline of health and illness; a disruption that is poorly understood in medical and academic terms.

23 women who have undergone treatment for early-stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS), were interviewed using feminist methodology and a narrative approach. Preliminary findings suggest that women continue to experience themselves and their lives as disrupted as the effects of treatment become embodied reminders of their experience, and both current and potential relationships are affected.

Societal expectations of behaviour and an impetus to ‘move on’ comes not only with the completion of treatment but reflects the current push towards happiness in society generally (Ahmed 2010) and a ‘pink positivity’ within breast cancer culture in particular (Ehrenreich, 2009). Women may experience this as oppressive when trying to come to terms with a changed body they feel they can no longer trust, in a situation where they feel that the end of active treatment has coincided with the withdrawal of social support.

Tubaro, P., Casilli, A.A. University of Greenwich

Problematising pro-ana: a study of eating disorders on the web

In the last decade, the escalating number of personal websites, blogs and discussion forums appealing to persons with anorexia nervosa and bulimia nervosa (“ana” and “mia” in web parlance) have puzzled both health practitioners and policy makers. While offering emotional and practical support to persons living with eating disorders, these online communities sometimes grow into pro-ana or pro-mia advocacy groups employing distinctive rhetorics revolving around self-determination and empowerment motives.

Our study focusses on the role of computer-mediated communication networks in the spread and maintenance of eating disorders. We have fielded an interactive survey inviting users of French-language pro-ana/mia websites to provide information about their personal networks and their health-advice network, together with questions on their eating behaviours and IT usage. To gain a better insight into the subjects’ relational structures and health behaviours, in-depth interviews have also been conducted.

The paper presents the first results of the analysis. The response rate has been encouraging, mostly from women, 22 years old on average, geographically evenly distributed, and with a wide range of eating disorders. Online networks seem however to provide substitute for follow-up therapies or to compensate for inadequate treatments. Sizeable overlaps between online and offline social graphs are visible, online ones making for a complementary social structure. More interestingly, resort to online or offline ties for support depends on the stage of advancement of the disorder and the level and type of care received.

Public health implications are discussed.
**Friday 16th September 2011**

**Death & Dying**

Westminster Building Room CWE124/2

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**Tubridy, J.**

*Independent Consultant*

**Questioning Identity:**

**Personal Connections with Alzheimer's Disease**

**QUESTIONING IDENTITY**

Personal connections with Alzheimer’s Disease

This paper has emerged from my experience over the last six years in taking ‘time out’ from my work as a researcher, with a PhD in Sociology, to care for my elderly parents. In that sense, it follows in the tradition of Julius Roth’s (1963) classic, *Timetables*, in which he used his experience as a TB patient to explore the structuring of time in hospital careers.

The particular issue which I address is the way in which identities are challenged by perceptions of Alzheimer’s Disease and dementias as forms of ‘social death’.

My lived experience with my father strongly suggests that there is a very different paradigm within which people with Alzheimer’s Disease and dementias can be perceived. This is one in which the emphasis is on maintaining ‘connection’ with the individual and the continuities within his/her social identity. This is an approach which is very much advocated within the work of cultural anthropologist, Dr. Phil Stafford of the Center for Aging and Community in Indiana as well as by Memory Bridge Foundation, founded in the US in 2004.

Within this paradigm, Alzheimer’s Disease and dementia are not viewed as an ‘ending’ and the focus is on the capacity of people with Alzheimer’s Disease and related dementias to maintain emotionally meaningful relationships. Taking this approach, identities remain intact but what alter are modes of communication. Thus, ‘father’ and ‘daughter’ may communicate using social ‘memory bridges’ such as poetry, music, photography, food, and touch, as well as ‘conversation.’

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**Thursday 15th September 2011**

**Science Knowledge & Medicine**

Westminster Building Room CWE218

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**Tutton, R.**

*Lancaster University*

**A history of futures in personalized medicine**

In the first decade of the twenty-first century, personalized medicine became a powerful vision of how medicine should be practiced in the near future. Its advocates imagine significant changes to the way that drugs are developed by industry and prescribed to patients, to the early detection and prevention of disease, and to doctor-patient interaction. We might locate the rise of personalized medicine within a broader trend of ‘biomedicalization’ (Clarke et al 2010) that entails both the stratification of patients and the customization of prevention, diagnosis and therapy. As sociologists have argued, today’s future expectations are prefigured through a long history of events, material practices and ‘past futures’. Personalized medicine is no different: while visions of a future personalized medicine are defined in opposition to the past, these visions are also prefigured by previous discourses of personalization in medicine. The paper focuses on the ‘person-as-patient’ initiative in the early twentieth century that was a response to the perception of medicine becoming a ‘high tech’ and impersonal science that neglected the ‘art’ of clinical practice and failed to properly take account of the social determinants of health and disease. For advocates of this perspective, individual variability repudiated the idea that medicine could be predicated entirely on a scientific basis. Clinical practice required an ‘artistic’ as opposed to a ‘scientific’ mode of thought and practice. Drawing on this account, the paper discusses how visions of personalizing medicine have changed over time in relation to ongoing epistemic contestations between laboratory and clinical medicine.
Wagner, E.  

Johannes Gutenberg-Universität Mainz

Healthcare Ethics Committees as Emotional Self-Government

This paper shows how the critique of the physician and medical decision making in Health Care Ethics Committees in Germany operates in the modus of emotions and not in the modus of better knowledge and arguments. The critical talk in these committees takes the shape of feelings instead of better arguments. This is not only the case in the critical talk of medical lay participants of the committees. In their case this kind of emotional turn would certainly be expectable. The astonishing thing is that the physician himself seems to apologize for his medical expertise and turns over to emotional communication as a committee-member. This seems to contradict the way in which Sociology traditionally conceptualizes the practice of critique and public discourse. For Habermas it is the better argument and the justified reason which generates critique and public discourse. It is the constriction to the monolithic Reason which Habermas sees emerging in public debate. The critical medical discourse in German Healthcare Ethics Committees instead multiplies the way critique on medical decision making can be gained and produces diverse speakers who can not be restricted to the one Reason Habermas sees emerge. Thus ethical participation democratizes the modus in which medical decision making has traditionally operate: the modus of the better reason. The paper shows this finding on the basis of interviews with participants of for healthcare-ethics-committees in Germany and ethnographic protocols of committee-meetings. The findings are the result of a triannual research project financed by the German Research Foundation (DFG).

Wahaj, Z.  

University of Glasgow

“But I am not an ‘ordinary’ widow”: Lives of HIV infected widows in Pakistan

AIDS is a disease of promiscuity in the collectivist society of Pakistan. It therefore demands complete secrecy even from the wider kin. In the event of an HIV infected widow whose husband’s HIV status was kept in secrecy till his death and even after that, she is left with to carry the burden of the disease, and its secrecy. This makes her experience of living as a widow with HIV even more complex. This paper is based on the interviews that I carried out with HIV infected widows. These women were young widows of Gulf migrant workers, and had remained married for an average of three weeks to four years. Findings show that these widows see themselves as different from an ‘ordinary’ widow because of an added layer of HIV to their widowed status. The narratives of these women show that due to the maintenance of secrecy, they are afraid of remarrying since their remarriage would threaten the maintenance of the secrecy of the disease, they fear the loss of sympathy from other women and therefore cannot share their ‘real’ grief of living as HIV infected widow with other women, and they fear becoming a source of bringing dishonor to their natal families in the event of leakage of the secrecy of their HIV infected status.
Deliberation and preservation: the role of tissue banking in the decision to donate eggs and embryos for stem cell research

This paper will draw on data from two studies: one by Waldby and colleagues which asked women in fertility treatment about their preparedness to donate oocytes and embryos for stem cell research; and one by Ehrich, Williams and colleagues (2010) which compared willingness to donate fresh or frozen embryos to stem cell research. In the first study, ART patients were distinctly unwilling to donate oocytes, and in the second, patients were equally unwilling to donate fresh embryos. However both study groups were willing to donate frozen embryos after their fertility treatment had terminated. I argue that this pattern of willingness and unwillingness to donate point to the decisive role that cryopreservation plays in patient deliberation in this area. The ability to bank tissues creates a capacity to both defer and rationally apportion reproductive potential. Hence it creates a margin for deliberation which is not present in the case of fresh embryo or oocyte donation. While much bioethical inquiry focuses on the ontological or religious value of reproductive tissues as the decisive factor in donor preference, it is evident from these studies that the pragmatics of tissue storage trump these considerations in shaping potential donors preparedness to give. While the oocyte donation group demonstrated an entirely instrumental valuing of their oocytes, simply the means to an end, and both groups demonstrated an appreciation of the special status of the embryo as the beginning of human life, it was in fact the capacity to bank tissue or not that determined preparedness to donate them to stem cell research.

Mechanistic versus Natural Body imagery in the Context of Contraceptive use

The images and metaphors that we use to comprehend the physical and social world around us shape our understanding of that world. Although prominent in sociological research into health and illness, this social and linguistic understanding of our actions has been largely neglected in clinical practice. This research looks at the images used by contraceptive users to communicate their ideas about their own bodies and considers how these images interact with biomedical body imagery. Sixteen women and eighteen men were interviewed about attitudes to the body and about contraceptive experience. Interview analysis was undertaken based on an Interpretive Phenomenological Approach. This paper discusses one of the five overarching themes which emerged from the data, that of the ‘mechanistic versus natural’ image of the body. There is considerable dissonance between the mechanistic body image presented by biomedical discourse and the ‘natural’ body image drawn upon by some lay users of contraception. It suggests that this dissonance may inhibit successful communication between clinicians and lay users of contraception. Furthermore those users of contraception who draw upon a ‘natural’ body image in this research expressed particular discomfort with the concept of hormonal contraception. For a minority of women hormonal methods may present such obstacles in terms of self and bodily definition, that they are not used consistently or effectively. If clinicians were able to identify patients who draw upon a ‘natural’ body image, they might empower such patients by discussing and emphasising non-hormonal contraceptive methods, if hormonal methods seemed unacceptable.
**Wednesday 14th September 2011**

**Experiences of Health & Illness**
Westminster Building Room CWE126/1

**Walker, L., Price, E.**  
University of Hull

**Transitions to Illness: The Early Stages of SLE**

This paper reports on preliminary findings from a qualitative study that explores the lived experience of chronic illness, specifically Systemic Lupus Erythematosus (SLE). SLE has received limited attention in the sociological literature, despite there being some 50,000 people diagnosed with the condition in the UK. It is a condition that has the potential to disrupt normative life expectations and this research explores the transition to an illness identity. This is a qualitative study organised into three phases. The first is an on-line research blog established for the project where participants were asked to respond to five discussion threads. The second includes narrative interviews with people diagnosed with SLE and the final phase involves interviews with health and social care professionals. In this paper we will present our findings from phase one. We will focus specifically on our respondents’ accounts of their early symptoms of SLE and their experiences of acquiring a diagnosis. In this research we explore our respondents’ 'transition to illness' – this paper charts the early stage of this journey which appears to characterised by continual drift and transition between health and illness; legitimacy and illegitimacy, fear and doubt.

**Thursday 15th September 2011**

**Mental Health**
Westminster Building Room CWE124/1

**Ward, J., Bailey, D.**  
Durham University

**Improving outcomes for women who self-injure using an action research approach in a women’s prison**

The prison setting provides both a custodial and a clinical environment and prison staff of all disciplines are required to meet a range of clinical needs including those relating to mental health and self-harm. Due to the custodial nature of the environment however many of the initiatives that have become part of the clinical culture, such as service user involvement, have not been realised in prisons. This has lead to the Sainsbury Centre to highlight that service user involvement in the prison system is still in its infancy. This paper outlines an research project which utilises an action research approach, engaging both the staff and women who use self-injury, in an English prison. Both staff and women identify gaps in therapeutic interventions and opportunities for the development of services in prison. Recommendations for improvements included more meaningful activity, increased equivalence of care through access to self-care items, accessible staff training and targeted support of staff dealing with self-injury. The findings also suggest that women in custody are enthusiastic to participate in action research, a little used methodology in the prison setting. They have insightful experience to offer in improving care outcomes and the associated benefits of this collaborative approach are discussed.
McDonaldisation or Restratisation: new modes of medical control within a ‘liberated’ health economy?

This paper contributes to and makes connections between theories related to the bureaucratization and the re-stratification of medicine. Taking as its focus plans to ‘liberate’ the UK National Health Service through diversifying and pluralising the mixed economy of care, it draws on the recent experience of Independent Sector Treatment Centres to explore how contemporary reforms might impact on the control of medical work. Within these private sector providers the research finds, on the one hand, enhanced standardisation and rationalisation of medical work through the use of more commercial and protocol-driven pathways that tightly specify clinical roles and responsibilities. These subject medical work to increased forms of bureaucratisation, coupled with enhanced management legitimacy to influence both the content and context of practice. On the other hand, the study finds evidence of restratification as doctors assume leadership roles within these private sector providers. These ‘elites’ are active in the application of protocols to direct and control colleagues performance. The findings suggest the creeping McDonaldization of medicine through pressures to deliver a commercially-viable business and customer service. Unlike those assuming leadership roles, however, the clinicians most clearly subject to such bureaucratic control tended to occupy perceived ‘low status’ positions in terms of speciality, nationality and years of service. Moreover, those acquiring leadership roles were also found to more often be shareholders or directors within the parent companies or subsidiaries of the private healthcare providers. Like those in General Practice, this might suggest a new form of ’commercial restratification’ within hospital medicine.

'A lot of the things we do ... people wouldn't recognise as health promotion': health promotion in settings of neighbourhood disadvantage.

Health promotion is a profoundly social science: the science of clinical practice and the application of evidence-based medicine to improve population health; and an engagement with socially-situated subjects via techniques including community engagement and development and partnership building. The latter is particularly important for working with the most disadvantaged populations. This presentation explores tensions that are being generated between the science and practice of health promotion. The tensions involve, on one hand, the increasing professionalisation of health promotion as a specialised set of activities and technical knowledge for disseminating health information, and emancipatory struggles for broad-based goals of equality, which include but are not confined to health equalities. This latter approach targets the social factors that contribute to health inequalities and emphasises goals of community empowerment through community development. I explore these tensions in qualitative data that were gathered from health promotion workers and lay community members involved in an area-based initiative that included aims to reduce health inequalities associated with socio-economic disadvantage. The findings revealed two distinctive approaches to community engagement for health promotion which are characterised as ‘procedural’ and ‘cooperative’. Procedural approaches maintained clear differentiation between lay communities and professionals, imposed predefined channels for community input, relied on ‘off the shelf’ health promotion packages, suggested limited insights into the constraints of people’s circumstances, and placed strong emphasis on developing horizontal professional partnerships with other service providers. In contrast, cooperative processes were grounded in empathetic understanding of the impact of socio-economic and other disadvantages on everyday life, inclusive approaches to partnership-building, and focussed on developing ground-up, locally-relevant health promotion initiatives. The findings explore the characteristics, opportunities, challenges and implications of these approaches and build evidence for the benefits of cooperative approaches for promoting meaningful community involvement and empowerment, improved health outcomes in disadvantaged communities and enhancing staff satisfaction and success in health promotion initiatives.
**Empathic understanding through creative interactions: Making meaning of mental health in public art galleries.**

This paper is based upon a series of ethnographic observations conducted at one of the UK’s largest public modern art galleries with patients from an acute mental health ward. It charts the experiences of patient participants as they navigate the spaces of the gallery; interweave with other public patrons; and fashion expressions of meaning from the various installations and exhibits.

Discussion considers how patients with their carers and gallery curators, used the public spaces of the art gallery and its objects to rearticulate a sense of self-identity less controlled or dominated by their psychopathology; and extracted and assembled a highly personalized, emotional and often critical biographical narrative through creative abstraction - using the art work as an orienteering/translation device inducing empathic understandings of their mental health and its impact in framing their social subjectivities and role as public citizens.

Forms of aesthetic abstraction were therefore mobilized to unpack, demythologize and destigmatize the complexity of patients’ mental health issues, providing a communicative channel to ‘rationalize’ aspects of their behaviour self-identified as ‘irrational’ or aberrant yet reflected as a normative dimension of their being members of an integrated public. In other words, the abstract and public qualities of the gallery were studied for their potential in generating a secure and therapeutic space for personal catharsis and ‘momentary-epiphanies’, which were collectively engineered, yet individually conceived. Finally, these sessions were considered for their prospect as learning events, especially where gallery practice might be transported back to positive effect on the ward.

**Exploring the working role of hospice volunteers**

Volunteering is now a regular feature of health and social care service provision with volunteers working in diverse contexts such as day care centres, ‘after school’ clubs, hospitals and hospices. The promotion of the idea of an active civil society by successive UK governments has led to the professionalisation of some voluntary work as the product of a partnership between the voluntary sector, government and business. More standardised working practices and semi-formalised aspects of voluntary work have changed the experience of volunteering because, as Morrison (2000: 109) argues, ‘there is a particular and very significant tension between a professionalised managerial approach and a more traditional volunteering ethos’. Volunteers have a well-established place in palliative care, particularly in the hospice setting. Using a case study approach, this paper discusses the diverse roles of volunteers in palliative care highlighting the increasing importance of their work to the successful delivery of hospice services. Issues such as volunteer motivation, training, support, accountability and ethical concerns regarding establishing and maintaining boundaries, are considered. Evidence from the case study suggests that ‘being valued on a professional level’ and ‘doing something useful’ are key motivating factors. The emotional burden of this volunteer work is explored and points to the need to establish personal and social boundaries to help maintain resilience in this sensitive care setting. Whilst there is a high level of commitment by volunteers to the work of hospice, evidence points to the need to nurture these contributions that cannot be taken for granted.
Weaver, S. J., Martin, G.  
University of Leicester

The influence and interplay of structure and agency in achieving medium term sustainability

Offering early results on a qualitative, comparative case-study research project of four sites in which novel ways of delivering genetics services were developed, this paper will outline descriptions of structure and agency in interviewee accounts of developing, or failing to develop, a sustainable service. There is growing evidence on the challenges of introducing new ways of working into complex organisational environments such as the NHS. This considers the difficulties of achieving changes in professional bureaucracies infused with powerful institutional forces, and the interventions that can be developed in order to increase the likelihood that such changes are accepted by diverse stakeholder groups who determine success or failure. The four genetics services were developed as pilot initiatives funded by the Department of Health. The paper will account for the importance of structural constraints and facilitators, such as the national climate, local politics, accessible funding, and the existence of networks, alongside a discussion of the importance of individual agency, as exhibited in dynamic and charismatic personalities, original thinking, exceptional working practice, evidence collection and network building.

Will, C. M., Weiner, K.  
University of Sussex

An Experiment in Self-Care: Practices of Preventive Health and Over-The-Counter Statins

This paper offers an empirical assessment of a ‘failed’ policy experiment: the decision, in 2005, to reclassify low dose statins to make them available without prescription, i.e. over the (pharmacy) counter. Following limited uptake of the first licensed product, which resulted in its withdrawal in 2010, we present data from interviews with some of the rare people who did purchase it, and with people who accepted or rejected prescription statins for cardiovascular risk reduction in the same period, as well as commentary from pharmacists and other health care professionals. Drawing theoretically on recent work by Annemarie Mol, we explore the different identities for the statin user that emerge in these accounts, and the wider logics that inform everyday practices and technologies around monitoring and maintaining (heart) health, to consider the implications of this experiment for other attempts to promote the self-care agenda in the field of prevention.
Willis, R.  
*London School of Hygiene and Tropical Medicine*

**Good food and bad air: lay and professional perspectives on young children’s health in indigenous Peruvian Achuar communities**

This paper explores how young children’s health and well-being is created and sustained amongst Achuar communities in the Peruvian Amazon. It is based on a mixed methods ESRC/MRC funded PhD study of social and environmental determinants of indigenous children’s health. Semi-structured interviews were conducted with 28 families and 30 local stakeholders in a remote rural case study area undergoing social and environmental change driven by extractive industry.

Amazonian discourses of child health and well-being draw on understandings of a child’s body as the product of careful physical and social formation, derived from the cultural knowledge and appropriate social behaviour of parents and other community members. Failure to behave appropriately – through lack of knowledge, lack of consideration, or intervention of uncontrollable outside influences – contributes to children’s’ ill-being or illness symptoms. Among communities in this case study, this local belief system combines with evangelical Christian and western biomedical explanations to pattern explanations of young children’s well-being. In contrast, local health professional’s discourses of child health reflect international priorities in low-income settings; malnutrition, sanitation, infectious disease diagnosis and treatment.

Despite these differences in conceptual approach, both lay and professional groups identified food and protection from the environment as key to creating and maintaining young children’s health and well-being. Less agreement was found regarding who holds responsibility for these factors and who has ability to control them. The implications of these different perspectives for health policy both in the case study area and for other isolated communities exposed to rapidly changing environments is explored.

Woolven, M.  
*ENS Lyon (GRS)*

**Diagnosing dyslexia: a medical process?**

The Diagnostic and Statistic Manual of Mental Disorders provides criteria for diagnosing “reading disorders”, also referred to as dyslexia. In France and the United-kingdom, practices of identification of such reading difficulties are relatively consistent with the diagnostic definition; yet, they are never strictly medical as they involve other practitioners. Furthermore, research into the aetiology of dyslexia resort to other theoretical and practical tools and consequently bear little resemblance with the diagnostic definition.

The purpose of this paper, based on a current PhD research, is to question the assumption that dyslexia might only be a mere form of medicalization of educational underachievement, by considering the actors and technologies which contribute to its identification or diagnosis, and assessing their implications, focusing on discourse as well as practices. The empirical data includes interviews and observations in diagnostic settings (in both countries) and the study of professional literature.

The point will first be to understand, in a socio-historical perspective, how the identification of reading difficulties results from a division of labour between different professions (medical doctors, educators, psychologists…). Then, I will analyse the implications of asserting the medical-biological nature of dyslexia (as opposed to educational or social causes), in terms of actors’ interests and norms. I will finally study the use of technologies in the aetiological definition (neuroimaging…) and practical identification (psychometric testing…).

My purpose is to better understand the relations between aetiology and diagnosis through a case-study, which may be relevant to medical sociology more generally.
Wednesday 14th September 2011 14:45 - 15:15
Tissues/Blood Westminster Building Room CWE017

Wright, J., Dixon-Woods, M., Eboral, H.I University of Leicester

The Battle of the Standard: Competing standards for cancer tissue banking

International calls have been made for organisations that collect, store and transport human tissue samples for research purposes to standardise their practices to enable more effective scientific collaboration. Cooperation between cancer tissue banks could encourage higher quality samples and data, allow larger, more powerful research projects to take place, and provide opportunities for rare cancers to be studied. However, lack of standardisation and non-cooperation remain the prominent features of the field. We seek to use ethnographic data and social science theory to explain why.

We map current standards for cancer tissue banking – from international organisations to individual labs – identifying both the source and the motives of these standards. We present preliminary findings from ethnographic research in two NHS teaching hospitals to address the question of which standards are followed in practice, and why. We locate non-cooperation with standardisation in the mundane practices of everyday organisational life, and also in wider institutional battles about scientific collaboration. We show that standardisation in cancer tissue banking is not a simple matter of technical specification, but is subject to structuring by institutional and organisational contexts and the norms and values governing scientific cooperation.

Thursday 15th September 2011 14:35 - 15:05
Cancer Westminster Building Room CWE124/2

Ziebland, S. B., Chapple, A., Evans, J. University of Oxford

The role of the internet for people with pancreatic cancer: a qualitative study of an illness with a very poor prognosis

The aim of the study was to explore the role of the internet for patients with pancreatic cancer to help us understand the potential negative effects of the internet for people with a life threatening illness. Qualitative semi-structured interviews were collected throughout the UK with 32 people with pancreatic cancer and 8 relatives of people who had recently died of pancreatic cancer.

In contrast to our 2004 study in which people using the internet for cancer information were aware they were in a vanguard, internet use is now routine. People with pancreatic cancer and their relatives talked about using the internet for health information as if it were an unremarkable part of life. People used the internet for a wide variety of purposes before and after the consultation, in ways that were similar to studies of other cancer patients. However the limited treatment options encouraged some to look for experimental treatments and clinical trials on the internet and the poor prognosis caused alarm to those who stumbled across on-line survival statistics (including those on sites run by voluntary organisations). Patients gave no other examples of harm, nor of damage to relationships with health professionals, from using the internet. Patients and family carers reported strategies for handling alarming information, including asking partners and family to filter what they found. It is probably counter-productive to try to steer people away from the web; instead clinicians might recommend websites and be open to discuss what patients and their families have found.
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**French Women Surgeons and feminist attitudes**

As American female surgeons studied by Joan Cassell (1998), the French one’s are a minority: about 10% of the surgical population. In both national contexts, female students in surgery are always suspected of being less involved in their jobs as they are potential mothers, they are discredited in advance in matters of physical capacities, and are considered as to weak emotionally to “cope” in this difficult profession, but their reacted to this male ostracism in very different ways. A few years ago, a French female surgeon tried to federate her female colleagues in a professional organization of women following the example of the Association of Women Surgeons (AWS) in the USA, but this project failed. We can analyse the success of the AWS and the failure of the French association as the affirmation of two kinds of feminism. Therefore, we can speak of a position of universalist feminism to characterize French women surgeons, while American women surgeons impose themselves with an essentialist feminist position (Gubin et. al., 2004).