

**Alderson, P., Hawthorne, J., Killen, K.**

**Institute of Education, University of London**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 11.55 - 12.25*

### **TIME IN THE NEONATAL UNIT**

One in ten babies in Britain stays in special or neonatal intensive care units (NICU), with concerns about their future welfare and neuro-development, especially for those born <18 weeks early. Our research, 'Foretelling Futures: dilemmas in neonatal neurology', studied how practitioners and parents talk about the babies' present care and uncertain futures. Concepts of time pervade the highly technical NICU and discussions: counted and costed clock time, rhythms of natural time, and elastic perceptions of social time. 'Born out of time', premature babies wait and grow towards their discharge date. NICU staff try to synchronise babies' natural functions with mechanically regulated optimal clock timings. In the four observed NICU, flexible or strict organisation of the babies' care and the parents' access differed markedly according to clock, natural and social time. Some units offered more flexible individual care for babies, besides psychological support to help staff and parents to reflect on present difficulties and future uncertainties. Scarce resources and staffing accentuate clock time's inexorable pressures. If the baby dies, a lifetime is compressed in retrospect into a few days or weeks. When babies survive, their potential disability is quantified by the calendar time lag behind normal - how much later and slower the child's development might be - and the extra time-burden on parents and health services. Prognoses are informed by longitudinal life-course studies that look back from recorded futures already past. Time perspectives illuminate complex problems for the adults who organise and discuss the babies' current and future healthcare.

**Allen, K.**

**Leicester University**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

### **MANAGING THE BODY: HEALTH AND THE EXPERIENCE OF CHILDREN WITH PRADER-WILLI SYNDROME**

Prader-Willi syndrome (PWS) is a chromosomal disorder, which has among its clinical sequela an increased interest in food, which may develop into an insatiable obsession (likened to an addiction). Unless diet is carefully controlled, weight gain can be very rapid, leading to obesity, disease and early death. Control of diet is crucial to the management of PWS, but this is something, which is difficult to achieve since the majority of sufferers also experience borderline to moderate learning disability and developmental delay.

In practical terms the research aims to extend existing knowledge of the everyday problems that are faced by those with PWS and their families during childhood and adolescence, paying particular attention to dietary control. This is important since even though guidelines have been developed for the management of hyperphagia (increased appetite), knowledge of how children and their families actually cope with dietary regimes and deal with problems of weight gain and body image tends to be anecdotal rather than systematic. Moreover little is known about how social circumstances impact the management of PWS. Significant variations are possible, for example, in terms of the socio-economic resources of the household and the family structure.

As well as providing a practical contribution to management of diet and PWS, the research aims to extend sociological understanding of the experience of chronic illness and the body in childhood. It draws together hitherto largely unconnected research literatures on the sociology of childhood, food and dietary control, genetics, disability and the body.

**Arber, S., Marshall, H., Raats, M., Lumbers, M., Davidson. K.**

**University of Surrey**

*Stream: Lifecourse*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**OLDER PEOPLE, FOOD AND HEALTH: THE IMPACT OF GENDER AND SOCIAL NETWORKS ON THE QUALITY OF FOOD CONSUMPTION IN LATER LIFE**

Food is essential to health and well-being, yet there has been relatively little research on how social factors influence the pattern and quality of food consumption in later life. Gender roles and relationships fundamentally impact on food consumption, but we know less about how this changes when an older person is widowed or no longer has a partner to share or prepare meals.

This paper examines the pattern and nature of food consumption among older people; first, how this is influenced by gender and degree of embedment in social networks of family and friends; second, how food consumption patterns are linked to health, and whether this differs by gender and partnership status.

The paper analyses data on 80 older people (40 men and 40 women, equal numbers living alone and with partners), drawn from an EU-funded study (Food in Later Life, QLK1-CT2002-02447). One week food diaries measure d patterns and nature of food consumption and how this varies by gender, whether the older person lives with a partner, and whether food is consumed with family and friends. Extensive health data were collected, including SF-36, which is linked to the quality and nature of food consumption, and the older person 's embedment in social networks. Patterning of food consumption differs by gender and partnership status, and is associated with differential health status. Social networks of family and friends influence quality of food consumption, particularly among older people living alone, but in gender differentiated ways.

**Arber, A.**

**University of Surrey**

*Stream: Health Service Delivery*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**BUILDING REPUTATION: THE SIGNIFICANCE OF PAIN TALK IN HOSPICE AND PALLIATIVE CARE TEAM MEETINGS**

My research is concerned with understanding, from a sociological perspective, how palliative care professionals talk about pain. I position my research as an ethnography of institutional discourse. I have taken an ethnomethodological approach to how everyday life in palliative care teams is organised through language (Miller 1997). Using tools taken from linguistic analysis I focus on how talk about pain shapes the boundaries of professional work with patients in pain. Such talk enables one to understand how pain is constructed by the professionals as 'pain in the body', as well as the 'person in pain'. Through talk-in-action that focuses on pain, a space is opened up that enables the palliative care team to develop a unique identity around expertise related to pain, and in this way they build a reputation for themselves and for palliative care. By use of linguistic and rhetorical resources palliative care professionals' construct their competence by comparison with those who do not have this expertise. Analysis of "pain talk" enables an understanding of how expertise and identity is negotiated. The expertise that is made visible in the talk is primarily biomedical expertise but other forms of expertise are also made visible through psychosocial talk. I conclude by arguing that the 'total pain' concept discussed within palliative care is more visible in texts than in practice.

**Ariss, S.**

**University of York**

*Stream: Inequalities*

*Friday the 17 September 2004 at 15.45 - 16.15*

### **LOCATING THE 'PROBLEM' OF FREQUENT ATTENDANCE IN GENERAL PRACTICE**

The General Practice consultation is recognisable as a 'service request-service response' type of interaction. Even in situations where no explicit request is made, the patient's presented problem is treated by the practitioner as a request for medical services. There are also many other ways in which the participants both demonstrate their orientation to the interaction as comprising a request, which then makes an appropriate response relevant. In simple terms this 'request-response' structure is reflected in the medical model of the consultation which develops from problem presentation through the examination and onto diagnoses and treatment decisions.

Using a combination of interviews, questionnaires and conversation analysis of recordings of actual consultations, this paper analyses General Practitioner's difficulties with frequently attending patients. Whereas some patients' frequent consultations were justified by their GPs, other patients were considered to attend "more often than they should". 'Legitimate' frequent consulting was justified not only on the grounds of the patient's illness but also on the grounds of what resources the doctor could draw upon in order to respond to the patient's requests.

In the majority of cases in which the patient was considered to attend too frequently, the practitioner expressed feelings of powerlessness and inefficacy regarding their ability to respond to the patients' problems. However, these feelings of helplessness had little impact upon the way in which the consultation was conducted, in many ways these consultations were treated as straightforward 'request-response' types of interactions. These findings have implications regarding more appropriate consulting methods for frequently attending patients.

**Armstrong, N.**

**University of Nottingham**

*Stream: Cancer*

*Friday the 17 September 2004 at 11.55 - 12.25*

### **'I'D BE ABSOLUTELY AMAZED IF I GOT IT': HOW WOMEN DISCUSS THEIR RISK OF DEVELOPING CERVICAL CANCER**

In this paper I explore how individual women discuss the likelihood of them developing cervical cancer and engage in a process of self-positioning with regard to their own personal feelings of risk and/or vulnerability to the disease.

While current NHS policy guidelines suggest that all women between the ages of 20-64 years should have a cervical smear test at least every five years, I will use qualitative interview data to show how women negotiate and work out their own personal relationships to cervical screening based on perceptions of their individual risk. Within these interviews women discuss their personal feelings of risk and/or vulnerability drawing on such themes as genetics/family history, sexual activity, general health, and screening history. These considerations allow women to explore their relationship to cervical screening and to position themselves both in relation to the medical discourse and to other women.

Finally, I will consider what this self-positioning means for individual women's attendance for cervical screening and, therefore, whether a perception of risk is an adequate explanation for screening attendance.

**Arnado, J., Arnado, M.A**

**De La Salle University, Philippines**

*Stream: Mental Health*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**MENTAL HEALTH AND COPING BEHAVIOR OF INTERNALLY DISPLACED WOMEN IN SOUTHERN PHILIPPINES**

As part of the global war on "terror", the Philippine government has embarked an all-out war on the Moro Islamic Liberation Front in Mindanao, displacing almost half a million individuals including women and children. Simply dismissed as casualties of war, internally displaced persons are usually left on their own to cope with the economic and psychological effects of war. In this time of great turmoil, women provide care to their families, while leaving their own mental health needs unattended. This unattended mental problem, for example, resulted in death, as in the case of Jamaliah Acoon, a mother of twelve, who took the lives of her two youngest children inside their house, a few weeks after returning from the evacuation center.

This is an ongoing study which aims to examine the impact of war on the mental well being of women, as well as their coping behaviour. The study utilizes focus group discussions with 40 internally displaced women in Central Mindanao. The result of this study hopes to bring out the extent of mental health care needs of internally displaced persons not only within the evacuation centers, but more so, after they have settled back to their daily routine. In this new millennium, where terrorism is part of everyday life across the globe, the mental health and coping behaviour of innocent lives caught in armed conflict is very much relevant to sociology of health.

**Attree, P.M.**

**Lancaster University**

*Stream: Inequalities*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**CHILDHOOD DISADVANTAGE AND HEALTH INEQUALITIES: PARENTS' PERSPECTIVES ON 'MANAGING' POVERTY**

The importance of lay perspectives in influencing the UK government's health policy agenda is increasingly recognised. This paper draws on a meta-synthesis of qualitative research, to explore the strategies which disadvantaged parents use to help care for their children. A wealth of evidence indicates that children's health and life chances are strongly related to the socio-economic circumstances of their parents - poor children have shorter life expectancies and experience greater morbidity. How parents 'manage' in impoverished circumstances influences not only their own health, therefore, but also that of their children. Survey evidence, while useful in painting the broader picture, does not provide any sense of the everyday reality of coping with caring for children in poverty. This paper synthesises a small, but important, body of UK qualitative research that prioritises the accounts of parents managing in hardship, addressing the following topics:

- How do low-income parents 'manage' caring for children in impoverished circumstances?
- What are the 'costs' of managing for their own health and that of their children?

The paper describes how disadvantaged parents perceive, react to and deal with adverse circumstances, highlighting in particular the challenges faced by lone parents. It examines both the material and moral dimensions of managing in poverty, against a backdrop of gendered inequalities in both public and private domains.

This paper is based on research carried out for an NHS funded postdoctoral research fellowship, as part of a series of reviews intended to resource the public health evidence base.

**Audrey, S., Holliday, J., Campbell, R., Parry-Langdon, N.**

**University of Bristol**

*Stream: Methods*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**IMPLEMENTING PROCESS EVALUATION WITHIN A RANDOMISED CONTROLLED TRIAL TO EVALUATE A SCHOOL-BASED, PEER-LED SMOKING INTERVENTION**

It has been argued that Randomised Controlled Trials (RCTs) using only quantitative research methods to measure outcomes are inappropriate to evaluate the effectiveness of health promotion initiatives. The value of an integral process evaluation, asking questions about how an intervention is implemented, what its strengths and weaknesses are, and what activities occurred under what conditions is increasingly recognised. A mixture of qualitative and quantitative research methods enables researchers to consider not simply 'what works' but 'what works for whom under what circumstances?' ASSIST (A Stop Smoking in Schools Trial), which involved 11,000 students in 59 schools, combined peer education with diffusion of innovation theory to develop a school-based health promotion intervention. Year 8 students (12-13 year olds) identified as influential by their peers were trained to encourage non-smoking behaviour through informal conversations with other students in their year.

In this paper we discuss the research context within which the ASSIST process evaluation was developed, and describe the design and application of the process evaluation embedded within the RCT. Data were collected from students, teachers and health promotion trainers using a variety of methods including questionnaires, interviews, focus groups and non-participant observation. We identify some of the challenges encountered as the process evaluation was implemented and outline ways in which these challenges were addressed. To conclude, we make a number of suggestions which may inform good practice for future similar trials.

**Backett-Milburn, K., Airey, L., McKie, L.**

**University of Edinburgh**

*Stream: Gender*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**INTERSECTIONS OF HEALTH, WEALTH AND CARING FOR WOMEN IN THEIR FIFTIES**

The current cohort of women in their fifties has experienced profound changes in expectations of careers and family commitments. The fifties may also be differentially experienced by social class and gender, reflecting increasingly complex and diverse experiences of social and economic structures. Moreover, mid-life boundaries in general are shifting in terms of the social conception of women's ageing and what this means for their own conceptions of, for example, health, well-being and caring roles and how these intersect with their socio-economic circumstances and trajectories. A small qualitative study was carried out in Scotland in 2003, exploring how women aged 50-59, in differing socio-economic circumstances, perceived, managed and constructed the cultural, economic and health intersections of ageing.

Nineteen women were recruited, including some who were relatively isolated as well as those involved in varied forms of cultural expression/consumption. Previously we have presented on methodological issues. In this paper we report our substantive findings, focussing on how work and family commitments influenced the reported well-being of these mid-life women. Contradictions between respondents' expressed views and reported experiences are explored, which help to illuminate the ambiguities of roles and expectations for women in their fifties. Family, caring and work roles remained salient but, for most, there was an increasing feeling that this was a life-point where their own personal goals were becoming more salient. However, it was evident that women in their fifties are subject to differing structural and cultural constraints which intersect with their health, well-being, relationships and family lives.

**Badlan, K.**

**University of the West of England, Bristol**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 14.00 - 14.30*

**AN EXPLORATION INTO THE LIFE EXPERIENCES OF YOUNG ADULTS LIVING WITH CYSTIC FIBROSIS**

This aim of this qualitative, phenomenological study was to explore how adults live with cystic fibrosis and the impact this has on adherence to treatment regimen. Thirty - one adults participated in semi-structured interviews which were transcribed and the data collected was analysed using interpretative phenomenology. Emerging themes indicated that managing a life with a chronic illness as demanding as cystic fibrosis is complex. Factors considered as 'within Self' that appear to impact on adherence included: the need to integrate into society and aspirations to be 'normal'; establishing internal control and self - responsibility and developing coping strategies that enabled positive adaptation. 'External to Self' factors included the attitudes of one's peer group, parents or significant others; attitudes of the healthcare professionals; difficulties encountered with employment and financial restraints imposed by the illness.

Improvements in treatment regimen have dramatically increased life expectancy, however this has also increased the burden of care impacting on ones' quality of life. The findings of this study suggest that complete adherence is rare and is affected by a multitude of factors, set within the context of each individual's unique life experience. Healthcare professionals, particularly those working in the field of chronic illness, need to understand not just the objective medical management in delivering care, but they also need to develop further insight into the subjective experience of living with cystic fibrosis. Only then can their clinical practice evolve to one that truly empowers those for whom they care to determine how best to live their lives.

**Ballard, K.D., Gabe, J., Elston, M.A.E.**

**King's College London**

*Stream: Lifecourse*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**IF YOU CAN'T BEAT IT, WHY BOTHER TRYING? WOMEN'S EXPERIENCES OF AGEING DURING MIDLIFE AND THEIR USE OF AGE-RESISTING ACTIVITIES**

Much of the ageing literature is rooted in the notion of an age-resisting culture where individuals aspire to a youthful body image. Different 'masking' theories offer explanations about the ways individuals experience physical indicators of ageing and their impact on identity. Implicit in these theories is the idea that individuals are motivated towards creating a youthful image.

Following analysis of women's accounts of ageing during midlife, we identified two aspects of ageing - 'public' and 'private' - both having a distinct impact on the use of age-resistance. We suggest that public ageing is visible, arising from physical changes in the appearance of the body (i.e. greying of hair, wrinkling of skin). These changes have the potential for concealment, for some time at least, through a multitude of age-resisting activities. Private ageing is less visible, arising from physiological changes within the body (i.e. joint stiffness, reduced memory, the menopause, increased tiredness). We found that although women recognised that the flexible nature of the body in public ageing provided them with the potential for age-resistance, they also experienced the rigidity of the body associated with private ageing. This not only led to women's submission to growing old, but also deterred them from participating in age resisting activities.

Whilst masking theories focus on the experience of public ageing and the potential malleability of the body, this study highlights the importance of private ageing and the impact of this more rigid body on the use of age-resisting activities.

**Bancroft, A., Wilson, S., Cunningham-Burley, S., Masters, H., Backett-Milburn, K.**

**University of Edinburgh**

*Stream: Risk*

*Friday the 17 September 2004 at 11.55 - 12.25*

**MINIMISING HARM, MANAGING RISK: RESILIENCE AND CONTINGENCY AMONG CHILDREN OF DRUG AND ALCOHOL MISUSERS**

Children exposed to similar risks have a variety of outcomes. The concept of resilience was developed to describe the qualities contributing to relatively successful outcomes. We explored 'resilience' through the accounts of 38 young men and women (15-27 years old) who had a drug or alcohol misusing parent, examining the strategies adopted in adversity. We examined the combination of their own agency and the help they were able to draw on from other sources.

Respondents had been in a range of situations from better to worse, but all had attempted to enact strategies to deal with their experiences. The extended family, neighbours, friends and some service workers were able to fill some of the roles that substance-using parents could not. People that could help included: a parent who 'cared about' them; some relatives from the wider family network; siblings; neighbours; teachers; friends and friends' families; and people to love and care about themselves. Safe places to go to escape, such as friends' homes were also valued. The supports on which they could draw were seldom unconditional or long-lasting. Exclusively 'protective' factors were difficult to identify: most had some element of contingency to them. Resilience is an under-theorised concept that needs to be understood in terms of the choices and contingencies in children's own lives.

Project funder: Joseph Rowntree Foundation

**Banner, D.**

**University of the West of England, Bristol**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**DONE AND DUSTED: WOMEN'S EXPERIENCES OF WAITING FOR CORONARY ARTERY BYPASS SURGERY**

Coronary heart disease is a leading cause of mortality and morbidity for men and women within the United Kingdom. It is known to affect over 1.2million women, accounting for 54,491 female deaths in 2001 (British Heart Foundation, 2003). Historically, coronary heart disease has been presented as a disease primarily affecting men and consequently women have been overlooked in the media, health education and clinical research (Lockyer and Bury, 2000).

Increasing numbers of women are suffering with CHD and requiring cardiac surgery, yet little is know about their experiences. Consistent with the aims of the National Service Framework for Coronary Heart Disease to identify the service user's experience, this study seeks to explore the experience of women undergoing coronary artery bypass surgery (Department of Health, 2000 and National Assembly for Wales, 2001).

This paper examines first-stage data from a longitudinal qualitative study exploring the illness trajectory of a group of women undergoing coronary artery bypass surgery from two centres in England and Wales. Data has been collected from observation and semi-structured interviews and analysed using a grounded theory approach. The paper addresses women's interpretation and representation of coronary artery disease and will explore the illness trajectory of women waiting for coronary artery bypass surgery.

**Barbour, R.S.**

**University of Dundee**

*Stream: Methods*

*Friday the 17 September 2004 at 11.20 - 11.50*

**SHARPENING OUR FOCUS: A CRITICAL APPRECIATION OF FOCUS GROUPS AND QUALITATIVE RESEARCH**

A critical appreciation of the use of focus groups throws into sharp focus some of perennial dilemmas and challenges involved in doing qualitative research in the complex and diverse arena of health and health care research. This paper will examine the debates sparked by focus group research and will review its contribution both to medical sociology's knowledge base and development of qualitative methods. Debates about the use of focus groups methods illuminate fundamental issues concerning appropriate research topics, framing of research questions, matters of epistemology and methodology, politics, ethics, reflexivity and representation. It is argued that, whilst focus group studies can exacerbate the problems associated with the qualitative research endeavour, they also have considerable - and perhaps unparalleled - potential to interrogate time-honoured and often advocated qualitative research processes and to allow for critical and creative engagement with these. Topics addressed will include the concepts of 'purposive sampling', the 'constant comparative method', 'grounded theory', 'saturation', and 'theoretical generalizability'. The paper will aim to demonstrate that focus group methods, if employed thoughtfully, can produce qualitative research at its very sharpest.

**Barnes, M.C., Gabe, J.**

**Royal Brompton and Harefield Hospital/Imperial College**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**AN OUTBREAK OF OCCUPATIONAL ASTHMA; MAKING SENSE OF SYMPTOMS BEFORE AN OFFICIAL DIAGNOSIS**

Illnesses caused by work, unlike accidents that occur at work, are a neglected area of medical sociology. This paper, which is based on continuing doctoral research, explores various dimensions of the occupational illness experiences of a population of factory employees, among whom a large outbreak of occupational asthma occurred. Specifically, I explore the issue of how affected employees made sense of their symptoms before official recognition by the medical and factory establishments.

An ethnographic approach was used including extensive use of fieldnotes and 45 semi-structured, in-depth interviews. The interview sample reported here includes employees with occupational asthma who had either left the factory following diagnosis or had chosen to remain - their illness in some cases undisclosed to the factory occupational health staff. Field notes and interview tapes were transcribed and analysed using Atlas.ti.

During the early or 'pre-official' state, interviewees' description of causality could be broadly divided into internal and external factors. Internal factors included categories related to employees' own behaviours and lifestyles; external factors were those perceived as emanating from work structures or processes. These explanations were not mutually exclusive with interviewees drawing on various dimensions of each category to make sense of their symptoms.

Employees tried, rejected and associated many alternatives in attempting 'experiential coherence' in accounting for the causes of their illness. The findings interacted with a complex matrix of associated influences: employment status, job, length of service, gender and age.

**Bendelow, G.**

**University of Sussex**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 11.20 - 11.50*

**BREAST CANCER AND CAM'S: CHALLENGING BIOMEDICINE OR PALLIATIVE ONCOLOGY?**

Research on the role of complementary or alternative medicine in cancer is generally carried out under the rubric of surveys of CAM usage (CAM as a generic acronym encompassing a vast number of systems and practices of health care, which for a variety of cultural, social, economic or scientific reasons, have not been adopted by conventional biomedicine). Reviews of the major international medical journals indicate that usage of CAM by the general population has accelerated markedly in northern Europe, the US and Australia over the last decade. In cancer, the rubric of CAM covers a wide range of practices from psychological support, spiritual healing, relaxation and massage techniques, nutritional supplements and herbal remedies, as well as alternative forms of healing, and estimates of take-up vary between 40-80%. The demographic profile of cancer patients seeking CAM therapies tend to be well-educated females of higher socioeconomic status, thus women with breast cancer report higher than average usage. Oncologists stress the potential for financial and/or emotional exploitation and the lack of regulation of alternative remedies, whereas women report feeling more in control, more hopeful and more able to manage the inevitable emotional distress of the experience of breast cancer by experimenting with CAM's. This paper explores the tensions between the experiences of women, who find that treatments which focus on the interaction mind/body/spirit and quality of life very attractive, and the ambivalence (or even hostility) of the medical oncology orthodoxy.

**Berg, C., Meyer, J.L., Milmeister, M.**

**Centre d'étude sur la situation des jeunes en Europ, Luxembourg**

*Stream: RG15 and International Health*

*Friday the 17 September 2004 at 16.20 - 16.50*

**DIVERSITY OF YOUNG PEOPLE AND ACCESS TO WELL-BEING FIRST RESULTS FROM HBSC-STUDY  
SECONDARY ANALYSIS AND REPLICATION STUDIES**

We will give a brief outline of the design of and present first results from the DJAB 1 study which we started in June 2003 and which is mainly devoted both to secondary analysis and replication studies of the Luxembourg HBSC study. The idea is to investigate the relationship between diversity, inequality of the youth population and young people's health behaviour and their access to well being. The data basis consists of the original national HBSC-data which are broken up by different indicators of social and cultural inequality as well as by data from HBSC replication studies lead with marginal young people in different natural settings (soldiers, drug addicts in therapy, young people in enforced residential care, unemployed). The results we present come from selected domains: nutrition, drug abuse, leisure, well-being. The inquiry of each domain consists of the construction of relevant new variables (on the basis of the original HBSC questionnaire) and the comparison by different factors (language background, nationality, educational background, gender, social background, family affluence etc). We will confront the analysis of the representative sample with those of the deliberately biased samples. By the time also qualitative feed-backs from the institutions where the replication data have been collected will be available. The study wants to contribute in providing a knowledge-based frame for the targeted planning of educational and policy measures aiming at young people at risk.

**Blackshaw, T.**

**Thames Valley University**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 09.00 - 09.30*

**FATHER -IDENTITIES WITHIN THE UNITED KINGDOM PROTO-MIDWIFERY AND MIDWIFERY  
DISCOURSE: AN ARCHAEOLOGY OF MIDWIFERY KNOWLEDGE (1887-2000)**

The journal Nursing Notes has been in continuous publication since 1887, as such it can be viewed as being both expressive of the 'professional midwifery discourse', and a unique repository within which the unfolding midwifery discourse during the later part of proto-midwifery can be seen and read. Drawing upon the work of David Armstrong, and utilising Foucauldian discourse analysis, the proto-midwifery and midwifery discourse were 'excavated', This Foucauldian 'archaeological dig ' reveals much about the origins and location of the Midwifery Discourse. Through the selection and analysis of texts and statements it has been possible to dissect the construction and representation of Fathers in the midwifery discourse, and thus offer an account of the discursive shifts and formations in their regard.

This presentation will be examining; The conditions of possibility that established Midwifery as a discipline and enabled it first to recognise the husband and then the father within its discourse? The origins and characteristics of the subsequent discourse about fathers? The common misperception that fathers only appear within the midwifery discourse after the nineteen sixties? Thus the diverse ways in which fathers have been constructed and represented will be explored, illustrating the historically contingent nature of father-identities within the midwifery discourse, and thereby revealing that the father has always been present within midwifery discourse, not as an ahistorical entity, but rather as a fragmented subject.

**Borowiec, A.**

**National Institute of Cardiology, Warsaw, Poland**

*Stream: RG15 and International Health*

*Friday the 17 September 2004 at 15.45 - 16.15*

**HEALTH BEHAVIOUR OF THE MIDDLE CLASS VERSUS OCCUPATIONAL WORK**

The arising Polish middle class has recently become a subject of a great interest of Polish sociologists also those interested in health behaviour issues. Protestant Ethics which demands hard, systematic work in order to accumulate and multiply goods as well as to restrain from consumption is believed to be a basis of the western middle class development. Self-reliance and individualism are considered as important indicators of belonging to the middle class.

Healthy behaviour is a very important component of the western middle class lifestyle. However some results of Polish studies indicate that is not the case in relation to the arising Polish middle class which is not homogeneous as regards health behaviour.

The aim of my presentation is an attempt to answer the question whether the healthy behaviour of the arising Polish middle class is determined by self-reliance and individualism as well as declared tendency to behave in accordance with the Protestant Ethics.

The empirical data were collected during the study carried out in Warsaw, Poland in October 2003 among 500 people occupying the occupational positions which are characteristic of the middle class: owners, managers and professionals. Dimensions describing health behaviour were identified by means of a factor analysis. A multiply regression analysis confirmed the relationship between some dimensions of health behaviour and self-reliance, individualism and declared tendency to behave towards work in accordance with the Protestant Ethics.

**Bradby, H., Minnis, H., Varyani, M.**

**University of Warwick**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 15.45 - 16.15*

**GOSSIP, STIGMA AND MENTAL HEALTH. BARRIERS TO CAMHS USE BY A MINORITY ETHNIC GROUP**

A case note review of a community-based child and adolescent mental health service (CAMHS) showed an under-representation of patients of South Asian origin and suggested that the route of referral and eventual outcome differed compared to the ethnic majority (Minnis et al 2003). Six focus group discussions were convened with 35 people of South Asian origin who had child care responsibilities and no known contact with CAMHS. Participants were presented with vignettes of three emotional or behavioural problems typically referred to CAMHS and asked about sources of advice and courses of action.

All six groups were audio-recorded, translated and transcribed. The transcripts were coded for the types of advice, solution or treatment offered and for barriers that might hinder their pursuit.

All participants mentioned the GP as a pivotal figure for help-seeking and language was widely seen as a barrier to consultation. Despite this knowledge, statutory services were seen as unsuitable for problems with a complex social background. The main barriers identified to using any health services for children's emotional and behavioural problems were the fear of gossip and stigma. The suggestion that the quality of services was irrelevant to uptake by this minority group is discussed in the light of concerns about equity of access, uptake and the assessment of differential needs in diverse populations.

**Brady, G., Brown, G., Letherby, G.**

**Coventry University**

*Stream: Gender*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**TEENAGE PREGANCY AND YOUNG PARENTHOOD: LINKING RESEARCH TO PRACTICE AND PRACTICE TO RESEARCH**

In this paper we detail and discuss our experience of developing a training pack for health and social care professionals whose remit is to support pregnant teenagers and young parents. The impetus for this project came from the recommendations we made following a study of the ante, birth and post-natal experiences of young mothers in Coventry. We begin by outlining our approach to the development of the training pack including reference to content (e.g. challenging stereotypes, scenarios from the research, encouraging reflexive practice and young mother 'story boards') and trainer (i.e. members of the research team and young mothers) trainee relationships.

Following this we consider the practical and theoretical significance of the project to our continuing research in the area of teenage pregnancy and young parenthood. For our funders the development of the training pack is a practical outcome of our earlier research, for us it also impacts on our role as researchers and informs our future work and theoretical developments.

**Bridgens, R.**

**Cardiff University**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 11.20 - 11.50*

**SANGUINITY OR BITTERNESS? : NARRATIVES OF POLIO AND POSTPOLIO SYNDROME**

In a recent BBC radio programme, Tony Gould, who had polio and wrote a polio history, 'A Summer Plague', said, "one of the things that struck me most forcibly about all of us, really, was that we have quite a sanguine outlook on life and there is very little bitterness about the illness." How many people who had polio would agree with this?

In my study of polio illness narratives, interviews were conducted with 30 people who had had polio in childhood or early adulthood, and some also supplied diaries, stories, autobiographies and photographs. This paper will show, through spoken narratives and other media, the difficulties people had talking or even thinking about their experiences of having had polio. They found themselves, during childhood, in a liminal state, recovered but not quite recovered, knowing but not knowing that they were disabled.

Comaroff and Maguire (1981) wrote about childhood leukaemia, "an existing cultural bias within our wider society and our medical practice discourages overt acknowledgement of mortality and related fears." The social pressure to be positive leads to ambivalence, confusion and hidden vulnerability (Zola 1981), which some people can only express, if at all, in autobiographical or fictional writing. New weakness, fatigue and pain, called postpolio syndrome, has forced many people who had polio to rethink their childhood experiences and face what had been ignored at the time. Having seen themselves as 'sanguine', many began to recognise complex and mixed reactions, combining anger, sadness, fear or bitterness.

**Broom, A.**

**University of Leeds**

*Stream: Cancer*

*Friday the 17 September 2004 at 15.45 - 16.15*

**THE EMAL: PROSTATE CANCER, MASCULINITY AND ONLINE SUPPORT AS A CHALLENGE TO MEDICAL EXPERTISE**

This paper argues that experiences of, and attitudes towards, online communities are deeply embedded in understandings of masculinity, the perceived character of the Internet, and changes in the roles of the patient and the expert within decision-making processes. Drawing on the accounts of a group of Australian men with prostate cancer and prostate cancer specialists, this qualitative study explores experiences of and attitudes towards online support groups. Results point to three unexplored and important factors influencing how both patients and clinicians perceive and experience online support. First, online support groups provide some men with a method of managing constraints posed by dominant constructions of masculinity within their experiences of prostate cancer, allowing for increased sharing and intimacy by limiting inhibitions associated with face-to-face encounters. However, other men view online support groups as havens for deception and misinformation, and computer-mediated communication as a highly problematic form of social interaction. Lastly, this paper shows how some medical specialists experience online support groups as a threat to their expert status and control over decision-making processes, outlining the nature and possible implications of their responses to this threat.

**Buckley, E.J., Jones, P., Morrall, I., Morris, C., Silcox, P., Pugh, R.N., White, D.W.**

**Staffordshire University**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**THE EFFECTS OF COMMUNITY BASED SYPHILIS SCREENING AND HEALTH PROMOTION ON GAY MEN'S SEXUAL RISK TAKING BEHAVIOUR**

**Background**

During 2003 there were 54 new cases of syphilis detected in Walsall, which usually has 1 to 2 cases per year. Approximately 70% were detected in men who have sex with men (MSM). The incidence of sexually transmitted infections (STI) in MSM has been increasing in the past ten years, suggesting an increase in sexual risk behaviours within this population. This research aimed to increase awareness of syphilis, encourage screening for STIs within a community setting (a sauna frequented by MSM), and to determine whether the dissemination of health promotion alongside screening in the community will reduce the incidence of STIs.

**Methods**

Questionnaires measuring sexual risk behaviours, knowledge of HIV and syphilis, and screening history were distributed to MSM in the sauna. Once questionnaires were completed, men were offered sexual health screening, and provided with information about the symptoms of syphilis and its transmission.

**Findings & Implications**

163 questionnaires were completed (98% response rate) by gay and bisexual men. There was a high incidence of sexual risk behaviours (98%), low use of GUM services (46%) and significant knowledge gaps about risks of contracting syphilis from specific sexual behaviours (only 18% were aware of all potential routes of syphilis transmission). This clearly identifies a need for interventions in this group using innovative methods, for example service delivery in community settings. Follow up studies are being implemented to re-examine knowledge and behaviours after the screening and health promotion, and also to qualitatively examine reasons for sexual risk behaviours, these findings will also be presented.

**Budge, F., Harris, C.**

**University of Plymouth**

*Stream: Ethics*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**ORPHANED ETHICS FOR ORPHAN DISEASES?**

Inherited metabolic diseases (IMD's) are a special subgroup of diseases that form a large heterogeneous group of over 1300 known genetic disorders. Most of these diseases are rare, but collectively they impose a substantial health burden on society. Encouraged by orphan drug legislation, recent advances have, for the first time, made it possible to biomedically correct the metabolic deficiencies of IMD's by the use of exogenous drugs. Treatments for metabolic diseases such as neuronopathic Gaucher disease (type 3) and Nieman Pick (type C) are currently undergoing clinical trials. We are clearly entering a new era of treatments for IMD's. From our experience of working with IMD's, various ethical and social issues have arisen. Some of these are already in the public arena, such as access to treatment and the high cost of such treatment. Other issues are more subtle and have become apparent to those, like us, who are involved in research and treatment of IMDs. These include, amongst others, (non-) standardisation of treatment regimes, emergence of influential support groups, the role of ethical committees given the global reach and strategies of pharmaceutical companies, informed consent for developing children, drug trial durations, protocols and inclusion/exclusion criteria. Different stakeholder groups are likely to have differing perspectives on these issues and how best to reconcile competing priorities and interests. As research on treatments for neurometabolic diseases looks set to increase dramatically, we feel that a consideration of ethical practice in relation to research into and applications of treatment is urgently needed.

**Bullers, S.**

**University of North Carolina at Wilmington, USA**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**ETHNIC, SEX, AND COHORT DIFFERENCES IN DRINKING NORMS IN THE U.S.**

The literature concerning ethnic differences in alcohol consumption patterns in the U.S. suggests that there are ethnic differences in alcohol consumption rates as well as in differences in gender disparities in drinking rates. This study uses eighteen in-depth interviews to examine differences in alcohol consumption norms among three ethnic groups focusing on inter-generational and gender differences. The sample includes one male and one female from each of three cohorts (those born in the 1930's, 1950's, and 1980's) for each of three ethnic groups (White, African American, and Hispanic). Descriptive statistics are presented on perceptions of normative quantity, frequency, type, stigmas, and drinking environment for these groups, as well as perceived changes over time.

**Cameron, E., Mathers, J., Parry, J.**

**University of Wolverhampton**

*Stream: Primary Care*

*Thursday the 16 September 2004 at 15.20 - 15.50*

### **THE CONCEPT OF 'WELL-BEING' - TIRED, DANGEROUS OR PROMISING?**

This paper raises some questions about the concept of 'well-being' - its meaning, status and usefulness across a range of arenas and settings.

We present selected findings from a two year study in the Black Country and Shropshire, funded by the Department of Health under its Health Inequalities Programme, which aimed to find common ground between communities and professionals about 'measures' of health. As part of the research, discussion of 'well-being', other health concepts, and influences on health took place in 27 two-stage focus groups.

We link findings and comparative analysis of community and professional perspectives around 'well-being' to notions of 'well-being' found in the wider context. We reflect on the increased and widespread use of 'well-being' across a range of spheres including public health and the media, and the concept's many interpretations and applications. The term continues to be fruitful in contributing to an understanding of health as both a social construct and as socially constructed, and may also inform the challenging and important search for better health measures. However, in many arenas, including much of public health, we suggest the term is typically ill-defined, over-worked and unhelpful, or, arguably, its use may be actively misleading. Greater conceptual clarity in the use of health concepts generally, and 'well-being' in particular, especially within the arena of public health, is needed and also timely, given tensions between the increasing use of broad psychosocial health frameworks and the pressure for better health measurement and evaluation of health interventions.

**Cane, R.S., Abraham, J.W.**

**University of Sussex**

*Stream: Risk*

*Friday the 17 September 2004 at 11.20 - 11.50*

### **GENETICALLY ENGINEERED MICE AND THE CARCINOGENIC RISK ASSESSMENT OF PHARMACEUTICALS**

Assessing the risks of new products such as pharmaceuticals poses major challenges at the interface of medicine, science and politics. Non-clinical carcinogenic risk assessment is particularly fraught with technical uncertainties because predicting whether substances are likely to cause cancer in people typically involves extrapolation between different species and time spans. Indeed, the extent to which such risk assessment should be entirely the province of scientists is open to question. In this context the construction of the science of carcinogenic risk assessment needs to be scrutinised and related to wider matters of social judgement, such as public health policy and ethics. Drawing on 53 interviews with toxicologists, geneticists, regulators, and representatives from industry and other NGOs, plus extensive documentary research between 2001 and 2004, in this paper we examine the role of new genetics and associated networks of expert scientists in government and industry in altering the scientific standards of carcinogenic risk assessment in the EU, US and Japan during the 1990s. Specifically, we consider the public health implications of the introduction of genetically engineered mouse models as replacements for long-term studies in rodents, together with subsequent attempts to 'validate' these new forms of carcinogenic risk assessment. This is, in effect, a new regulatory science in the making with far-reaching public health consequences with major problems as yet unresolved technically or politically.

**Carmel, S.**

**University Hospital Lewisham**

*Stream: Health Technologies*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**KNOWLEDGE AND PRACTICE: THE CRAFT OF HIGH TECHNOLOGY MEDICINE**

This paper presents an answer to the question 'how can the relationship between knowledge and practice in medical work be conceptualised?' A traditional conception of this relationship posits medicine as an amalgam of 'science' and 'art' (e.g. evidence-based medicine is scientific; clinical decision-making is an art). However, a synthesis of sociological conceptions of the term 'craft' reveals that this term is particularly apposite for medical work in intensive care. The term both captures the way that knowledge is used in medical practice (the application of knowledge) and connotes the practical and material aspects of work (the interaction with the material world). These two aspects of 'craft' are elaborated by an analysis of ethnographic data collected on three intensive care units.

The application of knowledge was seen in that medical workers need to make prompt, often immediate, interpretation of all kinds of 'evidence', including non-written information and machine and laboratory readings. By contrast, formal text-book knowledge was hardly explicitly implicated in their routine work, and is assumed to be somehow internalised.

The interaction with the material world was seen in that ICU workers demonstrate considerable skills in relation both to their practical work with machines and bodies and the embodied manual skills they have learnt. Many of the doctors in ICU had a characteristically hands-on approach. Furthermore, junior ICU practitioners could be seen to develop their knowledge about medical equipment and technology in an apprenticeship manner.

**Chapple, A., Ziebland, S., McPherson, A.**

**University of Oxford**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 10.45 - 11.15*

**STIGMA, SHAME AND BLAME: A QUALITATIVE STUDY OF PEOPLE WITH LUNG CANCER**

**Introduction**

Some research suggests that stigma ascribed to controllable causes elicits greater negative reaction than when stigma is ascribed to uncontrollable factors. This paper explores the contexts in which people with lung cancer described stigma and ways they attempted to resist blame.

**Design and setting**

Qualitative interview study in UK.

**Participants**

Forty five people with lung cancer, recruited through general practitioners, consultants, and support groups.

**Results**

The people interviewed for this study, for [www.dipex.org](http://www.dipex.org), experienced stigma commonly felt by people who have other types of cancer. In addition, they felt particularly stigmatized because lung cancer is so strongly associated with smoking. Many people, particularly those who had given up smoking years ago, or had never smoked, felt unjustly blamed for their illness. Those who resisted victim blaming maintained that the real culprits were tobacco companies. Some people concealed their illness, which sometimes had adverse financial consequences, or made it hard to gain support from others. Some suggested that recent newspaper and television reports may have added to the stigma surrounding lung cancer. Television advertisements usually portray a dreadful death, which may exacerbate fear and anxiety. A few people were worried that diagnosis, access to care and research, might be adversely affected by the stigma attached to the disease.

**Conclusion**

Efforts to help people to quit smoking are most important, but clinical and educational interventions should be presented with care, so as not to add to the stigma experienced by people with lung cancer and other smoking related diseases.

**Charles-Jones, H., Latimer, J.**

**The School of Primary Care, University of Manchester**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 16.55 - 17.25*

**JUST BY LOOKING, JUST BY LISTENING: TELEPHONE TRIAGE AND THE EXTENSION OF NURSES' EXPERTISE AND IDENTITY**

The paper examines nurse telephone triage, to explore how this 'new technology' elicits changes in nursing expertise and identity-work.

The paper presents analysis of data drawn from an ethnography of organisation and patient care in three general practices (Charles-Jones 2003). Some nurses in this study are able to assess patients 'just by listening'. The analysis revisits nurses' accounts and practices from an earlier study (Latimer 2000). In this earlier study nurses, in an acute medical unit, emphasised how they know 'just by looking' what patients need. Patients' meanings were converted into the visible, while the auditory was relegated to supplementing the visible or even got transformed into the visible in the mind's eye. However, according to the nurses, knowing 'just by looking' depended upon face-to-face interaction. The question addressed in the current paper is how do nurses know what patients' needs are when they are assessing them on the telephone? Specifically, we explore how the telephone mediates nurse-patient interaction, and whether telephone triage in this case elicits an extension or reconstruction of nursing expertise and identity.

**Clayton, J., Ruston, A.**

**University of Greenwich**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**PROFESSIONALS' PERCEPTIONS OF THE IMPORTANCE OF JOINT WORKING IN TACKLING HEALTH INEQUALITIES IN A LONDON BOROUGH**

A health mapping exercise conducted in a London borough revealed that residents living in some areas had consistently poorer health than those in the rest of the borough. Sociologists continue to be challenged by the study of inequalities in health, and in response to this exercise a social audit was conducted in order to assess needs in these areas and identify ways in which these needs could be met.

A social audit attempts to reveal the health or quality of life in particular communities, which results from the interplay of public services, housing, employment, the environment and other relevant factors. A key challenge in tackling health inequalities is working in partnership across traditional boundaries and in the course of interviewing key public sector workers, community leaders and others who were seen to potentially influence the wider determinants of health, respondents were asked about interprofessional or joint working, and its role in the work of addressing health inequalities. A number of local initiatives were identified which represented good practice in partnership working, and respondents talked of the benefit both to the wider community and to individuals of good communication between public sector professionals. The financial implications of having joint budgets meant scarce resources could be used to best effect to help communities under stress, and joint working was also seen to provide support to professionals working under difficult and challenging circumstances.

**Coleman, C., Lohan, M.**

**Trinity College Dublin**

*Stream: Lay/Professional Interface*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**EXPLAINING OF THE ABSENCE OF THE LAY VOICE IN PUBLIC HEALTH THROUGH SOCIOLOGICAL THEORIES OF HEALTHCARE**

This paper seeks to use sociological theory to present different perspectives on why the lay voice has been conspicuously under-represented in public health and, in particular, in sexual health services. The paper arises from an on-going empirical study of the use of contact tracing amongst men who have sex with men in the context of a syphilis outbreak in Dublin and is developed in a partnership between a health practitioner in the field and a sociologist. The value of the paper is the way in which it presents different social theories of health and healthcare so that a panel of explanations for the relative absence of the lay voice in public health measures and alternative scenarios of change can be compared and contrasted. We begin with a structural functionalist model, which justifies the division between lay and expert and the dual expectations and obligations on both parties. We move to a Foucauldian account which, of course, problematises public health medicine, including the specific area of sexual health, as a form of surveillance and control by the state. We then move to critical theory and, in particular, the communicative action theory of Habermas as a means of exploring disjunctions of life and system worlds in public health. We finally develop the critical theory approach by drawing on the theoretical and empirical research of critical men's studies and queer theory. This is a body of work which has developed 'life-world' perspectives through explorations of sexuality and health in the context of men's lives.

**Collin, J.**

**University of Montreal, Canada**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 09.00 - 09.30*

**PRESCRIPTION DRUGS USE AND THE ELDERLY: THREE METAPHORS**

Medication use-to relieve physical and psychic pain, prevent disease, improve health, and enhance performance-depends on a host of medical and non-medical factors that are in constant interaction. Thus, the growing consumption of drugs and the continually expanding volume of their use give rise to a number of questions, especially for certain population groups like the elderly. This increase in use is accompanied by an obscuring of the boundary between the normal and the pathological. Moreover, it raises questions about the construction of knowledge about drugs, the role of the media (particularly Internet) in legitimating consumers' viewpoints, and its potential to move boundaries between professional and lay knowledge and to change the balance of power in the patient-physician relationship.

To advance the understanding of social processes that shape the increasing importance of medications in everyday life in our societies, this paper will focus on the case of the elderly. It seeks to make a contribution to sociocultural approaches to the issues linking aging and prescription drugs and is based on research results coming from different studies I have conducted in this area. The paper uses three metaphors to analyse the perceptions of medications among the elderly: "obligation-medication" as qualifier of the relationship that older people have with prescription drugs; "concession-medication" as backdrop to the therapeutic relationship between physicians and older patients; and finally "compassion-medication" as metaphor for the role psychotropic drugs play in determining the status of the elderly.

**Cotton, A.**

**St Martin's College of Higher Education**

*Stream: Risk*

*Friday the 17 September 2004 at 10.10 - 10.40*

**WOMEN STEALING FOR DRUGS MONEY: INVINCIBILITY OR RECKLESS RISK TAKING?**

This paper has been developed from an ethnographic study which draws upon women's narratives of heroin use. A significant emerging aspect of data is explored: notions of invincibility, feeling powerful in the face of risk taking behaviours associated with illicit drugs use. The discussion will draw upon primary data which illustrates with almost paradoxical poignancy, the reckless sense of single mindedness experienced by women participants, whose perception of their need (for money for drugs) would seem to have the effect of undermining judgements of self preservation.

"Yeah you do feel worried you know you're taking something that isn't yours and you know why you're doing it and you think... if you get caught... when you do need the money, and you're ill through not having no heroin, you know, you don't feel as if anybody's gonna catch yer. You feel, you know, you're just gonna get it and get out of the shop quick... you know.."

The discussion will allude to issues of ambivalence, being swept along by one's desires and needs, yet almost knowing, but not acknowledging one's folly...

"and then you know you've got no money at all so you need to go shoplifting to support your habit all week because you need it 7 days a week and you need it about 2 or 3 times a day"

**Cox, D.**

**University of Central England, Birmingham**

*Stream: Health Policy*

*Friday the 17 September 2004 at 14.00 - 14.30*

**RACE AND HEALTH POLICY IN BIRMINGHAM - MANAGEMENT STRATEGIES AND RESPONSIBILITIES**

The presentation reflects on the way in which race issues have been " managed" within the Birmingham health economy since 1987. McNaught (1988) shows the failure of one health authority to come to grips with a strategy for either ethnic minority employment in health care or ethnic minority health needs. Committee membership is downwardly mobile and strategies fall apart. The author's experiences as an lecturer, CHC member, academic manager, serial committee member, conference organiser and PCT chair throws up many parallels. There have been series of local policies, strategies and activities as well as top down policy initiatives including The Vital Connection (2000) and Sir Nigel Crisp's recent Race Equality Action Plan for the Department of Health. To an extent the demographic transition in the City, alongside the impact of the Race Relations Amendment Act, is finally driving race equality issues higher up the managerial agenda. Cornelius' (2002) classification of Equal Opportunities and Managing Diversity approaches is helpful in analysing this history. Examples of current issues on employment and management development are outlined. The value of the Capability Approach (Cornelius 2002, Sen 1999) as an underlying conceptual framework enabling a PCT or a health economy to link equalities to choice, public participation, staff involvement and regeneration will be assessed.

**Cresswell, M.**

**University of Manchester**

*Stream: Mental Health*

*Friday the 17 September 2004 at 10.10 - 10.40*

### **IS THERE A CONTINUUM OF SELF-HARMING BEHAVIOURS?**

From the mid-1980s in the UK 'Psychiatric Survivors' have constituted a 'new social movement' consisting of psychiatric 'patients' and their allies. They have developed a distinctive knowledge-base, largely derived from personal experience, and opposed to that of 'official' professional expertise. Specifically, this paper focuses upon the 'official' category of Deliberate Self-Harm (DSH) and its correlative 'survivor' critiques. DSH refers to a range of non-fatal self-injurious behaviours (e.g. overdoses) which are today considered a public health concern. A key 'move' in the survivor critique is the thesis that there exists a continuum of self-harming behaviours (e.g. smoking too much, working too hard etc.) of which DSH is but one. If the argument holds, the potential import is to normalise a behaviour usually considered to be psychopathological. Moreover, for survivors, acceptance of the continuum concept necessitates a move away from the psychopathological status of DSH towards a concern with the 'rights' of self-harmers and the various perceived injustices from which they suffer. So, apropos DSH, this paper traces the development of 'the continuum concept' in a range of recent UK survivor publications (e.g. Louise Pembroke, Diane Harrison, Sharon Lefevre) and contrasts these with 'official' medical texts (e.g. Gethin Morgan, Keith Hawton). Theoretically, the question of DSH, normality and psychopathology is framed within the perspective of the French history of medicine/psychiatry tradition of Georges Canguilhem (*The Normal and the Pathological*) and Michel Foucault (*Madness and Civilisation/The Birth of the Clinic*), including recently translated work of the latter on normativity (Abnormal, 2003).

**Cunningham-Burley, S., Kerr, A., Burgess, M., Tutton, R.**

**University of Edinburgh**

*Stream: Genetics*

*Saturday the 18 September 2004 at 09.00 - 09.30*

### **CONSTRUCTING THE MORAL ARENA IN FOCUS GROUP DISCUSSIONS ABOUT GENETICS**

Legal and ethical analysis tends to dominate policy-making about genetics. Little is known about the everyday moral accounting of the diverse range of people who shape and are affected by policy and genetics. Although greater emphasis has been placed on public engagement, this has tended to focus on conclusions and values rather than the social context of their practical reasoning. In this paper we begin to characterise these processes by exploring what we have termed 'the moral arena' that people construct and inhabit as they discuss the governance of genetics, in particular issues related to access and ownership of genetic information. Drawing on data from nineteen small focus group discussions, we examine the types of arguments, ontologies and principles that people mobilise. For example, we analyse how appeals to 'the public good' are structured and used in different ways, by different people. We also explore how the familiar themes of ethics, such as 'the slippery slope', human rights, unintended consequences, attribution of responsibility and prevention of suffering form part of the moral arena. By comparing across different groups (which involved a range of so-called 'lay' and 'expert' participants) we also consider how such themes are mobilised and constrained in specific discursive contexts. To conclude, we reflect on the implications that this everyday moral accounting has for the professional arenas of policy-making and ethical analyses as well as public engagement in genetics.

**Davies, J.P.**

**St Cross College**

*Stream: Mental Health*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**ILLNESS AETIOLOGIES AND THE SUSTAINING OF CULTURAL TRADITIONS**

As a medical/social anthropologist I shall talk on the culturally diverse ways in which illness aetiologies are articulated and understood (points of comparison: Western biomedicine, psychoanalysis, and West African divination). My purpose being to show how understandings of aetiology are intimately tied to wider social beliefs, values, and institutional agendas.

Naturally, where we locate the cause of distress will influence all subsequent remedial intervention. If we locate the cause in psyche then our curative response will be via psychological means, if in body, then, in the West at least, predominantly via biomedical; and again if the source is seen in the supernatural world then at this domain curative action will be levelled. The neatness of this formulation is of course compromised if we notice that many curative systems are to differing degrees multi-causal - namely, they postulate several causes acting together. This means that individual, natural, social and supernatural causes need not be mutually exclusive, but are often linked together in a particular case. In such instances where no such strict first cause is postulated, I shall argue we must think in terms of a primary cause - that is, each curative discourse gives primacy to one causal domain over another. The method of identifying where any curative discourse locates its primary cause is to notice where it principally directs its alleviative action.

The methodological importance of the 'primary cause' I shall argue as by showing how it unravels patient experience, practitioner socialisation, and how it corroborates the perpetuation of curative traditions.

**De Maio, F.**

**University of Essex**

*Stream: RG15 and International Health*

*Friday the 17 September 2004 at 16.55 - 17.25*

**THE SOCIAL GRADIENT IN HEALTH IN ARGENTINA: EVIDENCE FROM THE 2001 ENCUESTA DE CONDICIONES DE VIDA (SURVEY OF LIVING CONDITIONS)**

**Background**

Income inequality is an important social determinant of health in advanced industrialized countries, and its importance for the middle-income countries of Latin America is now being examined. This paper lays the foundation for forthcoming multilevel analyses of the health effects of income inequality by examining the shape of the social gradient in health in Argentina.

**Methods**

Secondary analysis of the 2001 Encuesta de Condiciones de Vida (Survey of Living Conditions). Analysis was limited to respondents aged 18 years or over (N = 24,715 in N = 13,421 households). Two-level random coefficients logistic regression models were used to identify factors associated with poor self-reported health.

**Results**

A significant gradient in self-reported health status was observed by income quintile, with respondents in the lowest quintile being most likely to be in poor health (OR = 1.59), followed by respondents in the 2nd (OR = 1.45), 3rd (OR = 1.25), and 4th (OR = 1.22) income quintiles, compared to respondents in the 5th income quintile. This relationship remained significant after controlling for age, sex, marital status, education, employment status, type of health insurance and region. However, the effect of regions is surprising, with respondents from the North-East, one of the poorest regions, having significantly lower odds of reporting poor health.

**Conclusion**

The presence of a social gradient in health in Argentina is not surprising - however, important regional effects are also observed in these data. Further multilevel analyses are warranted to determine if income inequality is at the root of these regional effects.

**Denny, E.**

**University of Central England, Birmingham**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**'MY BODY'S LETTING ME DOWN' LIVING WITH ENDOMETRIOSIS: A PROSPECTIVE STUDY**

This research is concerned with women's experience of endometriosis, a long term gynaecological condition that causes severe pain. The first stage of the research used a storytelling approach to allow women to explain the effect of living with endometriosis on their lives, and the lives of those around them. The second stage is a prospective study following women over the course of one year in order to capture the changes in women's lives brought about by living with endometriosis and experiencing various treatments. Using the results of the first stage of the research a more structured baseline interview schedule was developed, which is followed up by interviews after 6 months and 1 year. In addition a diary is kept for one month during the year by those women willing and able to complete it. This paper utilises one of the theoretical frameworks of the research, the sociology of the body, in order to explore the empirical data on the way in which living with endometriosis, in particular the experience of chronic pain, affects perceptions of the body. This is also influenced by discourses of pain in which women are perceived as being able to 'cope' with pain (Bendelow 1993) and where menstrual pain, in particular, is viewed as a 'normal' part of being a woman (Denny 2004).

**Dingwall, R., Vassy, C.**

**University of Nottingham**

*Stream: Health Service Delivery*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**IN THE HEAT OF THE NIGHT: 'LA CANICULE', SCIENCE AND ORGANIZATIONAL FAILURES**

It is now established that the early August 2003 heatwave in France led to about 15,000 excess deaths. This mortality spike led to a political crisis in France about the adequacy of the state's response to an unforeseeable epidemic. Given the available Anglophone literature on heat-related death, not least Klinenberg's prize-winning book on the 1995 Chicago heatwave, the claim of unforeseeability must be questionable. This paper approaches the epidemic as a case study in organizational failure. Following the work of Turner and Pidgeon, Perrow, Vaughan and others, it asks how the agencies of French government failed correctly to assemble and interpret the emerging information. Why were the public health, health care and public order networks unable to bring together the emerging evidence of a sudden rise in the death rate among older people? What lessons might be drawn for the preparedness of UK health agencies to deal with a similar experience, which is now a reasonably foreseeable consequence of global warming?

**Drennan, V., Humphrey, C.**

**Royal Free & UCL Medical School**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 10.10 - 10.40*

**ARE DOCTORS DOMINANT OR NURSES SUBSERVIENT IN LOCAL NHS DECISION MAKING BODIES?**

Two occupational groups are pivotal to the provision of formal health care internationally: doctors and nurses. Analysis of the relationship between these two groups has long been the subject of sociological enquiry. The empirical challenges to theories of medical dominance of nurses are drawn from hospital environments and the clinical care interactions. Many of these studies discuss doctors and nurses as though they were homogeneous occupational groups and medical and nursing activities uniform irrespective of cultural or organisational context. Primary health care in the UK has a range of organisational features that set it apart from the organisation of medicine and nursing in institutional hospital care. General practice has a significant percentage of women, which is very different from the more obviously gendered division of labour in hospitals. This paper draws on historical and empirical data to examine the relationship between doctors and nurses in primary care rather than acute care and in local NHS decision-making bodies rather than in clinical care activities. It then draws on empirical data from eight local decision making bodies (PCGs) to analyse: The nature and extent to which medical dominance is structured and enacted in these settings. The nature and extent of the nurses exhibiting subordinate group behaviours and strategies (using a) Cohen and b) Friere theoretical frameworks).

**Duerden Comeau, T.**

**University of Western Ontario, Canada**

*Stream: Gender*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**BRITISH SURGEONS, CANCER DISCOURSE AND CONCEPTUALIZATIONS OF GENDER IN THE NINETEENTH CENTURY**

This paper examines how conceptualizations of gender influenced British surgeons' descriptions and classifications of cancerous disease. Medical sociologists and feminist scholars working from a social constructionist approach have demonstrated that gender ideologies shape how diseases are imagined and described in medical discourse. My analysis of nineteenth century medical periodicals and key surgical and cancer texts uses this same analytic framework to focus on conceptualisations of gender in cancer discourse. My findings indicate that there has been a long-standing historical association between women and cancer. In the early nineteenth century, there was an effort underway to scientifically classify tumours. I argue that the effort to scientize cancer classifications was structured by pre-existing assumptions that cancer was a 'woman's disease.' The tumours most common in women's breasts were exceptionally 'hard' in texture. In order to preserve the literal link between cancer and women, British surgeons emphasized that 'true' cancer was characterized by its 'hard' nature. This left the literal association between women and cancer intact; however, this association was short-lived and by the mid-nineteenth century, the classificatory importance of 'hardness' to signify 'true' cancerous disease was abandoned in favour of what I am calling 'reproductivity' to denote cancer both metaphorically and literally. Ultimately, cancer discourse encapsulated and expressed prevailing gender ideologies in the nineteenth century and these patterns demonstrate that British surgeons drew upon socio-cultural themes in their medical discourse on cancer.

**Dwan, K.**

**Australian National University**

*Stream: Theory*

*Friday the 17 September 2004 at 16.55 - 17.25*

**THEORISATION AND EMPIRICAL VERIFICATION OF "THE PROFESSIONAL IDEAL"**

Weberian ideal types are a useful heuristic device, as Freidson demonstrates in his recent work, Professionalism: The Third Logic. In it he examines alternative means of organizing professional work through three ideal types based on the market, the bureaucracy and professionalism. This paper also employs professionalism as an ideal type, but treats this choice of organising principle as a given and seeks to demonstrate how professionalism can be used to explain the responses of the medical profession to both internal and external challenges. In contrast to both early 20th century accounts, which adopts a functionalist and therefore a supportive position vis-à-vis the professions, and scholarship from the second half of the century, which is explicitly critical of the state sponsored benefits secured by the medical profession for its members, my approach seeks to understand the medical profession from the perspective of medical professionals; that is, to explore the frame of reference through which these professionals perceive and understand the world and their place within it. In this sense the research embodies Weber's notion of verstehen. My construction of the professional ideal draws upon the notions of service, knowledge and autonomy that are employed in both the functional and critical literature. The resultant ideal type is then empirically explored by drawing upon in-depth interviews with over 30 Australian general practitioners, and subsequently, proves a useful tool for explaining how general practitioners perceive both internal and external challenges, and hence how they respond to such challenges.

**Edgley, A.**

**University of Nottingham**

*Stream: Health Service Delivery*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**DRUGS OF CHOICE: REGULATING ACCESS TO STATINS**

The growing drugs budget is an issue of increasing concern to the government. The pharmaceutical industry meanwhile continues to seek ways of expanding the market in medicine consumption. One way they can do this is to expand the indications on the drug label. An alternative is to push for Direct to consumer marketing. Such a move is justified using a consumerist discourse that emphasises increased choice, control and access for consumers. This expansionist rationale for pharmaceutical companies is currently undermined by the governments concern to limit the drugs budget. However, were the government to shift some drugs from Prescription Only to Over the Counter, then both the governments desire to contain the drugs budget and the pharmaceutical industry drive to expand can be met.

The changing political economy of medicines governance is producing changes in state market relationships, and in professional client relationships. Responsibility for the drugs budget is being pushed onto the consumer, and control by doctors for prescribing is being eroded. To explore these shifts a case study will be made of the governance debates around Statins.

**Edwards, E., Timmons, S.**

**University of Nottingham**

*Stream: Mental Health*

*Thursday the 16 September 2004 at 16.00 - 16.30*

### **EXPERIENCE OF STIGMA IN WOMEN WITH SEVERE POSTNATAL ILLNESS**

Though there has been extensive research on the phenomenon of stigma in mental illness, there appears to be little published about whether or how women with severe post-natal mental health problems experience stigma. In addition, experience from practice suggests that stigma may be a factor in women with postnatal illness being unwilling to seek treatment, which can lead to deterioration in their condition.

This study draws on several theoretical perspectives, including Goffman, and feminist approaches to postnatal illness. Interviews were conducted with six women who had been sufficiently ill to be admitted to an in-patient mother and baby mental health service. Their medical diagnosis included severe PND and puerperal psychosis. The interviews were qualitative, semi-structured, and of about 90 minutes in length. They were conducted in the womens' own homes by the (female) primary researcher on this project (Liz Edwards). Interviews were conducted, on average, six months after discharge from the mother and baby unit.

Preliminary results suggest that though women with these conditions do experience stigma, it does not manifest itself in the forms described in the literature.

**Ehrich, K.**

**Kings College London**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 09.00 - 09.30*

### **TRUST AND TELLING: 'CULTURAL' ISSUES FOR STAFF REPORTING CONCERNS ABOUT COLLEAGUES IN THE NHS**

Recent health policy initiatives promote a 'no blame culture' and learning from adverse events to enhance patient safety in the NHS. But at the heart of these initiatives is a paradoxical question: when individuals are identified as accountable for such events, how can trust and reporting on colleagues be simultaneously achieved?

This paper will address 'whistle-blowing' by staff with concerns about colleagues; and some 'cultural' factors that have a particular bearing on staff reporting their concerns within the NHS. These issues were central to the findings of the Bristol Inquiry, and continue to point to conflicts between principles of clinical autonomy and professional self-regulation, increasing imperatives to protect patients, and the growing role of external regulation.

These topics featured strongly in independent inquiries into the performance and conduct of Richard Neale and Clifford Ayling, and to investigate, in particular, the organisational and cultural factors that allowed their failings to go unchecked, yet known of, for many years before they were finally struck off.

The paper draws on work by the author in planning and attending seminars held for the two inquiry panels, and analysing a range of policy, legal and advisory documents considered by the inquiries in forming their recommendations. It offers a contribution to a long-standing stream of work by medical sociologists to understand the political, professional, cultural and organisational contexts of professional autonomy and self-regulation.

**Elston, M.A, Gabe, J., Valsecchi, R., Smith, C., Mueller, F.**

**Royal Holloway**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 15.10 - 15.40*

### **TELE-NURSING IN NHS DIRECT: MOVING UP OR PASSING THROUGH?**

NHS Direct's 24 hour telephone advisory service can be seen as a paradigm of NHS modernisation, promising nurses both career advancement and leadership prospects and family-friendly flexible working conditions that foster retention of a mainly female workforce. However, call-centre work in general has often been associated with high turnover and flexible working conditions that advantage employer rather than employee. Drawing on qualitative and quantitative data from an ESRC-funded study of two NHSD sites, we examine the career paths and aspirations of nurses who join NHSD.

Both sites were characterised, as is NHSD nationally, by high turnover and sickness absence and staff shortages. There were a small number of nurses, mainly early recruits to NHSD, who had risen rapidly to supervisory or managerial positions, but prospects for career were now seen as diminishing and the tensions between nursing and call centre management increasing, as the national service stabilises. Most of the nursing workforce were orientated to NHSD as providing flexible, and usually temporary, employment, with marked differences between the two sites. At Site A, NHSD work was seen as a stepping stone towards retirement as much as a route back to nursing. At Site B, the typically younger nurses saw NHSD's flexible working conditions as enabling them take on other professionally related commitments, such as part-time degrees. Our findings suggest that local nursing labour markets affect the development of this national service and that NHSD work is unlikely to foster tele-nursing emerging as a distinctive nursing speciality.

**Ettorre, E.**

**University of Plymouth**

*Stream: Methods*

*Saturday the 18 September 2004 at 09.00 - 09.30*

### **THE CONTRIBUTION OF AUTOETHNOGRAPHY TO MEDICAL SOCIOLOGY: TELLING AND FEELING WITH ILLNESS STORIES**

This paper looks at the rich tradition of medical sociologists who reflect upon their own illness experiences. Different genres shaped by modernist observers and postmodern witnesses are identified from these reflections which have a major role to play in an ill person's quest for authenticity. Based on this tradition, autoethnography is introduced as a methodological tool for telling and writing illness stories as well as creating sociological insights into patienthood. Autoethnography adds to broader academic debates within medical sociology which call for more innovative methods of data collection and show that chronic illness may have a major impact on identity and embodied selfhood. Through its use, acute illness, as a neglected area of research, can be understood as a movement towards re-embodied health and productive desire. With reference to my own illness story, I explore two key concepts, sentimental work (Strauss, A. et. al 1982 Sentimental work in the technologized hospital, SHI, 4, 3: 254-78.) and technologies of the self (Foucault, M. 1984 The Care of the Self London, Penguin Books). I also challenge medical sociologists to construct more stylised 'infirmity' identities that defy closure, while resisting scopic regimes which authorise and legitimate a morality of health. Looking at autoethnography within the multiple contours of embodied illness and health, I demonstrate that the experience of acute illness such as thyrotoxicosis causes embodied adjustments and an awareness of the need for nomadic flexibility.

**Eyers, I.**

**University of Surrey**

*Stream: Health Policy*

*Friday the 17 September 2004 at 16.55 - 17.25*

### **TIME TO CARE. TIME AS A RESOURCE IN THE PROVISION OF CARE**

In the provision of care, time is a key commodity. For the care recipient it is perceived to be plentiful whereas for care givers time is a resource that requires budgeting. This research undertaken in four English and four German care homes meeting the needs of frail older people, contributes towards understanding the role of time in the provision of care. Data from eight care home managers and 50 semi-structured interviews conducted with qualified staff and care assistants provide an insight into care home work. Responses to care-related vignettes used during the interviews indicate how 'taking time'; 'making time'; and 'spending time' are important elements in the provision of care. This in turn identifies the use of emotional labour to balance 'process time' and 'clock time' in the provision of care. Thus establishing the link between emotional labour and time.

This research and its dissemination was funded by ESRC studentship (R42200024125) and ESRC Postdoctoral Research Fellowship (PTA-026-27-290)

**Featherstone, K., Atkinson, P., Pilz, D., Clarke, A., Latimer, J.**

**Cardiff University**

*Stream: Genetics*

*Friday the 17 September 2004 at 15.10 - 15.40*

### **DYSMORPHOLOGY AND THE SPECTACLE OF THE CLINIC**

Focusing on the genetics service of a British teaching hospital, the paper explores the interaction of new genetic technologies and clinical judgement in the construction of genetic identities. The question we address is to what extent are these genetic technologies leading to the 'death of the clinic'. Drawing on ethnographic research we focus on one clinical specialism, dysmorphology. Dysmorphology is the medical study of abnormal forms and is concerned with the identification and classification of a variety of congenital malformations. Such diagnostic work is the province of professionals in clinical genetics. It still rests, however, on the inspection of images of affected individuals. On the basis of physical appearance individuals have been classified in terms of a wide range of conditions, often with exotic nomenclatures. Contemporary dysmorphology preserves many features of earlier forms of physiognomy and iconography. It has in recent years also been subject to technical change. It thus stands at the crossroads of the old clinic and the new technologies of genomic science. This paper describes some features of the dysmorphology meeting, at which 'slides' of individuals are displayed and discussed, and on the basis of which categorization is performed. We suggest that the contemporary dysmorphology meeting can be understood in terms of long-standing forms of medical knowledge, medical representations and medical discourse. Notwithstanding the new forms of technology provided by genetic science, 'the clinic' still asserts its symbolic and functional power: the 'gaze' of the clinician, and the clinician's warrant of personal knowledge still exert their influence.

**Fernandez, J.**

**Islington PCT**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

### **AN ANALYSIS OF THE EFFECTS OF CULTURAL DIFFERENCE IN DRUG USE IN EMERGING ETHNIC GROUPS**

#### Background

When Camden and Islington Drug Services were audited, it was found that a group of British Muslims had differences in their route of administration in comparison to other ethnic groups in substance misuse services (Fernandez, 2000).

A literature review was conducted to examine the socio-economic position of British Muslims in English society in relation to isolation. This found that the British Muslim population was the poorest and most economically disadvantaged, when compared to other ethnic groups (Mahood, 1998).

#### Research methodology

A research project was set out to examine the extent of the economic and social polarisation upon health needs. Also, to assess from the local ethnic population perspective whether their needs are met.

The research approach was a case study conducted in Camden in the area of Somers Town. A qualitative design was adopted using a semi-structured interview that also had a space for informal data to be gathered.. The analysis was conducted through a sociological theoretical perspective to examine these patterns of use and what they could illustrate sociologically.

#### Outcomes

The implication for specialist care services is to try and understand the social dimensions in which they are working from the evidence of polarisation found from the study. It is also important in addressing issues of access and reducing inequalities of care and hopefully improving care, as the population is concentrated in Somers Town with arguably tight-knit communities which has a great potential for distributing health educational and promotional messages upon substance misuse.

**Fincham, L., Copp, G., Caldwell, K., Jones, L., Tookman, A., King, M.**

**Kings College London**

*Stream: Cancer*

*Friday the 17 September 2004 at 15.10 - 15.40*

### **SUPPORTIVE CARE: EXPERIENCES OF CANCER PATIENTS AND HEALTH CARE PROFESSIONALS**

With the increasing incidence of cancer, longer survival times and limited resources, cancer care has evolved from focusing on survival to maintaining or improving quality of life (Ferrans 1990). The need to explore the nature and provision of 'supportive care' for patients with cancer has become paramount. To date few studies have investigated patients' experiences of supportive care at different stages of the disease process together with the quality of and patient satisfaction with supportive care services.

This collaborative study involving Middlesex University, The Royal Free Hospital and Marie Curie Cancer Care investigated how patients with cancer and the health care professionals caring for them, experienced supportive care at different stages of the disease trajectory. Qualitative data from two focus groups was used to develop a survey tool. Data from the questionnaires was used to test relationships between variables and allow possible generalisations to be made to larger populations. The Mental Adjustment to Cancer Scale (Greer Morley and Watson 1989), the GHQ12 for psychiatric screening (Goldberg 1970), EuroQol quality of life measure (Kind et al 1998), and the MOS Social Support Survey (Sherbourne and Stewart 1991), were used to provide patient measurement scales. Ten in-depth interviews (5 patient and 5 staff) facilitated the search for explanations of the relationships found the focus groups and questionnaire data. This paper will report the findings of the focus groups, development of the survey tool and initial questionnaires findings.

**Fitzpatrick, P., O'Hanlon Brown, C., Fitzpatrick, J.M., Watson, C., Lennon, L. Kinsley, B., Firth, R., Wyllie, M.G.**

**University College Dublin**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 16.20 - 16.50*

### **ERECTILE DYSFUNCTION: PREVALENCE AND IMPACT ON QUALITY OF LIFE IN A MALE DIABETIC POPULATION**

Recent developments in the treatment of erectile dysfunction have revived interest in this common problem. Reported prevalence studies of erectile dysfunction in diabetics have largely used non-standardised techniques, and there is a lack of quantification of the loss of erectile dysfunction-related quality of life in diabetic patients. The aims of this study were to determine the prevalence of erectile dysfunction in diabetic patients using an abbreviated, standardised sexual health questionnaire, and to examine the impact of erectile dysfunction on quality of life.

218 male diabetes mellitus patients completed a questionnaire which included a variant of the abbreviated form of the International Index of Erectile Function, the IIEF-5, customised to expedite the interview process, and the Short Form-36 questionnaire, a measure of health status and quality of life.

The mean age was 51.1 years (range 20-77). Using the IIEF-5 the overall prevalence of erectile dysfunction was 51.8% (95% CI 45.0 - 58.6; 113 patients). The prevalence among documented insulin-requiring diabetics (n=105) was 36.2% (95% CI 27.2-46.2) and among non-insulin requiring diabetics (n=103) was 57.3% (95% CI 47.2-66.9). All SF-36 domain scores were significantly reduced in patients with erectile dysfunction. Lower mean scores were found in all domains in the older agegroups. Among younger men with erectile dysfunction significantly reduced scores were seen in two domains: 'mental health' and 'role limitation due to physical problems'.

Physicians treating diabetic patients must be aware of the likelihood of erectile dysfunction with resultant reduction in quality of life, and be prepared to discuss this problem.

**Fitzpatrick, P., Daly, L., Cusack, D., Leavy, C.P.**

**University College Dublin**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**DRIVING UNDER THE INFLUENCE OF DRUGS IN THE REPUBLIC OF IRELAND: RESULTS OF A NATIONWIDE SURVEY**

Driving under the influence of drugs is illegal under statute in the Republic of Ireland. The aim of this study was to examine drug taking among stopped/tested drivers in Ireland using specimens received by the Medical Bureau of Road Safety.

2000 specimens (57% blood, 43% urine) were selected from drivers tested on suspicion of driving under the influence of an intoxicant, 1000 under the legal limit for alcohol and 1000 over the limit. Screening and confirmatory analyses were performed for seven common drugs. Weighted analysis allowed population estimates for all tested drivers.

33.1% of those under the limit for alcohol and 14.2% of those over tested positive for drugs; this corresponds to a population figure of 15.7% of all tested drivers. The drug-taking prevalence reduced steadily as alcohol levels increased. The proportion of drivers positive for more than one drug was higher in those under the limit (54.4% of drug-positives) than over (17.6%). Cannabinoids was the most commonly found drug class (20.9% under the limit and 8.5% over), followed by benzodiazepines (9%, 3.4%), M-amphetamines, amphetamines, opiates, methadone and cocaine. The majority of specimens were from male drivers, but there was little difference in drug-positivity between the sexes. The prevalence in all tested drivers was strongly related to age; highest in the under-25 agegroup (24.9%) and lowest in those 55+ (1.9%). Positive results were much higher in drivers tested in urban areas than in rural areas.

Driving under the influence of drugs presents a significant problem which must be addressed.

**Flynn, R.**

**University of Salford**

*Stream: Risk*

*Friday the 17 September 2004 at 09.00 - 09.30*

**KNOWING THE UNKNOWN: ISSUES IN THE PUBLIC PERCEPTION OF RISK**

The debate about risk society (Beck) and trust in abstract systems (Giddens) has intensified scrutiny of the relationship between lay and expert knowledge. There are important parallels between ideas about this relationship in the sociology of health and illness, and critiques of the public understanding of science and technology. This paper explores some of these parallels, and illustrates some of the problems of investigating public perceptions of risk in the prospective development of the 'Hydrogen economy' (Rifkin) - a radically new energy system which potentially could transform existing economic and social structures.

The paper reviews two different but related literatures. First it examines arguments and evidence about lay or folk beliefs in health and medicine, the so-called 'problem' of 'patient compliance' and the power of professionals in medical encounters (Gabe; Popay & Williams). Second it reviews arguments derived from recent sociology of scientific knowledge and social studies of technology, particularly about the so-called 'problem' (or 'deficit model') of the public understanding of science (Irwin; Wynne). The latter suggests that we must move beyond the realist versus constructivist dualism, and acknowledge both the socially-constructed character of scientific knowledge itself and the contextualised interpretation of risks.

These two approaches to the construction and perception of risk are then used to address the question of how to investigate public awareness of, and attitudes towards, the Hydrogen economy, when it is largely 'unknown'.

**Gabbay, J., Dopson, S., le May, A.C.**

**University of Southampton**

*Stream: Health Service Delivery*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**ORGANISATIONALLY EMBEDDED EVIDENCE: HOW SURGICAL KNOWLEDGE-IN-PRACTICE WAS CONSTRUCTED FROM RESEARCH FINDINGS**

The recent literature on knowledge management emphasises the crucial role of social networks in negotiating what comes to be accepted as "knowledge" in a given milieu. Various models have been suggested to explain how both codified and tacit knowledge are iteratively negotiated among "communities of practice" as they construct- or "combine" - many sources of relevant information in an act of collective sensemaking and enactment. The processes described contrast markedly with the simplistic and rationalist approach to "research implementation" advocated by most proponents of evidence-based healthcare.

Our paper reanalyses case-study data from an evaluation that was carried out of an attempt in the 1990s to influence surgeons in their use of the insertion of grommets for glue ear. We present a detailed account of the processes by which knowledge from the research world was introduced into clinical policy and practice. We develop a model that reflects the essentially contingent social and organisational determinants of the ways that knowledge became accepted and used in a given local environment. Key elements of the process were the nature of the scientific evidence, and the motives and interests both of those in the higher echelons of the health service in promoting it, and of the local protagonists who were negotiating a guideline for the management of the condition. We use our model to analyse how these elements impacted upon the formulation and reformulation of the research evidence as key actors attributed meaning and action to the research findings in the context of their work.

**Geoghegan, L., De La Harpe, D., Fitzpatrick, P.**

**University College Dublin**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 11.55 - 12.25*

**I NEED TO LIVE - I NEED A LIFE! REHABILITATION FOR TRAUMATIC BRAIN INJURY PATIENTS IN IRELAND**

Each year in Ireland, up to 13,500 people sustain a traumatic brain injury (TBI). With advancing medical technology more patients are now surviving their initial injury. There is a perceived lack of rehabilitation services available to patients, their family members and carers, in the Irish health care system. TBI service providers are increasingly concerned that current service provision falls short of internationally recommended guidelines.

In the first study of this nature in Ireland, a series of 12 semi-structured interviews and 3 focus groups were conducted with TBI service providers, family members and carers of TBI patients, using a grounded theory approach. Purposeful and snowball sampling ensured participants represented several disciplines, working in acute, post-acute and community services. Qualitative data were transcribed and analysed using the QSR\*Nudist software package.

Emerging themes include the enormous burden of TBI in Ireland. The data clearly identifies that this is a shared burden. Potential consequences of TBI are not only individual, but also affect family, community and society. Current TBI service provision was described as wholly inadequate. Significant service needs were identified and participants discussed possibilities for future TBI service development in the Irish health care system.

**Gibson, L., Peelo, M., Soothill, K.**

**Nottingham University**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 11.55 - 12.25*

**CHALLENGING THE PROFESSIONALISATION OF ALTERNATIVE MEDICINE: RE-INTEGRATION OF CARE AND HEALING THROUGH GENDER ANALYSIS**

The success of alternative medicine within informal and lay health sectors has prompted debate about its integration into formal healthcare systems. The focus has been about the need for alternative medicine to professionalise and conform to traditional models of professionalisation. However, such discussions merely replicate gendered debates about care and healing already familiar to the sociology of health and illness. Through focussing on the structural and technical basis of biomedical discourse and knowledge, there is little reflection on the appropriateness of this for alternative medicine. There has been little theorisation of gender in these discussions yet the practice and epistemology of alternative medicine has been noted to be highly feminised.

Drawing on empirical data from in-depth interviews with both alternative practitioners and elite decision making bodies, this paper considers the importance of discussing gender in this arena. It provides an analysis of the power relations within professionalisation that assumes a level of incorporation into conventional biomedical discourse. This replicates the traditional gendered division of labour seen in other professions such as nursing. I will argue that a gender analysis offers a re-contextualising of professionalisation for alternative medicine in the UK. Informal networks were found to be central to the practice of alternative medicine and, this paper suggests, they offer an heuristic device in which to access and develop perspectives of difference, resistance and 'other', particularly towards reintegrating theories of care and healing. The implications of this for the future of alternative medicine are considered.

**Graham, R.**

**Newcastle University**

*Stream: Theory*

*Friday the 17 September 2004 at 16.20 - 16.50*

**MAKING THE BEST OF A BAD JOB: CRITIQUE AND THE SOCIOLOGY OF HEALTH AND ILLNESS**

The sub-discipline of the sociology of health and illness is grounded in empirical research and is characterised by the theoretical strength of its parent discipline, sociology. This theoretical strength has helped the sub-discipline to maintain a highly critical perspective. For example, it critically reviews the medical profession and examines the characteristics of doctor-patient power relations. These are important, essential tasks. But in our quest to analyse the health care professions, do we critique or criticise?

Health care providers cope with uncomfortable situations, but often do so in creative, positive ways; yet these issues are often neglected. I draw on three examples to demonstrate this point. They all relate to how health care providers attempt to reconstruct unpleasant events into sources of professional satisfaction.

First, I consider the provision of removable partial dentures (RPDs) by dentists, which are disliked by both patients and dentists alike. Second, I consider the issue of male rape, which is written about by doctors but not by sociologists. Finally, I consider the issue of feticide (stopping a fetus' heart) in termination of pregnancy for fetal abnormality.

These examples help to demonstrate the very real engagement between health professionals and social problems. Yet we hear little of this engagement in social research on medicine. Does our research agenda reinforce a biased interpretation of the social world by emphasising the problematic at the expense of the positive?

**Green, E., Singleton, C.**

**University of Teesside**

*Stream: Gender*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**LANGUAGE ISN'T THE ONLY BARRIER: THE INTERPLAY OF GENDER ETHNICITY AND CULTURE IN THE COMMUNICATION PROCESS**

Effective communication is considered to be crucial to successful health outcomes and equitable use of health and social care services for Black and Asian women (Davies and Bath, 2001; Harper-Bulman and McCourt, 2002). However, research shows that issues of communication and interpretation/translation continue to pose significant barriers to accessing services for users who are not fluent in English (Bahl, 2001; Gerrish, 2004). Using new empirical data from an action research project on Black and Asian women's health and well being, this paper explores issues around communication and access to health and social care services in the North East of England. The data emerges from qualitative interviews and focus groups with service providers and diverse groups of Black and Asian women. The juxtaposition of service provider and user perspectives provides a useful comparative context within which to analyse processes of communication and interpretation in statutory and non-statutory health and social care settings. The paper focuses upon community interpreters as cultural brokers and gatekeepers of women's health information, and women's scepticism around the use of ICTs to aid and support the communication process. We also address the interaction of gender, ethnicity and culture in the effective accessing of services. Finally, the paper discusses confidential interpretation and empathy with cultural values and practices, as key components in effective communication processes between providers and users.

**Greenfield, S., Wilson, S., Roberts L., Singh, S.**

**University of Birmingham**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**PATIENTS' EXPECTATIONS AND EXPERIENCES OF GUT DIRECTED HYPNOTHERAPY**

The media is a powerful lay information source about medical issues. Media representations of hypnosis can be controversial. Some patients may be doubtful about complementary and alternative (CAM) treatment. It is not clear whether this affects their attitudes to treatment or its efficacy.

40 IBS patients receiving 'gut directed hypnotherapy' (GDH) in an RCT comparing GDH + usual treatment with usual treatment alone had; 5 weekly 30 minute hospital based GDH sessions; a self-hypnosis tape. A postal questionnaire after GDH, explored patients' expectations, actual GDH experience, rating of overall effect, specific symptom relief (5 point scale;0=no benefit to 5=great improvement).

33/40 (82.5%) patients returned questionnaires. 4 (12.1%) had previous experience of hypnotherapy, 17 (51.5%) described specific, mainly positive prior expectations. 27 (81.8%) described definite improvement from GDH. 18/33 (54.5%) said GDH improved their overall IBS symptoms more than expected. For specific symptoms greatest reported improvement was in panic (mean improvement rating=3.42; no. of patients reporting no benefit=0/14), constipation (3.25; no benefit=1/9), least was in cramps (2.95; no benefit=1/20), diarrhoea (2.77; no benefit=2/18) and pain (2.68; no benefit=2/25). Other GDH benefits GDH were; sleep (28/33, 84.8%), feelings of well being and confidence (20/33, 60.6%), relaxation (19/33, 57.5%), feeling in control of IBS symptoms (19/33, 57.5%), or other aspects of life (19/33, 57.5%).

GDH was an acceptable therapy for the study patients. Its benefits for relieving some IBS symptoms were rated more highly than others. Therapeutic benefits of GDH were perceived by patients not just to be confined to IBS symptoms

**Greenhouse, F.**

**Nottingham University**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 15.10 - 15.40*

**PRENATAL TESTING FOR THALASSAEMIA: MEETING THE NEEDS OF THE SOUTH ASIAN COMMUNITY IN THE UK**

With the increasing prevalence of genetic testing, antenatal genetic screening and counselling will gain greater importance in the UK, in particular as, from this year, universal screening for some haemoglobin disorders will be introduced in certain health authorities.

These new screening practices will result in many ethnic minority communities having an increased opportunity for haemoglobin prenatal testing. However, little work has been undertaken on the impact of genetic prenatal testing among ethnic minorities, or their decision making about prenatal testing, and their understanding of risk status for both themselves and their pregnancy.

The question arises of how women, at-risk of carrying a specific genetic condition because of their ethnic origins, will make decisions regarding prenatal testing. The aim of my PhD study is to consider how South Asian women make decisions about prenatal testing for the haemoglobin disorder Thalassaemia. Through the use of conversation analysis, the study aims to determine how women understand their at-risk carrier status, and how they make decisions about prenatal testing. An investigation of the relationship of the women with the antenatal-midwife and the structure of the antenatal appointment will be completed. This will be considered within the context of cultural and family explanations of illness and heredity, and midwives' sensitivities to the needs of this ethnic group. Consideration will be given to whether sensitivity to women's culture can actually impede the process of disseminating information and thus the process of informed decision making.

**Gregory, M.**

**CESAGEN, Cardiff University**

*Stream: Genetics*

*Friday the 17 September 2004 at 15.45 - 16.15*

**FAMILY EXPERIENCES OF THE CLINIC: THE CASE OF DYSMORPHOLOGY**

Dysmorphology is the medical study of abnormal forms and is concerned with identifying and classifying a variety of congenital malformations. Although contemporary dysmorphology continues to retain many features of diagnostic work that rely on the identification of conditions through physical features, it has been subject to technical change in recent years as a consequence of advances in genetic technologies. This means that testing may identify conditions as having a genetic basis, which might be inherited from parents or may have occurred for the first time as a de novo chromosomal mutation.

The data presented in this paper are derived from interviews with families who have been referred to the genetics service of a major British teaching hospital because their child evinces developmental or other difficulties. The majority of interviews took place with one or both parents. The paper explores family experiences of attendance at the clinic, the effects of obtaining - or not obtaining - a diagnosis for their child and the impacts that this has on their perceptions of the family. The paper explores how families experienced the clinical process; their need to understand why their child has the condition and the effect on their perceptions of the family identity.

**Halfmann, D.**

**University of California - Davis**

*Stream: Health Policy*

*Friday the 17 September 2004 at 14.35 - 15.05*

**THE MEDICALIZATION AND DEMEDICALIZATION OF ABORTION IN THE UNITED STATES AND BRITAIN**

The study offers a comparative historical analysis of the medicalization and demedicalization of abortion in the United States and Britain--examining these processes at conceptual, institutional and interactional levels. In the nineteenth century, doctors in both countries seized control of both the legal sanction and the provision of abortions from competing providers. In subsequent years, large numbers of abortions were provided by non-medical, and thus, extra-legal providers. In the late 1960s, feminist organizations in the US challenged medical control of abortions through the promotion of self-abortion and referral to extralegal providers. In the late 1960s and early 1970s, both countries enacted abortion reforms meant to make abortions more widely available. In the US, abortion was partially demedicalized as abortions became available upon request without requirements of medical necessity. In Britain, the reform codified medical control over the legal sanctioning of abortions. This control was later challenged by feminist organizations. In both countries, abortion was further demedicalized through the extensive provision of abortions in settings unaffiliated with mainstream medical institutions. In recent years, abortion rights organizations have sought (with limited success) to further demedicalize abortion through diffusion of the abortion pill (mifepristone) and emergency contraception. The study contributes to the medicalization literature through its rare crossnational approach and through its focus on the structural underpinnings of medicalization-in particular, public versus private health care systems.

**Harrow, A., Barbour, R., Cable, S., Wells, E.**

**University of Dundee**

*Stream: Cancer*

*Friday the 17 September 2004 at 11.20 - 11.50*

**KEEPING POSITIVE: NEGOTIATING CONFLICTING 'SCRIPTS'**

**Background**

This study sought to provide insights into the experience of male partners of women with breast cancer in the context of the current climate of care where women have shorter hospital stays and there is greater emphasis on out patient treatment.

**Design and method**

A questionnaire was used to provide a basis for purposive sampling for partners of differing ages, backgrounds, domestic circumstances and time since their partners' diagnosis. Respondents were invited to take part in one-to-one semi-structured interviews.

**Findings**

The experience of the men interviewed can be understood with reference to their responses to both 'scripted' and 'unscripted' scenarios. Media images of breast cancer provide a 'script' about recovery (often using powerful images of media personalities who have recovered) as do healthcare professionals who appeal to similar notions and stress the importance of 'keeping positive'. The 'unscripted' elements relate to uncertainties both with regard to treatment and disease progress and exactly how to remain positive (for example during their partners' chemotherapy treatment) in the face of lack of clarity or communication about the type of support required by the women. Additionally the data suggests that men and women were appealing to different 'scripts': women appeared unable to bring breast cancer to an end while the men actively sought to do this, viewing it as important in returning to normality. The men's accounts of their experiences show that both 'scripted' and 'unscripted' scenarios are problematic to apply and sustain, and that the messages thus conveyed are potentially contradictory.

**Hayter, M.**

**University of Sheffield**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 11.20 - 11.50*

**ANATOMO-POLITICS TO BIO-POLITICS: A FOUCAULDIAN ANALYSIS OF CONTRACEPTIVE USE AND THE SOCIAL POLICY OF BIRTH CONTROL**

The body, for Foucault, is the link between micro-power relations concerning the individual (anatamo-politics) and the macro-power relations operating at population level (bio-politics). Foucault proposes that the link between the government of the individual body and the regulation of the population exist in a mutually constitutive discursive network. The family planning clinic is a clinical space where individual women engage with a health professional to obtain contraception. The clinic is also an institution through which policy relating to birth control is deployed and a key site for the monitoring of unplanned pregnancies and levels of contraceptive use.

Data is presented from a grounded theory study into contraceptive consultations describing how women are tutored in contraceptive use through the discursive construction of reproductive risk, and the development of self-surveillance and regimen management techniques. It is argued that these discursive, micro-power relations can be mapped against broader, population level discourse relating to teenage pregnancy, birth control and the sexual behaviour of women.

It is proposed that the contraceptive consultation in the clinic is a clear example of the way in which contraceptive discourse at a micro level and population level discourse interact. The implications of this are discussed, particularly the issue of contraception, which, in addition to providing reproductive health benefits to women, is a technique of population control through the regulation of reproduction. It is also proposed that, to some extent, current discourses relating to unplanned/teenage pregnancy demonstrate some distinct echoes from the historical roots of the contraception/birth control movement.

**Heaven, B., Kaner, E., Rapley, T., May, C., Thomson, R., Murtagh, M., Graham, R.**

**University of Newcastle upon Tyne**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 10.10 - 10.40*

### **DECISION AIDS AND DOCTOR/PATIENT INTERACTION IN CONSULTATIONS AIMED AT SHARED-DECISION MAKING**

Currently there is an incomplete understanding of the means by which social factors impact on patient/clinician decision-making in health care. In particular, manifestations of communicative actions within the consultation room itself may be key to determining treatment decisions across a range of areas of medicine. However, it is difficult to unravel the relative contribution of participants to discussions about treatment and this task becomes more complex when technology acts as a third party in the consultation. This paper will; a) identify the overt behaviours that occur in the social interaction around treatment decision-making, and b) describe the impact of decision aids on these interactions.

Situated within a larger multi-method (quantitative and qualitative) observational study of a trial of decision support tools, this paper explores the verbal and non-verbal behaviour of patients and doctors during consultations focused on treatment decision-making in primary care. Twenty nine consultations were video-recorded. Patients (N=29) met with one of three study GPs (extended tool, concise tool or guidelines). A ten minute 'slice' of the consultation was purposively sampled for detailed content analysis, focussing on both interaction with the decision-aid and the subsequent process of decision-making.

The nature of patient/clinician behaviours around decision-making and tool use are presented. Whilst decision support tools by definition are designed to facilitate communication between patient and clinician, results reported in this paper illustrate a more complex interpersonal interaction via the use of these decision aids. Final interpretations of the findings are contextualised through in-depth qualitative interviews with patients.

**Hindmarsh, J., Reynolds, P., Gibson, B., Dunne, S.**

**King's College London**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 11.20 - 11.50*

### **DENTAL TRAINING IN ACTION**

Despite the burgeoning body of work concerned with professional-client communication in a variety of healthcare settings, very little attention has been devoted to explorations of social interaction within dentistry. This paper considers the organisation of interaction in dental training episodes within the GKT Dental Institute's Team Care Clinic. The Team Care Clinic is designed to provide an environment that integrates the teaching of dental care to both undergraduate dental students and professions complementary to dentistry within a team setting. The Clinic has various features that make it of interest to analyses of social interaction in health care. The dental work is delivered through real-time (multi-disciplinary) teamwork; the students are engaged in developing manual skills, such as administering local anaesthetic injections, dental extractions and restorative techniques; and the team is working with real patients. This provides an intriguing domain in which to consider the organisation of teaching and learning alongside and intertwined with the safe delivery of collaborative dental work. The paper delineates some of the practices in and through which members of the dental team (mainly students and demonstrators) coordinate their teaching, learning and dental work with and around the active patient.

The paper is based on the analysis of audio-visual recordings of naturally-occurring dental training episodes within the Team Care Clinic. The analytic orientation of the paper is drawn from ethnomethodology and conversation analysis.

**Hiscock, J.**

**University of Liverpool**

*Stream: Primary Care*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**A TYPOLOGY OF GP APPROACHES TO PATIENTS' RETURN TO WORK AFTER A PERIOD OF SICKNESS ABSENCE**

This paper presents a qualitative study of the behaviour of GPs in sickness certification and their role in their patients' return to work after a period of sickness absence. A typology will be presented, and discussed in light of the literature on typologies of GPs and GP behaviour.

Purposive sampling was used to select 54 GPs from 8 areas of UK, covering a range of characteristics of relevance to the study: GP characteristics (stage of career, full or part time, interest in occupational health, age, gender, ethnic group), practice characteristics (catchment area - urban/rural, socio-economic deprivation, unemployment levels; practice size - number of partners, list size). Data were gathered through in-depth interviews and focus groups and were analysed using 'Framework', a manual, matrix method of qualitative data analysis which facilitates analysis on both a thematic and case-by-case basis.

Significant differences in GPs' approaches were identified and a multi-dimensional typology developed:

1. Firm negotiator - actively involved in management of return to work, prepared to challenge patients, direct or quite tough in approach, expects patients to help themselves, prepared to refuse certification.
2. Soft negotiator - more flexible, accommodating, 'softly, softly' approach, uses coaxing manner which will not adversely affect relationship, tends not to refuse certification.
3. Non-interventionist - does not see management of return to work as key priority or responsibility, unlikely to intervene in patients' return to work. May be opposed to role in certification, may feel ill-equipped to give advice, may believe that patient knows best when to return to work.

**Hoad, P.**

**University of Sheffield**

*Stream: Lifecourse*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**VOLUNTEER ADVOCACY IN THE CARE OF OLDER PEOPLE**

Advocacy schemes involve the use of trained volunteers to act as the representatives of frail or confused older people and help them to access services or behavioural change from other organisations or individual. Three forms can be identified; specific issue, long-term citizens advocacy and dementia advocacy, although these may all operate in the same scheme. They are not advice givers, counsellors or mediators but the boundaries around what they do are rather vague and vary between schemes, which (in England,) are run by voluntary organisations and vary in their structure and organisation.

The research reported here is an exploratory study drawing on written reports and interviews with the project managers and/or volunteer co-ordinators in 11 advocacy schemes in different parts of the country.

The issues dealt with included finance (benefits and management), housing, social services, care homes, legal rights and relations with family members and neighbours. A crucial part of their work is to maintain links with other organisations to which they can 'signpost' people or give or take referrals. Although most users have health problems, health services seem reluctant to use the schemes and some special projects have been set up to deal with this.

To be effective, scheme organisers have to be aware of changing policies and legislation.

The conclusion is that there is a great diversity of schemes but all recognisable as advocacy and all of which appear to achieve some of their expected outcomes.

**Holland, P., Elliott, J., Burström, B., Whitehead, M.**

**University of Liverpool**

*Stream: Inequalities*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**WHAT ARE THE SOCIAL AND ECONOMIC CONSEQUENCES OF CHRONIC ILLNESS? A COMPARISON OF FINDINGS FROM BRITAIN AND SWEDEN**

This study aims to establish how chronic illness affects the employment, financial and social circumstances of individuals and their households, and whether these consequences are more deleterious for already disadvantaged groups. Reducing inequalities in health is a key priority in public health strategies at local, national and international levels. To devise effective policies and interventions, however, a better understanding is needed of the mechanisms which produce inequalities in health.

Research has shown that adverse social circumstances create inequalities in health but little is known about the impact of chronic ill health on socio-economic circumstances. Ill health itself may lead to poverty and other health risks, leading to more severe illness and disability for poorer groups and exacerbating existing social inequalities in health.

Using longitudinal data from the British Household Panel Survey, we investigate whether, and how, individuals' employment status, financial circumstances, social activities, and mental health are altered after the onset of a chronic illness. We also examine whether these social and economic consequences of chronic illness vary by social class, age, and gender. Similar analyses using comparable Swedish datasets are also presented to establish whether the social and economic consequences of chronic illness vary in differing welfare states. Understanding the nature and pattern of social and economic consequences of chronic illness will provide a starting point for future analyses of policies and interventions to address these adverse consequences.

This study is funded by the Medical Research Council.

**Holliday, J., Moore, L., Campbell, R., Starkey, F., Sidaway, M., Audrey, S., Bloor, M.**

**Cardiff University**

*Stream: Methods*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**PEER NOMINATION AS A METHOD OF SELECTING SOCIALLY INFLUENTIAL YOUNG PEOPLE FOR PEER-LED HEALTH PROMOTION: A SOCIAL NETWORK PERSPECTIVE**

The ASSIST (A Stop Smoking in School Trial) intervention is not a typical peer-led intervention. It adopts a similar approach to that used by Kelly who successfully implemented a peer-led HIV prevention programme amongst gay men in small towns in the USA. It relies on the diffusion of new norms of behaviour through social networks by influential students working informally as peer supporters. Following peer nomination, peer supporters were trained to talk informally to their peers about being smoke-free. Whilst the peer nomination process generally gave a good spread of young people from different classes and with good representation of both genders, it was important to identify how peer supporters were distributed in relation to the social networks of the year group, and whether they were equally represented in risk-taking and risk-averse friendship clusters. As a result, social network data were collected in all 59 schools in the trial at three time points over two years. On each occasion, approximately 10,000 students named up to six of their closest friends and provided information about the nature and strength of their friendship. This presentation will present the initial findings of social network analysis of data collected from 733 students in four schools at the first post-intervention data sweep. It will provide social network measures for the distribution of the nominated peer supporters and discuss the implications for the potential success of the ASSIST intervention. Broader lessons will be identified for the use of peer nomination in identifying socially influential students.

**Illingworth, N.**

**University of Stirling**

*Stream: Methods*

*Friday the 17 September 2004 at 10.10 - 10.40*

**EXPLORING THE BODY: GENDERED EMBODIMENT AND THE TIME OF INFERTILITY**

Despite attempts to retrieve the body within sociology and the assumption of a now 'embodied' discipline, how this should be done remains problematic, contentious and disputed. Current tensions more than partially revolve around the ontological status of the body, reflecting analytical and epistemological frameworks which bifurcate around foundationalist and anti-foundationalist approaches. Indeed, the status of biology itself still wrestles between the deceptive dichotomy of reductionism and constructionism. Overcoming these difficulties, particularly in relation to women's embodied experience within the field of infertility is central to my discussion.

I address the question of how the female body, reproduction and infertility can be both theorised and explored. Reflecting my recent doctoral studies, I argue understanding embodied experience must take place within the dialogical encounter over time, as part of the interpretive act itself and as part of the ongoing development of participants viewpoints during the telling of their experiences. During the course of my research, I conducted life story interviews and utilised solicited diaries as women both reflected upon and experienced assisted reproductive procedures. This underlines critical longitudinal components to my approach, focusing upon temporal markers and 'turning points' as the stories of women's experiences unfold. I argue understanding women's embodied experiences must reside in the exploration of the web of meanings illuminated as women negotiate their way through the ordinary events and encounters of their everyday lives. 'Meaning', in relation to embodied experience, does not exist externally, waiting to be grasped but is there to be understood and reached through time.

**Ismail, H.**

**York University**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 16.20 - 16.50*

**SOUTH ASIANS AND EPILEPSY: UNDERSTANDING HEALTH EXPERIENCES, NEEDS AND BELIEFS**

This paper presents the findings of a qualitative study that aims to examine the experiences and understanding of epilepsy amongst South Asian communities. The study also focuses upon the role of families in providing support to persons with epilepsy, the use of traditional South Asian therapies, and views of service provision. A sampling frame of persons with epilepsy over 18 years of age was compiled using data from the epilepsy register and hospital databases. The sample was divided by religious groupings: Muslims, Sikhs and Hindus. Fieldwork was conducted mainly in Bradford and partly in Leeds. A total of 56 one-to-one interviews were undertaken with 30 people with epilepsy, 16 carers and 10 health professionals. In addition, two focus groups were conducted with 16 people who did not have epilepsy, recruited from community centres. The framework approach has been adopted for data analysis. Five main themes have emerged from the data: (i) perceptions of the causes of epilepsy, including culturally specific beliefs about spirit possession and epilepsy as a punishment for sins of a past life; (ii) role of families in both providing care and support, including adopting an over protective attitude; (iii) impact of epilepsy on lifestyles, including disruption to education, unemployment, social life and relationships; (iv) use of culturally specific traditional South Asian therapies, including religious and herbal treatments; and (v) health service provision, including issues around lack of appropriate information and advice, language and communication barriers, interaction with health professionals and the potential merits of attending support groups.

**Ito, M., Yamazaki, Y**

**Osaka University, Japan**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

### **THE EFFECTIVENESS OF STIGMA COPINGS OF PEOPLE WITH EPILEPSY IN JAPAN**

#### **Purpose**

This study investigated the perceived stigma, the properties of stigma coping and evaluated the coping effectiveness on subjective well being of people with epilepsy in Japan.

#### **Methods**

1. Subjects: Japanese where their epilepsy was diagnosed and noticed. In addition, 629 questionnaires were distributed through a self-help group and referrals from 7 hospitals. Two hundred and eighty-eight patients (45.8%) were eligible, of the 299 (47.5%) that replied.
2. Variables: perceived stigma was measured by frequency of devaluated feeling, discriminated feeling and refused feeling among people who are aware of their epilepsy (Alpha=0.86). The three types of stigma coping made by multiple items were examined, which were 'concealment', 'self-acceptance and education', 'withdrawal'. Subjective-wellbeing was evaluated with life satisfaction and the subjective-restrictions caused by epilepsy.

#### **Results**

The mean of perceived stigma (range 0-9) was 3.44 (sd 2.91). In medical condition, obvious signs (e.g. seizure frequency) showed significantly high in perceived stigma, however, epileptic duration was not significant. In regards to social conditions, occupation, educational history and social support no significant differences were present. The higher score interval of 'Withdrawal' decrease and it lower subjective well-being and strengthen perceived stigma. 'Concealment' score showed two peaks, and it raised the restriction and showed no efficacy toward stigma coping. 'Self-acceptance and education' showed a contradiction, which it buffered the effect of perceived stigma influenced on subjective well-being, however, itself raised restrictions.

#### **Conclusion**

'Self-acceptance and education' is the most effective for stigma coping, however, limited people who have obvious medical signs of epilepsy adopt the style.

**James. V., Bissell, P., MAPP Group**

**University of Nottingham**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 16.20 - 16.50*

### **NURSING AND PHARMACY PRESCRIBING IN THE UK: A COMPARISON OF PROFESSIONAL CHANGE**

Professional nursing and pharmacy in the UK are undergoing fundamental change as government policies drive the introduction of prescribing as a core role. This not only challenges the monopoly on prescribing previously ascribed to doctors, but, unusually has largely been policy rather than professionally driven. Such a drive, unique in Europe also contrasts with developments in the United States.

In looking at the interplay of state and professions, this paper seeks to consider two key issues: the first is an examination of the circumstances that led a government to make increased access to medicines a central plank of health policy, and the second is why nursing, rather than pharmacy has led the change.

The paper is in four parts. Section one identifies current developments in the UK in terms of the regulation of professional involvement in prescribing. In the second section, nursing and pharmacy as professions are examined to identify the spaces through which prescribing authority has emerged. Issues of the respective knowledge bases, relation to the state, and relation to doctors, and professional drivers are addressed. In the third section, the context of state interest in prescribing change is examined through issues of policy, regulation, and education. The discussion draws together the strands to consider the unusual nature of government driven professional extension in the face of mixed professional views.

**Jenkins, K.N.**

**University of Newcastle**

*Stream: Health Service Delivery*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**EQUITABLE INEQUALITY? REFLECTIONS UPON THE CAUSES AND CONSEQUENCES OF ORGANISATIONAL VARIATIONS OF LOCAL SERVICES**

This paper reflects upon data collected as part of a pilot study of a new technology that would share information electronically, in real time, between Primary and Secondary Care organisations. The technology aimed to facilitate diabetic care clinics in Primary and Secondary Care: the social organisation of the collection of both shared and non-shared information, and the transfer of information between them. The pre-implementation data revealed very disparate forms of organisation between the two NHS Hospital Trusts as well as amongst the GP surgeries, yet all the organisations 'adhered' to the National Service Framework for Diabetes.

Initially, taking 'inequality' as a non-pejorative term representing variations of organisation and provision, I suggest these variations are the result local organisational conditions, including: the 'history' of each organisations development, personnel choice and skills availability, socio-economic-ethnicity-health of its service users, history and present 'position' on new technology adoption, involvement in local initiatives, role of local opinion leaders, inter-professional organisation and cooperation, and history and legacy of involvement in previous pilot schemes.

Rather than focusing on larger structural inequality in healthcare provision first, this paper initially looks at the social administration and provision of Diabetes Clinics and associated services, within and across organisations, and reflects upon local healthcare service 'inequality' within a local area. This paper reflects on the nature of health service inequality and asks is some 'inequality' inevitable, and perhaps even equitable? It also meditates upon the role of the National Programme for Information Technology and how this may impact on such 'inequality'.

**Jenkins, N.**

**Cardiff University**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 11.55 - 12.25*

**"YOU CAN'T WRAP THEM UP IN COTTON WOOL": A COMPARISON OF PARENT AND CHILD ACCIDENT NARRATIVES**

Drawing on a collaborative PhD research project between Cardiff University and Barnardo's, this paper will explore the ways in which cultural discourses on risk inform and structure narratives about children's recent accidental injuries. It will discuss how parents' narratives demonstrate attempts to wrestle with competing social expectations; on the one hand to allow children to take risks and learn through exposure to adversity, on the other, to simultaneously protect their "vulnerable" bodies from injury and harm. When injuries do occur, parental assessment, monitoring and surveillance of the child's body are crucial factors in the decision to use accident and emergency services. Through adopting the role of the lay medic, parents must decide whether their child's body is genuinely and significantly damaged. In reaching this decision, a wide range of factors is taken into account, including the personal attributes of the child as well as the nature of the physical injury. In contrast, young people's accident narratives frequently utilise exposure to danger in order to re-present socially competent, active risk-taking identities. However, young people are extremely sensitive to adult demands and expectations to use protective clothing when engaging in injury risking activities. Through a dramaturgical analysis, this paper will explore the socially situated conditions in which the use of protective clothing is both congruent and incongruent with young people's social performances.

**Jordan, J., O'Grady, J.**  
**Queens University, Belfast**

*Stream: Mental Health*

*Saturday the 18 September 2004 at 09.40 - 10.10*

### **CAN THE CONCEPT OF SOCIAL CAPITAL ADVANCE UNDERSTANDING OF THE OCCURRENCE OF SUICIDE AND DELIBERATE SELF-HARM?**

In recent years the notion of social capital has gained acceptance as having the potential to shed important insights into the relationship between health and its broader determinants.<sup>1-2</sup> However, the value of social capital in articulating, specifically, the relationship between suicide/self harm and these social determinants remains largely unexplored. Some indication of its value is provided by those analyses that recognise the importance of anomie (social fragmentation) in influencing suicide.<sup>3-7</sup>

The concept of social capital remains contested at both the levels of theory and measurement. The version currently dominating within social science literature is that developed by Putnam,<sup>8-9</sup> who focuses on the collective features of social organisation that facilitate action for mutual benefit. Alternatively, Portes<sup>10</sup> argues that (access to) social capital resides in the relationships between individuals as members of a group.

The aim of the proposed paper is to use research evidence, derived from a study of suicide/DSH in Northern Ireland, to consider, generally, the relationship between social capital and mental health. In so doing, the following issues will be explored: the implications of differing 'models' of social capital for researching suicide/self-harm; the interplay between social capital and a range of structural factors (e.g. gender) on suicide/self harm, and; the implications for the development of policy aimed at promoting positive mental health. In addition, the paper will seek to use the above discussion to make a contribution to theoretical accounts of social capital, including the development of appropriate indicators.

**Karlsen, S.**  
**University College, London**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 14.35 - 15.05*

### **WHAT'S IN A NAME? A QUANTITATIVE AND QUALITATIVE EXPLORATION OF PROCESSES UNDERLYING ETHNIC IDENTIFICATION**

The development of an ethnic identity requires the consolidation of external and internal processes. That an 'us' requires a 'them' is common sense. While there may be something inherent about ethnicities which provide for definitional consistency regardless of this 'other', who 'they' are and their attitudes towards 'us' have a critical influence on our sense of ourselves.

People decide the basis of their ethnic affiliation and how this identity is to be presented to the outside world. But such choices are externally structured. The reaction of 'others' to 'us' (racist stereotyping, for example) will affect how we see and choose to present ourselves and the salience which our ethnicity holds in our lives. Similarities in the reactions of (more powerful) 'others' to 'other' (less powerful) others', other ethnic minority groups for example, may also promote the engendering of identities which go beyond traditional ethnic boundaries. Previous research suggests that perceptions, experiences and fear of racism all influence health. These findings would suggest that racism also affects how we see, describe and promote ourselves. The implications for self-esteem and mental health may be profound.

This paper uses data from a quantitative and qualitative follow-up of respondents to the Health Survey for England, which explored the experiences of a nationally representative sample of Bangladeshi, Caribbean, Indian, Irish, Pakistani and 'white majority' people. Factor analyses were used to identify, quantitatively, principal dimensions underlying processes of ethnic identification for the different ethnic groups. A qualitative analysis was then undertaken to provide further depth.

**Kelly, M.J.**

**Queen Mary, University of London**

*Stream: Health Service Delivery*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**ROLES AND RESPONSIBILITIES: ORGANISATION OF HEALTHCARE IN INTERVIEW ACCOUNTS OF THE DEATH OF A SPOUSE**

This paper will examine the way in which lay people organise healthcare in the process of describing their experiences of terminal cancer care. The data were collected as part of a semi-structured interview study that aimed to evaluate healthcare for people who had died from cancer and their spouses (Seale and Kelly, 1997). An ethnomethodological approach has been adopted, meaning that the interviews are treated as locally situated, recipient-designed accounts. More specifically the membership categorisation and sequential work carried out in the production of the interview accounts has been analysed following Sacks (1992). Building on earlier research by Baruch (1981), detailed analysis of how the accounts are produced reveals complex moral work undertaken by the interviewees. This involves setting up lay and professional identities, and associated roles and responsibilities, in relation to events such as being present at the death. Importantly this displays how relations between lay people and professionals are constituted, and how this may influence the way in which care is assessed. The widespread use of interview data in health research means that this is a significant place in which healthcare becomes relevant.

Interviews are frequently used to elicit the views of 'the consumer' and the data are used to influence policy and practice initiatives. We need to pay greater attention to how healthcare is organised and constituted in interviews.

**Kendall, M., Worth, A., Murray, S.A., Boyd, K., Cormie, P., Macleod, U., Heaney, D.**

**School of Clinical and Community Health, Edinburgh**

*Stream: Cancer*

*Friday the 17 September 2004 at 10.10 - 10.40*

**DIFFICULT TIMES: PATIENT AND CARER ACCOUNTS OF OUT-OF-HOURS PALLIATIVE CARE SERVICES**

This qualitative study explored the out-of-hours needs and experiences of palliative care patients and their carers. Out-of-hours services are undergoing fundamental change, with potentially adverse effects on care for this group of users. Consequently exploring their perceptions and understandings, as situated within the cancer journey, is vital.

**Methods**

In-depth interviews with 32 patients with advanced cancer, who had recently used out-of-hours services, and 19 carers. 50 telephone interviews with key professionals; 8 focus groups of patients and carers. These interviews and group discussions were taped, transcribed, and analysed with the aid of Nvivo and the techniques of narrative analysis.

**Findings**

Three major themes emerged from the participants' accounts: the burden of decision-making; the difficulty of constructing oneself as a legitimate patient; and the struggle to maintain relationships with health care staff.

Patients and carers found it difficult to decide whether their needs were serious enough to warrant calling the out-of-hours service. Some did not know whom to contact, or were apprehensive about utilising the available services.

Most patients and carers felt that only physical needs could legitimate calling the service. However many spoke of experiencing fear and anxiety, feeling isolated from their usual support mechanisms. Most wanted a home visit, but this could bring them into conflict with professional priorities, thus threatening important and hard-won relationships.

**Conclusions**

This study highlights gaps in care and factors that could foster good out-of-hours care, responsive to the needs of palliative care patients.

**Kendall, K., Lathlean, J.**

**University of Southampton**

*Stream: Mental Health*

*Friday the 17 September 2004 at 11.20 - 11.50*

**WHO IS RESPONSIBLE AND WHO IS IN CONTROL? PATIENT PERCEPTIONS OF PSYCHOLOGICAL TREATMENT FOR ANXIETY AND DEPRESSION**

This paper reports on findings from 20 interviews with people who received psychological treatment from Community Mental Health Nurses for anxiety or depression. All participants were enrolled in a larger RCT designed to assess the effectiveness of problem solving treatment as compared to generic counselling. A key aim of both interventions was to improve emotional symptoms through the reassertion of control over one's own life.

Semi-structured, in-depth interviews were conducted in order to explore participants' perceptions about the intervention they received. The interviews, which typically lasted one hour, were audio-taped and transcribed verbatim. Informed by grounded theory methodology, the transcripts were analysed systematically through a process of constant comparison.

The key benefit from both problem solving and generic counselling was that that it helped participants to function in their expected social roles, such as work, parenting and marriage, by facilitating the thinking and decision-making around the problematic issues involved. At the same time, however, concerns were raised that since responsibility for dealing with the situation rested almost entirely with the participants, they may ultimately be disempowered rather than empowered. For example, participants reported changing their own behaviour and attitudes while remaining in harmful circumstances over which they had little or no control.

The authors argue that the provision of psychological treatment for emotional problems is emblematic of the current neo-liberal political climate. They conclude by demonstrating how their research offers a contribution toward the development of existing sociological theory, particularly around issues of agency, responsibility and risk.

**Kingdon, C., Lavender, T., Singleton, D.V.**

**Cartmel College, Lancaster University**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 10.10 - 10.40*

**EVIDENCE FOR CHOOSING CAESAREAN SECTION ON TRIAL**

What is the legitimacy of a woman's right to choose the way she gives birth in the British National Health Service? What are the risks and benefits of planned caesarean section compared with planned vaginal delivery in technocratic cultures? These are the two key questions underlying an ongoing piece of research that makes links between the lived experiences of over two hundred women giving birth for the first time in a large maternity hospital in the North of England and feminist science studies. In the absence of a clinical indication the decision to perform or refuse a planned caesarean section is currently made by clinicians within an unclear ethical framework and with contested evidence on the relative risks and benefits. This paper will focus on whether a randomised-controlled trial of planned caesarean section versus planned vaginal birth is inevitable in a healthcare culture that promotes evidence-based informed choice. The discussion will consider what kinds of knowledge are currently excluded from debates about the need for a trial using extracts from the presenting author's own fieldwork. Qualitative data from in-depth interviews is currently being triangulated with quantitative data from semi-structured questionnaires, validated physical and psychological outcome measures, and routinely collected hospital data sets. Methodological issues including the risks of privileging only certain types of knowledge in a hierarchy of evidence, how evidence may be constructed to perpetuate existing practice, and whether evidence is only accepted if it conforms to existing practice beliefs will all be explored.

**Kinn, S., Dalgarno, P.**

**Glasgow Caledonian University**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

### **WHAT ARE PATIENT CENTRED OUTCOMES? A REVIEW OF THE LITERATURE**

There is increasing emphasis placed upon the development of patient centred care and involving patients and members of the public in health care. In regard to measurement of patient centred outcomes, there is a large literature on the development and use of a range of different outcome measures. A number of authors have claimed to take the patient view into consideration, but the terminology used is very confusing and there are no standard definitions of terms used or concepts being measured. This study reviewed the published literature to identify how and when authors were using the terms 'patient centred', 'patient based' etc, to see if trends in the existing literature would lead to suitable definitions of terms. Eighty three papers were uncovered and sorted into three categories, based upon how the authors involved patients. A wide range of terminology was used by authors, with no consistency whether the main focus of the paper was patients as sources of data (35 papers), quality of life (21 papers) or where authors stated that they were identifying what was important to patients (27 papers). Additionally there was confusion about what was actually being measured; health status, quality of life and patient centred outcomes were used interchangeably by many authors. There was a focus on the design and evaluation of standardised measures and less attention placed on the individual and their response. For outcome measurement to become patient centred, measurement needs to be iterative and the results fed back into the subsequent clinical processes.

**Kirkman, A.**

**Victoria University of Wellington, New Zealand**

*Stream: Gender*

*Thursday the 16 September 2004 at 14.00 - 14.30*

### **MANAGING GENDER, SEXUAL AND MEDICAL IDENTITIES**

The experience of women doctors is now more fully documented in the sociological literature and this literature reveals how gender is still a point of differentiation for those in the medical workforce. While there has been increasing coverage of gender differences there has been less attention paid to sexualities. This paper explores the experiences of women doctors who identify as other than heterosexual and, in this particular case, lesbian or gay. This identity brings into sharp focus the way in which bodywork in medical settings involves the negotiation of situations of intimacy. This paper explores these experiences through the narratives of 10 women doctors. These reveal how both gender and sexual identities influenced the medical careers they pursued. More significantly their accounts reveal differences between them and women doctors more generally and these differences relate to the combination of sexuality and gender rather than gender alone. The career trajectories and the strategies used by these women to manage their everyday working lives are compared with the findings in the sociological literature on women doctors.

**Kordes, D.**

**The Australian National University**

*Stream: Mental Health*

*Saturday the 18 September 2004 at 11.00 - 11.30*

### **THE SHIFTING BOUNDARIES OF CARE: THE CHANGING ROLES AND RESPONSIBILITIES OF FAMILIES IN THE CARE OF MENTALLY ILL PERSONS IN 20TH C AUSTRALIA**

Historical trends in the management of mental illness in twentieth century Australia have to varying degrees been influenced by the rationalities of liberalism. The language and technologies of these political rationalities have underpinned changes in mental health governance by reconfiguring the agents and subjects of government and imbuing them with new capacities. The Lunatic Patient has been transformed into the Mental Health Consumer, a subject of freedom and choice, while families are now referred to as Carers, and invited by government to become agents in the management of mental illness.

This paper illustrates some of the ways in which governmental rationalities have reconfigured the roles and responsibilities of families in the care of mentally ill persons by drawing upon archival and interview material from a case study of the Australian Capital Territory, 1925 to the present day. Canberra families' interactions with Kenmore Mental Hospital are compared and contrasted with those of families in the current mental health care setting of the A.C.T. Analysis reveals the different ways in which roles and responsibilities ascribed to families mediate both the kinds of care they may provide for unwell family members and their interactions with other agents of government. The paper notes that, in comparison with families associated with Kenmore, the voice and influence of carers in the current mental health community has declined. This is attributed to the reconceptualisation of the mentally ill person as an adult with capacity; marketplace norms informing the purchaser/provider relationship; and psychiatry's reliance on biomedical treatments.

**Krones, T., Schlüter E., Richter, G.**

**Universität Marburg, Germany**

*Stream: Health Technologies*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**PRENATAL AND PREIMPLANTATION GENETIC DIAGNOSIS IN GERMANY- ATTITUDES OF EXPERTS, POTENTIAL PATIENTS AND THE GENERAL POPULATION**

In Germany, prenatal diagnosis (PD) is a common practice but preimplantation genetic diagnosis (PGD) is prohibited due to the restrictive German Embryo Protection Law. PGD as well as PD were vigorously debated in Germany during the last four years. Up to now, no political consensus could be achieved. In the German debate, political decisions did not go hand in hand with the consideration of opinions of relevant societal groups.

In our studies we assessed the attitudes on and (potential) usage of PD and PGD in five representative expert samples (geneticists, paediatricians, midwives, ethicists and obstetricians, n=879), the general population (n=1017) and couples with a high genetic risk (n=324) by face to face interviews (population, couples) and postal questionnaires (experts). Several medical conditions and psychosocial factors were also recorded. In every group, intensive qualitative interviews were additionally conducted.

In general, attitudes of all groups surveyed were more liberal as discussed in parliament and in the German National Ethics Council. The majority of all groups voted for a moderate legalization of PGD, regardless of the high moral status ascribed to the preimplantative embryo by most of the interviewees. PGD was the most probable reproductive option for 17% of the high risk couples with a persisting desire for a child. Several independent influence factors on the attitudes towards PD and PGD could be found by multivariate analysis

Our results have several implications for addressing ethical issues in Health and Parliamentary Technology Assessment and for a strive towards a global bioethics perspective.

**Kuhlmann, E.**

**University of Bremen, Germany**

*Stream: Gender*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**MAINSTREAMING GENDER INTO THE PROGRAMS FOR CHD - NEW STRATEGIES TO IMPROVE QUALITY OF CARE IN GERMANY**

CHD is the major reason for mortality and morbidity of men and women all over the world. However, it is mainly perceived as problem of men's health and women's needs are neglected. In this paper I make the case for a gender sensitive approach. I argue that significant gender differences observed in many nations and all areas from prevention to treatment and outcome in many cases are caused by the health care systems themselves. These systems currently are undergoing fundamental change. My aim is to explore the links between new programs for CHD in Germany and the introduction of a gender perspective in health care, and its contribution to quality improvement.

Method: 1) literature review of gender specific data and analysis, 2) expert interviews and written statements from high status actors in German health care, and focus groups with patients in CHD self-help groups.

Results show a wide variation in treatment of women and men with CHD. Women are mostly under-served and less seldom treated according to EBM and guidelines, whilst men are possible over-served with diagnostic and surgical procedures. New models of organizing health care open pathways to negotiate seemingly objective and neutral criteria of biomedicine and the underlying, but hidden gender order. Gender assessment can serve as a strategy to bring structural deficits of health care systems into focus and to improve the quality of care.

**Lanceley, A., Jacobs, I., Menon, U., Savage, J., Warburton, F.**

**University College London**

*Stream: Cancer*

*Friday the 17 September 2004 at 14.35 - 15.05*

**THE MULTIDISCIPLINARY CANCER TEAM MEETING: AN ETHNOGRAPHIC STUDY**

The multidisciplinary team (MDT) meeting is recognised by the Department of Health as 'the engine room of improved care' (Cancer Collaborative, 2003). As yet there is little empirical research on cancer teams in action; their evolution, functioning and dynamics. Where evidence exists it highlights the complexity of developing teamwork arrangements and considerable ambivalence about the success of teams.

Drawing on observation, interview and questionnaire data from a six-month ethnographic study of a weekly gynaecological cancer multidisciplinary team meeting in one Cancer Network, we present findings on the clinical decision-making practices contributions and experiences of team members.

Our findings relate to issues of power, control and forms of knowledge at the heart of relationships between health care professionals. Drawing on theories of professionalisation and emotion in groups we consider how health professional's contributions to decision making within the weekly MDT meeting help to define professional identities. We acknowledge that the MDT is not the sole arena for clinical decision-making. However a clearer understanding of the different contributions and variations in perceived role of members of the MDT in decision-making during their formal meeting has implications for the working of multidisciplinary groups and the training of health care professionals.

**le May, A.C., Gabbay, J.**

**University of Southampton**

*Stream: Health Service Delivery*

*Thursday the 16 September 2004 at 14.00 - 14.30*

**FROM "MINDLINES" TO CODIFIED KNOWLEDGE: THE SOCIAL CONSTRUCTION OF KNOWLEDGE-IN-PRACTICE: FURTHER WORK FROM AN ETHNOGRAPHY OF PRIMARY CARE**

This paper builds on the findings reported at the 2003 Medical Sociology conference, where we explored how practitioners in a highly regarded 8-partner GP practice use various sources of knowledge to shape their individual and collective healthcare decisions. We suggested that practitioners collectively develop "mindlines" - internalized, tacit guidelines based on earlier training, brief reading, experience, interactions with opinion leaders, patients, pharmaceutical representatives, and other sources of largely tacit knowledge ; the mindlines were strongly influenced by their interactions with each other and by their organizational demands and constraints. Here we explore how practitioners influenced each others' mindlines, and how the formulation of policies for the management of common conditions was mediated by their social, political and technical context.

The study - which still continues - has employed ethnographic methods over two years. As part of that work we have been following two collective processes that engaged the GP partners, all the other clinical practitioners, and administrative staff. During their regular meetings we observed how they exploited their internal and external social, professional and organisational networks in order to pursue the collective aim of turning tacit knowledge into explicit codified protocols that would meet the requirements of external bodies while also optimising both the quality of care and the practice's income. One interesting feature, which we shall explore in detail, has been the way in which particular definitions of clinical conditions and agreed treatment protocols arose from negotiations about competing external demands, professional aspirations, technical IT constraints, and organisational roles and needs.

**Leeson, J., Richardson, B., Poland, F.**

**University of East Anglia**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 09.35 - 10.05*

### **HOW ARE MEETINGS USED FOR INTERPROFESSIONAL COLLABORATION BY CHILD DEVELOPMENT TEAMS?**

Meetings can be seen as a particular type of social gathering with a purpose, a place where "social systems are constructed" and individual members can "make sense of them" (Schwartzman 1988 p309). They constitute part of everyday work routines and rituals where the organisation or organisations can be seen to come together, to talk, to problem solve or to make decisions (Boden 1994). However meetings are differently constituted in relation to their structure, participants and settings; the type of talk, involvement of the members, style of negotiation and associated paperwork. They can vary from formalised and timetabled events to impromptu "corridor" gatherings where chance encounters are used to progress interprofessional activity.

Child development teams are multidisciplinary groups of practitioners who usually come from more than one agency. Their purpose is the coordination of services for children with disabilities. Meetings held by these teams provide settings within which to access rich data about interprofessional working.

Using evidence from an ethnomethodologically-informed ethnography of two child development teams, this paper examines data from their meetings to problematise interprofessional collaborative practices. Differently-constituted meetings, both clinical and non-clinical, will be examined in terms of how teams use meetings to construct organisational activities, establish social communication, enable information exchange, and to negotiate shared goals.

**Leontowitsch, M., Stevenson, F.**

**Royal Free and University College Medical School**

*Stream: Lay/Professional Interface*

*Saturday the 18 September 2004 at 11.00 - 11.30*

### **FEASIBILITY AND ACCEPTABILITY OF CONCORDANCE IN PHARMACY PRACTICE**

The concept of concordance was developed following attempts to understand why some people do not take medicines as prescribed. Advocates suggest that there is a need to develop a different model of the patient-prescriber relationship that centres on the importance of an honest exchange of information between patients and professionals about medicines and medicine taking. Discussion and research thus far has generally focused on the relationship between doctors and patients however this paper, in the light of government support for extending the role of the community pharmacist, focuses on the pharmacist-customer relationship. We report on a study that investigates the feasibility and acceptability of concordance in pharmacy practice using data from observational field notes and tape-recorded consultations between pharmacists and their customers when considering a purchase of an over the counter medicine. The research is being conducted in two pharmacies that concentrate their services on medicines advice and dispensing, and aim to achieve concordance in their everyday practice. This allows us to examine the ways in which concordance may be operationalised under what can be described as an ideal setting. It also enables us to judge the extent to which factors such as time-constraints and resource pressures mitigate against the successful implementation of the principles of concordance. In sum the paper examines the extent to which it is possible to translate the theoretical ideals of a particular model of health care professional-client interaction in to practice.

**Lester, H., Tritter, J.**

**University of Birmingham**

*Stream: Mental Health*

*Friday the 17 September 2004 at 09.00 - 09.30*

**"LISTEN TO MY MADNESS": DEVELOPING A SOCIAL MODEL OF DISTRESS AND MADNESS**

**Introduction**

This paper explores the salience of the social model of disability for understanding the experiences of people with serious mental illness and the primary care health professionals who care for them.

**Method**

Focus groups were convened in six Primary Care Trusts (PCTs) across the West Midlands between May and November 2002 with users with serious mental illness, GPs and practice nurses. Separate user and health professional focus groups were followed, a week later, by a combined group of users and health professionals. The topic guide explored user experiences and health care responses and critical incidents along the care pathway. Focus groups were audio taped and fully transcribed. Data were organised into initial and then higher codes that provided insight into identified themes.

**Results**

Eighteen focus groups involved 45 users, 39 GPs and 8 Practice nurses. Most users described experiencing impairment as a result of the illness and from prescribed medications, and disability in terms of the geography of primary care, and health professional negative stereotypes. The interactions between disability and impairment had consequences for access to and use of health services and the conscious strategies users adopted to manage their situation. The heterogeneity of individual socio-demographic characteristics and the local health care context were important in explaining users' strategies and the response of health professionals.

**Conclusion**

A social model of distress and madness grounded in the social model of disability provides an innovative way of understanding and making sense of the experience of users and health care providers.

**Leydon, G.**

**London School of Hygiene and Tropical Medicine**

*Stream: Cancer*

*Friday the 17 September 2004 at 10.45 - 11.15*

**COMMUNICATING IN OUTPATIENT ONCOLOGY CONSULTATIONS: THE GOOD, THE BAD AND THE UNCERTAIN**

In this paper I examine how good, bad and uncertain information about diagnosis and treatment is shared during consultations between doctors and patients. Analysis is based on audio-recordings of 28 outpatient oncology consultations and draws on the principles of conversation analysis. All patients had already been diagnosed with cancer and were recorded while attending clinic to discuss adjuvant chemotherapy or radiotherapy for the first time. Analysis suggests that information delivery is organised to minimise the chances of the consultation becoming overwhelmed by the relatively 'bad' news, such as lymph node involvement. This is accomplished by emphasising the relative good (of what can be done), but is done so in the context of the uncertainty about treatment and cancer. In line with Maynard's (2003) discussion of good and bad news in primary and secondary care settings, participants' in the cancer consultation work to uphold the 'benign' order of everyday life, or at least the relative 'good'. Analysis contributes to a growing body of work that seeks to explicate how information is shared in the cancer setting. Findings are discussed in the context of recent policy and research recommendations for 'good' and 'sensitive' communication.

**Liljeroth, P.**

**Abo Akademi University, Finland**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 10.45 - 11.15*

**FEAR OF CHILDBIRTH IN THE OBSTETRIC DISCOURSE IN FINLAND AND SWEDEN: ACTIVE OR REACTIVE REDEFINITION?**

Obstetricians have, during the last 25 years, studied the causes and consequences of fear of childbirth and they suggest that fear of childbirth complicates some 20 % of pregnancies in developed countries. There is no uniform definition for the phenomenon but researchers have presented numerous different reasons for fear of childbirth. Fear of childbirth is said to be a common reason to request an elective caesarean section. In Finland "fear of childbirth" is a separate ICD-10 code; O99.80. In Sweden the term "humanitarian reasons for caesarean section" is used, while the term "caesarean on maternal request" is used in the UK.

This paper takes a closer look at how women's fears of childbirth are discussed in the obstetric fields in two countries; Finland and Sweden. My material consists of articles concerning fear of childbirth, written by Finnish and Swedish obstetricians, and published in medical journals. How does the medical discourse construct the concept "fear of childbirth"?

In the paper I explore on what terms one can talk about medicalization of the fear of childbirth. The medical interest in fear of childbirth could be explained as medicalization, in terms of paternalistic domination, of yet another field of women's reproductive health. However, medicalization can also be seen as empowering to birthing women. For them the medical discourse offers opportunities for the redefinition of the birthing experience. By using medicalization of their fear of giving birth as a strategy, individual women can enhance control over their own bodies.

**Lorimer, K.**

**University of Glasgow**

*Stream: Gender*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**COMMUNITY BASED APPROACH TO SCREENING YOUNG MEN AND WOMEN FOR CHLAMYDIA TRACHOMATIS**

Chlamydia trachomatis infection is the most common bacterial sexually transmitted infection in the industrialised world. The infection is largely asymptomatic, with up to 80% of females and 50% of males having no symptoms. Whilst reported rates in Scotland have increased by around 300% between 1995-2000 among under 25's, the true prevalence of C. trachomatis remains unknown. However, it is estimated that around 1 in 10 young people aged under 25 have this infection. No national screening programme for chlamydia is planned, but until recently the emphasis was on screening and treating women, with no screening for men and other services largely restricted to partner notification and contact tracing. With both a recent Health Committee report to the Department of Health (England & Wales) and an Independent Advisory Group advocating 'innovative' approaches to engage the male population in screening, the current climate supports screening in non-medical settings. But how far is this feasible? And are young people willing to be tested in such settings?

This paper is based upon an on-going PhD study, investigating the appropriate settings in which to best offer screening for young men and women. Three community settings (education, health and fitness and workplace) were chosen. Users (aged 16 to 24) were asked to complete a questionnaire and offered testing for chlamydia by urine sample (they could choose NOT to provide a sample and remain in the study). Depth interviews were also employed once positive results were sent out. This paper discusses current findings.

**Lowton, K.**

**King's College London**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 14.35 - 15.05*

**RELATIVES' EXPERIENCES OF CARE GIVEN TO FAMILY MEMBERS WHO HAVE DIED FROM CYSTIC FIBROSIS**

Immense progress has been made in the understanding and treatment of cystic fibrosis (CF) such that average survival age has steadily increased to 32 years. Much current research focuses on the impact of routine treatments and how future potential treatments such as gene replacement therapy may extend and enhance life. However, although those with CF do not tend to survive past early adulthood, understanding the social processes of death and dying in CF and describing how care is currently organised and experienced at the end of life are neglected research areas.

This paper aims to describe and understand families' experiences of end-of-life care given to those with CF through analysis of letters, cassettes and in-depth interview material obtained from those who had lost a family member with the disease during 1999-2002. Families' experiences were as diverse as the disease process itself; some adult children appeared to have shielded their parents from knowledge of their impending death, whilst others had organised their own funeral 'party' and made light of their dying. Many parents stated that they had difficulty believing that their child was dying, as clinic staff had previously told them that an episode of illness was 'the last'. Both those families who had had experience of organ transplantation, the final treatment option, and those whose children had refused this intervention viewed the process with ambivalence. Understanding the experiences of these participants represents a start in understanding how death and dying is managed amongst young adults with CF and their families.

**Macdonald, C.**

**University of Edinburgh**

*Stream: Inequalities*

*Friday the 17 September 2004 at 15.10 - 15.40*

**LIVE LONG IN SCOTLAND - THE RELATIVE CONTRIBUTION OF MEDICINE AND STANDARDS OF LIVING TO SCOTLANDS FALLING MORTALITY RATES**

This paper will discuss the contribution which medicine has made to the decline of tuberculosis and stomach cancer mortality during the 20th century. This is taken from my PhD, which is examining the wider influences of medicine and standards of living on the decline of mortality in Scotland since 1950.

This study follows on from the work of Thomas McKeown. McKeown examined the decline in mortality in England and Wales up until 1970, focusing mainly upon the earlier time period. He isolated tuberculosis as having been the principal contributor to the decline of mortality and concluded that medicine played almost no part in its overall decline; instead he placed improvements in diet at the centre of his explanation.

My PhD has drawn on the death returns of the Registrar Generals Office for Scotland over the period 1950 - 99, from these the causes of death which have contributed the most to the decline in mortality in Scotland have been isolated. This data has been related to changes in medicine and standards of living in Scotland, with three causes of death having been selected as case studies. My findings on the trends and influences on mortality for stomach cancer and tuberculosis will be discussed in this paper.

**MacEachen, E.**

**Institute for Work and Health, Toronto**

*Stream: Health Policy*

*Friday the 17 September 2004 at 15.10 - 15.40*

**SUBTERRANEAN DISCOURSES IN OCCUPATIONAL HEALTH: THE TRANSLATION OF POLICY IN EVERYDAY WORKPLACE PRACTICE**

Governmentality theory has been criticized for privileging official discourses thereby under-theorizing constitutive elements of resistance and human agency. In particular, the concept of 'government at a distance', which refers to neoliberalist strategies of administration through motivation, education, and persuasion, has been challenged for not considering 'government from below' and for characterizing actors as puppets of policy. For instance, what happens when locals fail to take their duties seriously, or when locals direct community activity in a way not intended by the programmers? This paper examines agency and 'government from below' in the case of how managers interpreted and applied occupational health and safety policy in Ontario, Canada.

Drawing on a qualitative interview study of how thirty five managers dealt with repetitive strain injury in four newspaper workplaces, this paper argues that managers 'translate' policy in ways that both meet legal mandates and make occupational health and safety policy look successful, but which also subvert and redirect policy. On the surface, occupational health policy appears to have successfully motivated workplaces to maintain safer work environments because compensation costs are down, and there are fewer reported injuries.

However, at a subterranean level, this study shows a level of complexity where managers have, in various local ways, reduced injury rates by re-defining worker injury, entitlement and access to compensation benefits. This paper describes the constitutive flexibility of government at a distance, and discusses the case of 'government from below' when these players, as agents rather than puppets, represent capital rather than emancipatory interests.

**MacFarlane, A., Murphy, A.**

**National University of Ireland, Galway, Republic of Ireland.**

*Stream: Primary Care*

*Thursday the 16 September 2004 at 14.00 - 14.30*

**THE IMPACT OF LANGUAGE AS BARRIER IN PRIMARY CARE FOR REFUGEES AND ASYLUM SEEKERS IN THE REPUBLIC OF IRELAND: AN ACTION RESEARCH STUDY**

**Background**

The recent Irish Health Strategy recognises that mainstream and specialist health services should be accessible to refugees and asylum seekers and delivered in a culturally sensitive manner. However, language differences and communication difficulties pose major problems in primary care consultations for refugee and asylum seeker and service providers alike. There is no data, however, about the impact of these problems on the process and outcome of primary care consultations.

The aim of the present study is to examine the impact of language as a barrier in primary care consultations. A specific objective is to document the ways in which the language barrier is experienced, and responded to, by refugees, asylum seekers, general practitioners and public health nurses.

**Methods**

Action research methods are being used. Purposeful sampling, disaggregated by ethnicity (Croatian and Russian participants) and gender, in urban and rural settings, is being used. A combination of participatory learning and action techniques (PLA) are being used to collect data including card sorts, direct ranking exercises and matrices.

**Findings**

In this paper, preliminary findings are presented about refugees and asylum seekers experiences of language as a barrier to primary healthcare. Findings about their use of formal and informal interpreters and their perceptions of the impact of the language barrier on the process and outcome of their primary care consultations will also be presented. The implications of our preliminary findings for health service delivery in an emerging multicultural Irish society will be considered.

**Martin, W.**

**University of Warwick**

*Stream: Lifecourse*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**RISK, HEALTH AND IMAGES OF AGEING: POSSIBILITIES AND DILEMMAS OF DEVELOPING A VISUAL METHODOLOGY**

The promotion of healthy lifestyles and positive ageing in later life has been a key development in recent health policy. Age is no longer viewed as a barrier to health promotion activities and now everyone is encouraged to adopt healthy lifestyles. These changes not only challenge the prevalent view of old age as an inevitable process of biological decline, but also signify the tendency of lay and expert discourses to increasingly use the notion of risk.

The aim of this paper is to consider how older people in later life negotiate their social identities and lifestyles. The paper will set out the research design of a study in progress that is examining: (1) the salience and limitations to the concept of 'risk' as a way older people construct meanings about their lifestyles, self-identities and bodies and (2) How older people negotiate their social identities in the context of contradictory images of ageing. In particular, the paper will explore the possibilities and dilemmas of developing a visual methodology to elicit insights into older people's social worlds and identities.

**Martin, P.A.**

**University of Nottingham**

*Stream: Genetics*

*Saturday the 18 September 2004 at 09.40 - 10.10*

**THE PROMISE OF GENOMIC MEDICINE: THE TRIUMPH OF HOPE OVER EXPERIENCE?**

Expectations of how genomics will transform medicine and healthcare remain high amongst UK policy makers, industry and the supporters of medical research. Official documents talk about the 'coming revolution in healthcare' and the promise of personalised prevention and treatment. However, this discourse of hope sits uncomfortably with the reality of the slow translation of discoveries in basic biology into routine medical practice. How are we to understand the co-existence of high expectations and disappointing clinical experience? Is this just the difficulty of translational research in a new field or does it represent a more profound problem with the concepts underpinning the molecular vision of disease? Can these high hopes, and the massive public and private investment mobilised by them, be justified? This paper will present summary data about the short- to medium-term prospects for the creation of a range of 'genomic' therapies and diagnostics, including therapeutic proteins, monoclonal antibodies, gene therapy, stem cell therapy, and DNA screening for common diseases. Drawing on this data and recent work on the 'dynamics of expectations' it will be argued that: 1) The medium term prospects for genomic medicine are greatly overstated; 2) The hopes contained in current policies and the increasing interest of social scientists in genomics and the geneticisation of medicine are themselves constitutive of this emerging field; and 3) Some of the fundamental assumptions guiding the pursuit of a reductionist molecular medicine may need critically rethinking.

**May, C., Finch, T., Mort, M., Mair, F.S.**

**University of Newcastle Upon Tyne**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 11.55 - 12.25*

**"BEING MORE MODERN": SHIFTING NOTIONS OF INNOVATION IN TELEHEALTHCARE**

'Modernisation' is a key policy objective in the British NHS. It extends across a range of service delivery and organisational contexts, but has also come to mean radical changes in perspective on professional behaviour and practice. Deeply embedded within the notion of modernisation is the assumption that new technologies - especially information and communications technologies (ICTs) - are key mechanisms through which reformed service delivery can be brought about. In this paper, we show how 'modernisation', 'innovation' and ICTs are intimately linked as devices to both engender and control professional territories and patients' access to these territories. We show how modest systems of practice, like telehealthcare, are formed around notions of progress in health care delivery and reductions in temporal and spatial inequalities in access, but can may come to be used to buttress and support those inequalities.

The study from which the paper is drawn is part of the ESRC innovative health technologies programme, and comprises interviews with 45 professionals, managers, patient advocates and service users, along with a citizens' panel and observations of professional and other meetings and presentations. Our particular interest in this work is to explore policy and practice linkages, and explore their connections with policy responses to chronic illness, and with the wider field of ICT infrastructure in the NHS. In particular, we will draw attention to the shifting definitions of 'innovation' in the NHS, and the ways that these define a move away from technological advances towards management control.

**McDonach, E., Barbour, R., Williams, B.**

**University of Dundee**

*Stream: Lay/Professional Interface*

*Saturday the 18 September 2004 at 09.40 - 10.10*

### **STAKEHOLDER INVOLVEMENT IN DEVELOPING DIABETES SERVICES: RHETORIC AND REALITY**

#### **Background**

This PhD study aims to capture the complexities in the process of stakeholder involvement in diabetes service development across Scotland. The Scottish Executive has launched a number of diabetes initiatives which emphasise the involvement of key stakeholders in diabetes service development. Understanding more about the particular processes of this involvement is important because different philosophies and models may be in operation.

#### **Design**

A longitudinal process evaluation using a range of qualitative methods is being conducted. The study is organised in two distinct phases. This paper will report findings from Phase 1 consisting of telephone interviews and teleconferences with key stakeholders across the 15 regions in Scotland. A content analysis of strategy documents (on stakeholder involvement in general, and diabetes services in particular) was also undertaken. Preliminary findings from Phase 1 will inform the selection of two or three health board areas as case studies for more in-depth investigation in the next phase of the study.

#### **Analysis/findings**

Data will be used to critically examine the concept of user involvement. This will include consideration of the historical background of each area, the development of involvement, the political, cultural and geographical context, as well as policy initiatives (both national and locality-specific). Comparing and contrasting professionals' perspectives from a range of disciplines and those of lay representatives' provides insights into how strategies of stakeholder involvement are translated into practice and ways in which potential benefits can be maximised and barriers reduced.

**McDonough, P., Sacker, A., Wiggins, R. D.**

**University of Toronto, Canada**

*Stream: Inequalities*

*Friday the 17 September 2004 at 16.20 - 16.50*

### **TIME ON MY SIDE? LIFE COURSE TRAJECTORIES OF POVERTY AND HEALTH**

Our study examines the relationship between poverty and health in time. Following the argument that time is significant for shaping the experience of being poor or not poor, and growing evidence of heterogeneity in long-term patterns of poverty, we investigate whether different kinds of poverty have distinct consequences for long-term health. Using data from the 1968-1996 annual waves of the Panel Study of Income Dynamics Data, we estimate a general growth mixture model to assess the relationship between the longitudinal courses of poverty and health. The model allows us to first estimate latent poverty classes in the data, and then determine their effects on latent self-rated health. Four types of long-term poverty patterns characterized as stable nonpoor, exiting poverty, entering poverty, and stable poor were evident in the data. These different kinds of poverty affected self-rated health trajectories in distinct ways, but worked in concert with age, education, and race to create gaps in initial health status that were constant over time.

**McKie, L.**

**Glasgow Caledonian University**

*Stream: Theory*

*Friday the 17 September 2004 at 14.00 - 14.30*

**VIOLENCE IS BAD FOR YOUR HEALTH: THE IMPLICATIONS OF WAR AND TERRORISM FOR HEALTH AND HEALTH CARE**

The health implications of the recent gulf war, on-going civil unrest, and terrorist activities are vast, not least for those who live in the midst of the violence. For those not residing in these localities, the violence and violations that emerge from geo-political tensions can appear unconnected with their everyday lives. However, recent bombings in Madrid, and allegations of foiled plots for suicide bombings in England, have brought the implications of conflicts elsewhere quite literally close to home.

Much of the recent response in the UK has focused upon so-called scientific acts of terrorism, and in particular, threats posed by chemical substances to water and air supplies. Groupings of scientists and public health practitioners have also responded with health authorities concerned to develop and test emergency plans. Threats posed by ETA, the IRA or UVF seem almost pedestrian in comparison to those emerging from the range of groups associated with Al-Qaida. The everyday impact of this apparent franchising of terrorism is evident in the choices people make about travel and the engagement of themselves or family and friends in certain public or social contexts. A heightened sense of risk for some exists alongside feelings of inevitability for others.

It is my contention that an evolving sociology of violence, especially one that is concerned with the experiences of communities, families and practitioners, must engage with the sociologies of the body, and health and illness, to offer a mediation of the everyday, bodily and organisational consequences of terrorism.

**McNamara, B.**

**University of Western Australia**

*Stream: Genetics*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**BETWEEN RISK AND TRUST: CREATING A POPULATION GENETIC DATABASE**

In this paper I discuss recent social and ethical debates surrounding population-based human genome research. Drawing upon a range of ethnographic data including a public survey, public forums and interviews with biomedical and public health researchers, I explore the early stages of the creation of a genetic database in Western Australia. The 'Family Connections' Population Genetic Database plans to link identified DNA samples recruited from families considered at risk of a range of common diseases to pre-existing health data. The first of its kind in Australia, and one of a selected number internationally, the planned database is small by comparison to the United Kingdom's biobank initiative. However, the relatively small and geographically isolated nature of the project presents unique epidemiological, clinical and methodological opportunities for the researchers involved in its implementation. Western Australia already has a record linkage facility that required an act of the Icelandic Parliament to enable the Icelandic Health Sector Database to come into fruition. It has a history of community participation in public health initiatives, and public survey and focus group data indicate a high degree of trust and support for genetic research. Issues of future governance and community consultation are also made more manageable in the view of the public's general receptivity to genetic research. In analysing the processes involved in proposing, marketing and developing the Family Connections database I consider the ways in which moral debates about genetic technologies are shaped within a particular local socio-cultural context of risk and trust.

**Meerabeau, E., Ruston, A., Clayton, J.**

**University of Greenwich**

*Stream: Primary Care*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**'A LOT OF THESE THINGS ARE GOOD IN THEORY': IMPLEMENTING RESEARCH GOVERNANCE IN PRIMARY CARE**

The Research Governance Framework for Health and Social Care was established by the Department of Health and is a framework of responsibilities and quality checks for researchers, employers of researchers, NHS care providers, funders and sponsors of research.

It requires the establishment of systems for being notified of any research activity, peer review and scientific support, approval registration and monitoring of all projects, liaison with ethics committees, safeguarding patient confidentiality, ensuring indemnity arrangements are sound, managing intellectual property and ensuring that Data Protection and Health and Safety laws are upheld. Primary Care Trusts were required to comply with a substantive proportion of the framework by 31 March 2003.

This paper examines academics' perspectives and experiences of complying with the Framework. Taped telephone interviews were conducted with 23 experienced academics from a range of primary care, acute care and social science disciplines within four institutions.

The findings are discussed using the literature on the governance of science, and risk management.

**Meyer, J., Lanceley, A., Bentley, J., Abbott, S.**

**City University**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 10.45 - 11.15*

**PATIENT ADVICE AND LIAISON SERVICES (PALS): LIFE IN THE FRONTIERLAND OF NHS CULTURE**

Patient Advice and Liaison Services (PALS) have been introduced as part of the Government's plan for patient and public involvement. Core functions are that they should: provide NHS users with an identifiable person for problem resolution or information; and act as a catalyst for service improvement in their host trusts.

This paper draws on selected data from a 27-month qualitative evaluation of London PALS. To explore both experiences of establishing and running these services and the views of direct and potential users of PALS, a range of methods were used. These included: semi-structured interviews with PALS officers, relevant Trust personnel, service clients and community group representatives, observation of PALS network meetings and focus group discussions.

We consider the work of PALS officers and the nature of their relationships to clients and NHS organisations with reference to Bauman's concept of 'cultural frontierland'. The meeting ground (the 'frontierland' of cultures in Bauman's thesis) is one in which boundaries are constantly drawn, only to be violated and redrawn. In part this is because partners emerge changed from every successive negotiation. We argue that, in their interaction with clients and staff, PALS officers are working as 'frontierlanders': for example, to understand not to censure; and to interpret not to legislate. In so doing PALS have the potential to effect cultural change in the NHS. However PALS struggle to make sense of uncoordinated, contradictory experiences engendered by the NHS Modernisation Agenda, which currently mitigates against the chance of the NHS being a 'frontierland'.

**Mitchell, J.D., Litva, A.C., Mair F.S.**

**University of Liverpool**

*Stream: Mental Health*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**'MENTAL HEALTH AND HEART FAILURE: THEORETICAL UTILITY OF A 'SHAME'-BASED INTERACTIONIST APPROACH**

This paper explores the utility of Symbolic Interactionism and Scheff's notion of 'Shame' as the theoretical starting point for a doctoral research project to investigate the quality of life of Chronic Heart Failure (CHF) patients and those around them. CHF is a disabling, terminal medical condition affecting a growing proportion of the population. There is evidence that mental health consequences of CHF are substantial, reducing quality and length of life. These consequences are often under-recognised and poorly managed.

Medicine generally locates these "problems" within the patient, typically categorising them as anxiety or depression. We explore the utility of Scheff's concept of 'Shame' as "master emotion" for understanding mental health in CHF. 'Shame' is understood as a family of emotions that emerges in the Self and "originates in threats to the social bond". We feel it may be a key influence on the interactions within a web of relationships around a CHF patient. The patient may feel 'Shamed' by the condition, its effects and causes. Significant others may experience 'Shame', as might health professionals. These perceptions may be different but can be characterised as threats to social bonds, hence 'Shame'-producing.

This web of interactions is located within a constructed social background, deriving from health politics, public health discourse and health promotion practice. These have contributed to a society that blames and stigmatises those suffering the consequences of what are perceived to be the result of personal behavioural shortcomings. Even the name of the condition, emphasising Failure, is open to pejorative interpretation.

**Mobasheri, M., van Teijlingen, E., Smith, C.**

**University of Aberdeen**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**OBESITY AND OVERWEIGHT IN POOR PEOPLE**

**Introduction**

Although obesity as an epidemic is well documented in developed countries some studies focus on the increasing prevalence of obesity and overweight in poor people in developing countries.

**Aim**

The main objective of this study is to systematically review search on prevalence of obesity and overweight among poor people and population indicated by forms of disadvantage such as, low income, unemployment, poverty, social class, educational level and socially isolated.

**Methods**

Search strategies included key words such as obesity, overweight, low income, unemployment, poverty, social class, educational level and socially isolated. The search strategies were run through MEDLINE from 1966 to March 2004 and Social Sciences Citation Index (SSCI).

**Results**

In first instance 1810 studies were found which appeared relevant, from reading the titles 75 studies were included, of these 21 matched the inclusion criteria of the review.

The review revealed a very high prevalence of obesity and overweight in low income, multiethnic populations. Obesity is rapidly replacing undernutrition in most regions of the world and income strata of the adult population in both genders. Rising national incomes in developing countries and increased 'Westernization' will most likely lead to increased levels of obesity in developing countries in the future.

**Discussion/Suggestions**

The increasing prevalence of obesity and overweight in low-income populations means it is a serious public health risk in the lower social strata of society, but always that is rapidly becoming a social inequality issue.

**Moffatt, S.**

**University of Newcastle**

*Stream: Inequalities*

*Friday the 17 September 2004 at 14.35 - 15.05*

**A QUALITATIVE STUDY OF THE PERCEIVED IMPACT OF INCREASING RESOURCES THROUGH A WELFARE ADVICE SERVICE ACCESSED VIA PRIMARY CARE**

In 1997-98, over one in four pensioner households were living in poverty and estimates suggest that around one million do not claim the financial support to which they are entitled. This qualitative study examined the perceived impact of receiving financial and non financial benefits. 25 men and women aged over 60 were purposively selected from a larger random sample (N=125) recruited for an RCT. The group comprised those eligible for: financial resources only; non-financial resources only; both and none. The total weekly amount recouped in unclaimed financial benefits was £671.70 and there were 9 successful claims for non-financial resources. Most participants lacked any knowledge of non-means tested health-related benefits, yet had one or more chronic health problems or were caring for a chronically ill relative. The reported impact of receiving extra resources included affordability of basic necessities, 'one off' payments and improved capacity to cope in a crisis. This, in turn, helped maintain independence, a sense of security and reduced their marginalisation. Overall, their ability to participate in society was increased. Although no-one indicated any improvement to physical health, most participants described benefits to their mental health and sense of well-being. Knowledge of, and access to, welfare advice services also appeared to have a therapeutic affect. Two key factors emerged regarding the welfare advice service: the fact that it was offered and that recipients were assisted to claim their entitlement, indicating that access to welfare advice services can have a direct impact on quality of life for older people

**Monaghan, L.**

**University of Newcastle**

*Stream: Gender*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**BIG HANDSOME MEN, BEARS AND OTHERS: REINTERPRETING FAT MALE EMBODIMENT ONLINE**

Social studies of fatness overwhelmingly focus upon women. There are important reasons for this, but sociology must also explore fat male embodiment if it is to more fully engage with the body-society nexus. Drawing from interpretative sociology, other relevant literature (e.g. on cultures of technological embodiment, the study of men and masculinities) and qualitative data readily available via the internet, this paper furthers the sociology of gender and fatness. Substantively, it presents a typology of fat male bodies (e.g. Big Handsome Men, Bears, Chubbies, Gainers, Belly Builders, Feedeers, Gluttons) and supportive/admiring others (cybersociates). These 'fat friendly' typifications are unpacked by referencing self-body relationships (i.e. orientations towards being or becoming fat or fatter), sexualities (which are relational constructs) and the meanings of food. Discussion then turns to the virtual construction of acceptable, admirable or resistant masculinities for those with offline discredited bodies and discreditable desires. Embodied themes include (1) appeals to 'real' or 'natural' masculinity; (2) the admiration and eroticisation of fat male bodies; (3) transgression, fun and the carnivalesque; (4) the pragmatics and politics of fat male embodiment; and (5) the interrelationship between virtual and actual life. While the internet may provide alternative (positive) understandings of fatness, discrepancies between virtual and actual identities (between normative expectations and undesirable attributes both on and offline), render stigma an ever present possibility for those with real fat bodies. These understandings are particularly relevant for medical sociologists at a time when so-called 'overweight' and 'obesity' are reportedly reaching epidemic proportions.

**Mulholland, J.**

**Thames Valley University**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 16.55 - 17.25*

**MANAGING DIFFERENCE IN SEX THERAPY PRAXIS: THE TENSIONS OF MULTICULTURALISM**

Sex therapy is comprised of a basket of therapeutic interventions concerned with enabling clients to achieve some form of resolution in respect of a 'problematic' dimension of their sexuality. Sex therapy can be understood as a terminal through which a range of 'socially worked' discourses pertaining to the nature and implications of ethnic diversity become mediated. Of particular importance in the context of sex therapy has been a range of deliberations pertaining to the implications of ethnic diversity for patterns of human sexuality, sexual problems/dysfunctions, and sex therapy praxis.

In respect of sex therapy praxis, ambivalence and indeterminacy have characterised accounts of the necessary and sufficient conditions for delivering non-oppressive, effective and equitable therapeutic practice within a context of ethnic diversity. Reinvigorated by the ascendancy of the 'diversity agenda', questions regarding the 'management' of ethnic diversity within practice have become more pressing for the sex therapy constituency.

Drawing upon a qualitative data set derived from semi-structured interviews with practicing sex therapists, this presentation offers an account of sex therapy as a complex constituency struggling with the tensions produced by incommensurate impulses towards an ambiguous multiculturalism, and a philosophical individualism valorized as the necessary pre-condition for therapeutically effective and ethical care. Utilizing Wieworka's account of multiculturalism, the paper will map the principle contours of sex therapy's difficult engagement with multiculturalism as a framework for the conceptualization and management of ethnic diversity in sex therapy praxis.

**Murtagh, M.J.**

**University of Newcastle**

*Stream: Ethics*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**AUTONOMY, FREEDOM AND RESPECT IN THE PATIENT AND PUBLIC INVOLVEMENT AGENDA:  
PRODUCING THE ACTIVE AGEING SELF**

The patient and public involvement agenda in contemporary UK health policy and practice is imbued with discourses of participation in which concepts of empowerment, decision making and choice are deployed. In the context of an ageing population these discourses and a long standing politics of ageing with emancipatory aspirations produces the contention that the active participation of older people in planning the health policy, health care service delivery and research that affects their lives ("Nothing about us without us!") is inherently a good thing. Yet, the active older citizen produced by discourses of participation is juxtaposed against contemporary constructions of older age as a time of passivity and dependence. Suspicious minds identify in these political agendas regimes of control.

Concepts of power, ethics and freedom in the work of Foucault and Rose enable us to read in practices of participation, decision making and choice forms of freedom that themselves limit freedom. Specifically, the production of an ageing self which obliges engagement, an ethic of autonomy, serves to intensify power relations in the context of apparently mutually exclusive co-constructions of ageing as autonomous and dependent.

Even in critique this reliance on autonomy and freedom constrain our considerations of what is at stake for older people's involvement in shaping health care practice and policy. Acknowledging the problems of empowerment as a goal for older people's participation, I reflect on the possibilities afforded by notions of respect in conceptualising participation; perhaps a post-Kantian respect disinvested of assumptions about the Enlightenment individual.

**Nettleton, S., Burrows, R.**

**University of York**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 11.20 - 11.50*

**"I AM WARY. I DON'T JUST BELIEVE EVERYTHING I READ THERE. BUT THEN SOME PEOPLE DO":  
AN ANALYSIS OF ACCOUNTS OF INTERNET USE FOR HEALTH**

The rapid growth in Internet use has been one of the most prominent social trends during the last decade. There is now a growing sociological literature that has contributed to our understanding of the ways in which both professional and 'lay' people make use of e-health resources, how they access and assess information from the internet and the implications this has for professional-patient interactions. The focus of this paper however is rather different. Rather than examining people's accounts to examine their views of such resources, we focus instead on how their accounts of internet use are organised in-and-of-themselves. We ask how people account for their own use of e-health. Drawing pragmatically upon some of the analytic insights of ethnomethodology the paper is based on an analysis of 69 qualitative interviews with a sample of parents and children in England.

**Nicholson, C.**

**Kings College London**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 15.10 - 15.40*

**THE STORIFIATION OF EXPERIENCE: THE PERSONAL AND COLLECTIVE STRUCTURING WITHIN NARRATIVES OF THE DYING**

A dominant discourse within Palliative Care is the importance of journeying with patients through their dying, facilitating them to express emotion, find meaning and possible acceptance as they face their own mortality.

This paper draws on data collected during a qualitative study exploring how dying people themselves make sense of being "terminally ill." In depth narrative accounts of six people, living at home, were built up over time during a four-month period.

Emergent themes from the narrative analysis suggest that those dying have a particular way of expressing themselves, which changes over time as the body disintegrates and death becomes more apparent. Stages in this process, to be expanded during the presentation, include: the presentation of a morally "good" life; getting the story "right"; presenting the past and remembering the future; and with the inevitability of death, movement towards presentation of life as "good enough".

Findings from this study challenge the overly dominant emotion focused model traditionally used by sociologists and practitioners within the field of Palliative Care. The study highlights the importance of looking beyond an emotion based stage approach to dying to an encompassing construction of meaning in terms of social relations, moral responsibility, and behaviours through which people negotiate the highly problematic experience of both living and dying.

**Nielsen, A.B.S., de fine Olivarius, N., Gannik, D., Hindsberger, C., Hollnagel, H.**

**The Research Unit of General Practice in Copenhagen**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**THE EFFECT OF STRUCTURED PERSONAL DIABETES CARE IN GENERAL PRACTICE ON GLUCOSE LEVEL IS LIMITED TO WOMEN**

Background

Diabetic men and women differ in lifestyle and attitudes towards diabetes and may benefit differently from interventions to improve glycaemic control. We explored the relation between average glucose level measured by glycated haemoglobin (HbA1c), sex, type of care and their interactions with behavioural and attitudinal characteristics in patients with type 2-diabetes.

Methods

Six years after diabetes diagnosis, a population-based sample of 874 primary care patients randomised to structured personal care (intervention) and routine care (comparison) reported lifestyle, medication, number of diabetes consultations, social support, and attitudes towards diabetes and treatment.

Results

An intervention effect on HbA1c was confined to intervention women. Median HbA1c was 8.4 and 9.2 ( $P < 0.0001$ ) in intervention and comparison women, respectively, 8.5 in intervention and 8.9 in comparison men ( $P = 0.052$ ). Comparison women had a 1.10 times higher HbA1c than intervention women, ( $P < 0.0001$ , adjusted for consultations, diabetes duration, BMI, interactions between diagnostic HbA1c and age group, interactions between food habits, antidiabetic treatment and exercise). Intervention women had more consultations than comparison women and intervention men, but neither consultations nor other covariates contributed to explain the HbA1c difference. Women expressed, irrespective of type of care, more adaptive attitudes towards diabetes and were more likely to follow a diet, but lacked support and exercised less than men.

Conclusion/discussion

Did the intervention favour women because they are more inclined to comply with regular follow-up or was the intervention unwittingly tailored to women? These issues will be discussed together with the assumption of relative benefit across sub-groups in a trial.

**Novas, C.**

**London School of Economics**

*Stream: Genetics*

*Friday the 17 September 2004 at 14.00 - 14.30*

**'LIVING WITH 'RISKY' GENES: THE INTERNET, SCIENCE AND THE CARE OF THE SELF**

The growth of health related websites, in addition to personal webpages dedicated to discussing the experience of illness, creates unprecedented historical opportunities for the circulation of scientific and medical knowledge. This paper explores how persons who are at genetic risk, who suffer from a genetic illness, and those who care for these persons use the Internet to gain knowledge about their illness and as a medium to exchange life experiences. A key concern will be to examine how the Internet facilitates the translation of biomedical knowledge and personal experiences of illness into resources that can be appropriated by persons affected with a genetic illness.

Through the analysis of "sites" where persons affected by Huntington's disease interact, it will be suggested that the Internet constitutes a medium which assists the enfolding of medical authority and the experiences of others for the purposes of the care of the self. It will be argued that the enfolding of medical authority and the experiences of others which increasingly take place over the Internet are constitutive of the ways in which humans come to understand and act upon themselves. The paper will outline how the circulation of biomedical discourses and personal experiences on health related websites and personal webpages contribute to the production of the person 'genetically at-risk' and to the ethical problematisation of how to live one's life for the best.

**Ocloo, J.**

**University of Surrey**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 10.10 - 10.40*

**MEDICAL HARM AND PATIENT EMPOWERMENT: SOME 'CRITICAL' PERSPECTIVES**

This paper will look at the current demand within a changing and modernising NHS for creating an empowering culture of service provision with patients at its centre. This demand for change (seen in Friedson's work in the 1980's) will be explored by focussing on the concept of medical harm and looking at it from a patient's perspective. It will be argued that conceptually, medical harm is a phenomenon that is difficult to pin down, but as a process is not value free, but constructed and mainly determined by the medical profession and the state apparatus responsible for its regulation. In a context where the occurrence of medical harm has become fiercely contested, this paper will look at how patients are seeking to define key issues through self-organisation. Drawing upon action research with a range of self-help groups affected by medical harm, a range of arguments will be explored relating to accountability and patient empowerment. These arguments will be analysed within the loose framework of ideas referred to as medical imperialism, seeking to challenge a biomedical view that routinely associates health and illness with the body, rather than locating its origins in social processes. The social construction of medical harm will also be explored looking at ideas connected to political economy theory. This points to medicine's position enmeshed in the search for profits by big business, underpinned and supported by capitalism, and the activities of the state system, but working against the interests of the health of the wider population.

**Olsvold, N.**

**Lovisenberg University College, Norway**

*Stream: Theory*

*Friday the 17 September 2004 at 15.45 - 16.15*

**IS OPPOSITION TO MEDICALIZATION POSSIBLE? A CASE OF TAKING ON THE EXPERTS**

Sociologists do not generally challenge the medical establishment directly, neither as a group nor as individuals. The rage directed at the Swedish sociologist Eva Kärfve for daring to challenge the top guns in Swedish neuropsychiatry on their construction of the disorder DAMP (a Swedish version of ADHD), should teach us that direct opposition will not be taken lightly by the proclaimed experts. I will argue that this particular case shows that while the medical profession may have lost some power to health service management, it has lost none of its symbolic power, or its own belief in the justifiability of that power. This claim is supported by the ease by which the disorder ADHD and its treatment with central nervous system stimulants have spread from USA to Europe. Evidently resistance both in the professional and in the lay sector is low. Should this be of concern to sociologists? I will argue that it should since the case illustrates the totalitarian and impenetrable character of the medical system. This poses a threat to democracy. I will also argue that we should be concerned that the spreading of ADHD diagnosis may lead to the undermining of the role of parents and society in raising our children. Finding effective means of counteracting the medicalization of our life-world is therefore called for.

**O'Neill, D., De Maio, F., Karki, C.**

**University of Essex**

*Stream: Inequalities*

*Friday the 17 September 2004 at 16.55 - 17.25*

**THE HIDDEN POPULATION OF PEOPLE WITH LEARNING DISABILITY: AN EXAMPLE OF INTEGRATION OR A MAJOR UNMET NEED?**

**Background**

Of the 156,796 people living in Colchester, 3,135 might be expected to have some level of learning disability (LD), which can be associated with poorer health and socio-economic status, and difficulties in accessing services. However, a maximum of 1,343 adults have been identified by local specialist services. The central question is: what has happened to the other 1,792? Are they integrated within the broader community, not requiring additional services and support? Or do they constitute a 'hidden population' with significant unmet need?

**Methods**

A postal questionnaire asking about service use and self-reported need was sent to 351 young adults with LD in the Colchester area. In-depth interviews with five respondents allowed more detailed exploration of the survey questions.

**Findings**

37% of respondents had not been helped by any organization since leaving school. Employment was an important issue for many; employed respondents were significantly less likely than unemployed respondents to indicate that they had been helped by an organization (21% and 73%, respectively).

Of the respondents who did not get help from any organization, 50% had wanted help. Not knowing who to ask was a key reason given for not getting help.

**Conclusion**

Although the findings cannot be generalised beyond the population surveyed, this pilot study gives preliminary support to the idea of a 'hidden population' that is unable to access services. Improving communication about existing resources, rather than developing new services might help to address their unmet need.

Several methodological refinements are also suggested for future work.

**Østerlie, W., Skolbekken, J.A., Forsmo, S.**

**Department of Public Health and General Practice, Norway**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 16.40 - 17.10*

**SCREENING EXPERIENCES AMONG NORWEGIAN WOMEN INVITED FOR BONE MASS DENSITY MEASUREMENT**

The fracture incidence in Norwegian women is amongst the highest in the world. Osteoporosis is a major risk factor for these fractures, and screening for osteoporosis through bone density measurements is among preventive presently being considered.

In this paper we will give attention to the lay perceptions of screening for osteoporosis. Our aim is to gather knowledge about how ordinary people experience their participation in a screening program. We conducted a focus group study parallel to an osteoporosis screening project in the county of Nord-Trøndelag, Norway (The HUNT Study). The women were randomly selected from three different groups, 53-63 years old with and without prior osteoporosis screening experience and 70-75 years old with such experience. Three groups within each category were assembled, leading to a total number of nine focus groups (63 women). They were interviewed three times: A week before the screening, two weeks after and the last about six months after the screening comprising 27 interviews altogether.

Preliminary analyses of the data show that the women were grateful for being invited and taken care of, even though they did not consider themselves to be at risk for osteoporosis. The result of the examination was considered as a confirmation of being healthy. Uncertainties about the screening were linked to technology, measurement in wrist versus hip or spine, and how their life would change in case of a diagnosis.

**Panagos, M., Richardson, D. McNulty, A.**

**University of Newcastle**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**WORKING WITH YOUNG WOMEN AND YOUNG MEN: STUDENTS' VIEWS ON SEX AND RELATIONSHIPS EDUCATION PROGRAMME**

This paper reports on a study commissioned by a local consortium of health care professionals concerned about the effectiveness of the delivery of the Sex and Relationships Education (SRE) programme at schools in the North-East of England. In this presentation we will only report findings from a Catholic school. Data was collected from three sets of questionnaires, focus groups and one-to-one in-depth interviews with both young women and young men over a period of six months. The administered questionnaires were evaluated by SPSS while the focus groups and one-to-one interviews were audio-taped and transcribed. Thematic analysis was adopted into the data analysis. Gender differences were evident on issues relating 'contraceptive measures', 'attitudes to early parenthood', 'condom use' and the 'SRE programme evaluation'. Overall, the participants claimed to have a preference for single-sex and smaller-sized sessions, more time to explore emotional issues, and consistency across the sessions in terms of providing a safe learning environment.

**Pearce, M.D., Radley, A., Mayberry, J.**

**University of Loughborough**

*Stream: Methods*

*Friday the 17 September 2004 at 09.35 - 10.05*

**THE OUT- PATIENT CONSULTATION: EXPECTATIONS, INCIDENCES AND REFLECTIONS**

This paper reports ongoing work relating to the needs of patients with inflammatory bowel disease who attend for outpatient appointments in the hospital clinic. The project has involved the videotaping of three consecutive consultations with 14 patients, who have been interviewed both before and after each meeting with the doctor. The study examines whether patients seek to have doctors advise about life concerns as these relate to the problems of managing a painful, inconvenient and potentially stigmatising illness. In order to address this question, the analysis of data requires decisions to be made about ways of reading multiple interviews and watching several videotaped exchanges between doctor and patient. This paper focuses upon issues to do with the questions raised by different analytic approaches. We explore whether this, in turn, questions assumptions about how consultations are made meaningful and are judged as effective by the patients concerned. In particular, we discuss the way that various analytic approaches make possible different notions of relationship between what patients think they want from doctors, what they remember they were told or given, and what might never have happened at all.

**Phillips, R.**

**University of Edinburgh**

*Stream: Inequalities*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**THE CONCEPT OF 'COMMUNITY CAPACITY BUILDING' AND ITS IMPACT ON HEALTH**

Engaging communities and promoting public participation are key political strategies to address problems associated with social exclusion, including health inequalities. The concept of community capacity building (CCB) may help to understand how socially excluded communities and individuals can improve their circumstances.

This paper will present initial findings from a PhD study exploring CCB in the context of community development and health. This research aimed to examine whether certain dimensions of CCB, such as 'participation', 'resource mobilisation', 'links with others' and 'role of outside agents' impact on health. 'Health Issues in the Community' (HIIC), a Scottish-wide programme, uses a community development approach. Students drawn from urban, rural and island communities study themes such as power, participation, and definitions of health as well as completing a group project on a local health issue that concerns them.

Qualitative semi-structured interviews were conducted with HIIC stakeholders (management, policy & development level), tutors and students from across Scotland and transcripts analysed for emerging themes. It appears that a number of factors might influence the potential of the course to build community capacity. These include the background and personal circumstances of students accessing the course and associated group dynamics; the support available for students during and after the HIIC course; and the context in which the course is delivered. Illustrative examples will be given from the data.

**Philpin, S.M.**

**University of Wales, Swansea**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**THE USE OF RITUAL TO DEAL WITH ANOMALY IN AN INTENSIVE THERAPY UNIT (ITU)**

**Background**

Anthropological literature (cf Douglas, 1966; van Gennep, 1909) suggests that rituals are necessary to resolve anomaly when categories have become confused. Lawton (1998) introduces the concept of an 'unbounded' body to describe the anomalous situation of patients, who, because of their illness, are unable to maintain the boundaries of their bodies - such that normally contained matter would leak to the outside. I apply this concept of unboundedness and hence anomaly to ITU patients, suggesting that their bodies were unbounded in that the boundaries of their vital systems -their major blood vessels and airways -were open and accessible to the outside. Following Lawton and van Gennep I suggest that this unboundedness situates these patients in a state of liminality.

**Aim**

Having identified various anomalies inherent in ITU patients' conditions, I will describe and interpret the rituals used by the nurses to manage these anomalies as methods of dealing with their own anxieties and symbolising the importance of patient safety.

**Method**

This paper reports on a particular aspect of a larger ethnographic study of nursing culture. This ethnography was accomplished through participant observation over a twelve-month period in ITU, followed by interviews with fifteen nurses.

**Conclusions**

Notwithstanding the undoubted scientific reasons for particular nursing practices, I argue that there also ritual elements serving other more complex purposes. I demonstrate the role of ritual in both protecting patients and staff and symbolising the highly valued phenomenon in this culture of keeping patients safe.

**Pilnick, A.**

**University of Nottingham**

*Stream: Genetics*

*Friday the 17 September 2004 at 16.55 - 17.25*

**"IT'S SOMETHING FOR YOU BOTH TO THINK ABOUT": INFORMED CHOICE IN NUCHAL TRANSLUCENCY SCREENING FOR DOWN'S SYNDROME**

Antenatal screening programmes in both the US and UK have been the subject of widespread criticism by sociologists (e.g. Press and Browner 1997; Green and Statham 1996). Critics have suggested that that women do not properly understand the nature of the procedures they are asked to undergo, or that they have the choice to decline them. This paper uses data from 14 tape recorded pre-screening consultations between pregnant women and community midwives discussing nuchal translucency (NT) screening for Down's Syndrome to examine how the issue of choice is topicalised and discussed. The data are taken from a wider study including the same women's consultations with hospital midwives, as well as post screening interviews. The data presented here are analysed from a conversation analytic perspective, in an attempt to shed light on how it might be that women come to feel that they have no real choice in this scenario. It is concluded that, whilst there is clear evidence that midwives are at pains to explicitly invoke the issue of choice, there are other factors in the interactional presentation of screening tests, which serve to undermine this. These include presenting NT screening as a continuation of the discussion about 'routine' blood tests, presenting the benefits of screening while downplaying the possible downsides, and presenting NT screening as 'the best available test'.

**Pollard, K.**

**University of the West of England, Bristol**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 09.00 - 09.30*

**HOW DOES THE MOTIVATION OF DIRECT-ENTRY STUDENT MIDWIVES RELATE TO CURRENT DISCOURSES IN MIDWIFERY?**

Current discourses concerning midwifery include the view that it has been transformed from an informal activity supporting a normal life-event into a circumscribed role within a biomedical hierarchy which pathologises the female body. Mainstream western discourse sees birth as a medical event: an alternative discourse considers it a natural event, supported by an autonomous midwifery profession. Debate about these discourses continues. In the UK, where midwives attend over 90% of births, a key question in this debate concerns their professional identity: are they expert practitioners supporting a natural process, or nurse specialists normalising the biomedical approach to birth? Midwives themselves are unclear about this: an examination of midwifery literature reveals a variety of discourses about the midwife's role.

During an evaluation of an undergraduate curriculum offered by a Faculty of Health and Social Care at an English university, a cohort of midwifery students without a nursing background completed a questionnaire about their attitudes to collaborative learning and working. Two open-ended questions explored their motivation for entry to the profession and their views of the public perception of midwifery. 43 students (96% of the cohort) replied to these questions on entry to the Faculty.

The resulting qualitative data were subjected to thematic content analysis. In particular, discourses concerning the midwife's role were identified. This paper presents findings from this study, and discusses the impact these discourses may have on students' development of professional identity, as well as implications for the maintenance of the midwifery discourses identified in the literature.

**Potts, L., Nettleton, S.**

**York St John College**

*Stream: Risk*

*Friday the 17 September 2004 at 09.35 - 10.05*

**'YOU'RE BARKING UP THE WRONG TREE!' WHAT WILL SHIFT THE DOMINANT MEDICAL PARADIGM OF BREAST CANCER CAUSATION?**

Our ESRC Science in Society funded project aims to bring together different communities of interest through a series of local and national hearings, to engage with the range of contested evidence regarding the role of environmental hazards in breast cancer aetiology. While there is a considerable literature that addresses public participation in contentious decision making (Forester 1993 and 1999; Fischer 2000; Mayer 1997; Nowotny 2003), and an honourable history of 'lay' involvement in health issues related to the environment (Brown 1992; Popay and Williams 1996), there is little to theorise the reluctance of the medical profession to acknowledge the role of environmental risk.

We will attempt in this paper to make new sense of these dynamics, drawing on interviews with environmental social movement members, 'dissident' scientists, and with the public health workers and epidemiologists who have been most resistant to thinking outside the dominant aetiological paradigms of genetics ('blame the mother') and lifestyle ('blame the victim'). The paper will thus suggest how different epistemologies of health and disease and their political location; inter-professional communication; and the relations of citizens to governance, are all crucial to more effective deliberative policy making.

**Price, L.**

**Torbay Hospital**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 15.45 - 16.15*

**TREATING THE CLOCK AND NOT THE PATIENT; WHY AMBULANCE PARAMEDICS THINK GOVERNMENT TARGETS ARE PUTTING PEOPLE AT RISK**

The ambulance service is the Cinderella of the NHS, performing medicine's dirty work at the interface between community and hospital.

At the same time the role of the ambulance paramedic is rapidly evolving as paramedics take on roles vacated by GPs and other health professionals. Unlike other health professionals, and despite the high levels of risk, responsibility, autonomy and expertise inherent in their role, paramedics have almost complete lack of power in determining what they do. This is decided by doctors, by the Royal Colleges and by the government, who design protocols or set targets according to sets of interests and priorities which do not necessarily reflect those of patients or workers in the dramatic and unpredictable arena of pre-hospital emergency care, and are enforced by a command and control management culture left over from the ambulance service's military origins. One such government target is that 75% of emergency calls to the ambulance service should receive a response within eight minutes. This paper, based on qualitative analysis of 21 semi-structured interviews with emergency ambulance paramedics in the south west of England, will report on paramedics' experiences of trying to reach this response time target, and how they feel it affects patient care.

**Prior, L., Deb, S., Morris, P., Bryant, E., Haque, S.**

**Cardiff University**

*Stream: Methods*

*Friday the 17 September 2004 at 11.55 - 12.25*

### **STUDYING THE LIFEWORLD OF THE HEAD INJURED**

This paper concerns the lifeworld of the head injured. It draws on data from qualitative interviews with 32 head-injured patients, and 27 carers in South Wales as well as from responses to a postal questionnaire distributed to 113 injured and 78 carers in GB. In addition to using the data sets to describe something about the worlds of people with head injury, we also aim to say something about what the different modes of inquiry (survey based inquiry involving a structured instrument and qualitative interviews) can contribute to our understanding of such worlds. In this regard we believe that our work fits into a growing literature about the ways in which qualitative and quantitative methodologies can be integrated into health research.

With a specific focus on the concept of biographical disruption, we demonstrate how statistical analysis of questionnaire data and qualitative analysis of interviews can interconnect. As might be expected, our results underline the ways in which qualitative data has a depth and richness of detail that can be hinted at by quantitative findings, but rarely accounted for. Nevertheless, it is clear that 'depth' and 'richness' are far from being the preserve of the qualitative inquirer and there are instances where 'thick-description' is clearly enhanced by the use of standard statistical techniques.

**Prout, H., Evans, M., Prior, L., Tapper-Jones, L., Butler, C.**

**Department of General Practice, Cardiff**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

### **BARRIERS TO INFLUENZA IMMUNISATION IN OLDER PEOPLE**

Influenza in older people is a major cause of hospitalisation and mortality during winter months. In spite of studies, which show that influenza vaccine is both safe and effective, vaccine uptake in older people still remains sub-optimal. This study investigated beliefs regarding flu and the flu jab of older people and primary care staff in the Bro Taf area of South Wales to promote flu vaccine uptake in older people.

Stage one of this study used in-depth interviewing with 54 people aged 65 years and over, while stage two used in depth interviewing with 27 primary care staff; 9 GPs, 9 Practice Nurses and 9 receptionists.

Results of stage one identified that the majority of those interviewed did not feel at risk from flu whilst potential and actual side effects of the flu jab were reasons for low uptake. Results of stage two indicated that staff felt that flu is serious for older people although not a major problem for healthy older people. Moreover, many staff felt that if flu jab payments to practices were terminated, then flu jab uptake would decrease.

To conclude, clear communication of the risks of flu, particularly to healthy older people are an important determinant of flu vaccine uptake. Health professionals can promote immunisation both by personalising the risk of catching flu and by tackling misconceptions about side effects. Primary care staff need also recognise the risks of flu to healthy older people, while financial reimbursement for flu jab administration should still be prioritised.

**Pyett, P., Rayner, J., Venn, A., Werther, G., Bruinsma, F., Jones, P., Lumley, J.**

**University of Melbourne, Australia**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 14.00 - 14.30*

### **'TALLNESS IS NOT A MEDICAL CONDITION': A LONG-TERM FOLLOW-UP STUDY OF WOMEN TREATED WITH OESTROGEN TO REDUCE THEIR ADULT HEIGHT**

This paper reports findings from the first long-term follow-up study of girls who received oestrogen treatment (diethylstilbestrol or ethinyl estradiol) to reduce their adult height. This treatment dates back to the 1950s in the USA, Australia and Europe. The treatment was offered for perceived psychosocial problems girls may encounter in adolescence or as adult women. Although far less common, some paediatric endocrinologists still offer treatment to tall girls in Australia, the US and probably also in Europe. Findings from this study clearly have implications for current treatment practices. In this Australian study, questionnaires were completed by 396 women who had received oestrogen treatment, and 448 who were assessed but not treated. Data were also collected from focus groups, telephone interviews and medical records. The most significant findings include impaired fertility and a high level of dissatisfaction with the treatment decision amongst treated women. Untreated women were almost unanimously glad they were not treated, no matter how tall they ended up. There was no clear association between satisfaction with treatment and women's final height. However, dissatisfaction was related to whether or not the girls had an active say in the decision-making; to negative experiences of the assessment or treatment procedures; to side effects experienced during the treatment period; and to later side effects women believed were associated with the treatment. This paper will examine the nature of women's regrets as expressed in qualitative comments explaining their dissatisfaction with the treatment decision.

**Rankin, D., Truman, J., Backett-Milburn, K., Platt, S., Petticrew, M.**

**University of Edinburgh**

*Stream: Health Service Delivery*

*Saturday the 18 September 2004 at 11.00 - 11.30*

**HEALTHY LIVING CENTRES' CONCEPTUALISATION OF HEALTH AND INEQUALITIES: USE OF FOOD TO CONVEY HEALTH MESSAGES**

In the call for proposals under its Healthy Living Centre (HLC) programme, the New Opportunities Fund emphasised the importance of innovative approaches to address public health issues. HLCs were to be built on effective and dynamic partnerships between statutory, community and voluntary agencies and local communities which would tackle the broader social, economic and environmental influences on health. In this Scottish Executive-funded process evaluation of six HLCs in Scotland, we have found great diversity in service delivery methods and programme content, reflecting different conceptualisations of health and health inequalities. An illustrative crosscutting example, drawn from preliminary analysis of the first round of fieldwork data, shows that each HLC has attempted to effect changes in health using a range of food-based and food-related activities. Food has been used both to attract and target service users and to develop and deliver programmes that address inequalities. Several themes appear to characterise the approach to food in the six study sites, including: food as a tool to promote social inclusion; food as a means of health promotion; food as a commodity; and food as a method to enhance skill development. This paper will introduce the HLC concept and explore how HLCs conceptualise health and inequalities using examples of food-related services.

**Rapley, T., Kaner, E., May, C.**

**CHSR, University of Newcastle Upon Tyne**

*Stream: Health Technologies*

*Saturday the 18 September 2004 at 10.20 - 10.50*

**THE CURIOUS CASE OF ABI: DISCOVERING, LOSING AND FINDING ALCOHOL BRIEF INTERVENTIONS**

Alcohol Brief Interventions (ABIs) occupy a curious place in primary care. They are aimed at identifying and modifying risky behaviours of drinkers - work that GPs have historically been supposed to resist. ABIs have no single definition; yet numerous efficacy randomised controlled trials seem to show that they work. Surveys suggest ABIs are underused, implementation trials report only modest impacts and interview studies describe ABI as problematic to implement in everyday practice.

Qualitative interviews with 29 general practitioners explored their everyday work with patients with alcohol-related issues. Drawing on insights from interpretive social theory, we explore their accounts of alcohol-related practical action and practical reasoning. Their formal knowledge about ABI as a mode of practice was very, very, uneven, but in descriptions of their routine encounters with, and reasoning about, people with alcohol problems these GPs implicitly demonstrated pragmatic and informal knowledge of the practice of ABIs. In the policy and practice literature GPs are often characterised as unwilling, or unable, to implement ABIs. The assumption that GPs have somehow resisted being enrolled into the field of brief interventions is not borne out by accounts from our study group. This paper will therefore explore the (curious) case of ABI and raise some questions about the implementation, evaluation and application of behaviour-change health interventions and what they mean in practice.

**Reid, R.L.**

**University of Leeds**

*Stream: Cancer*

*Friday the 17 September 2004 at 16.20 - 16.50*

**BREAST CANCER IN THE MEDIA: WHAT DOES IT MEAN FOR WOMEN WITH A FAMILY HISTORY?**

Various studies have shown that English-language news and entertainment media favour stories about breast cancer over other conditions with similar rates of incidence and mortality. These studies have suggested that the media play an important role in providing information about breast cancer.

My research focussed on a group of women who are concerned that they or their families may be at increased risk of developing breast (or ovarian) cancer due to a family history or confirmed genetic mutation. Using semi-structured interviews with 29 women plus healthcare workers, I examined what they think about the media coverage, how they interpret it and how the media and other factors may have influenced them and their understanding of what it means to have a family history of breast cancer.

The results showed that any effect of the media on women's perception of their condition is far from straightforward. Thus, the media often served to misinform women about their condition, but other sources, including healthcare workers were also found to be unreliable.

The paper will conclude by demonstrating how existing studies have failed to grasp the complexity of health information and suggest ways in which the media might correct existing practices to provide more pertinent information.

**Reventlow, S., Schulze, I.**

**Panum Institute, Denmark**

*Stream: Risk*

*Friday the 17 September 2004 at 10.45 - 11.15*

**MAKING SENSE OF BIOMEDICAL EXPLANATIONS OF DISEASE AND HEALTH RISKS. METAPHORICAL PROJECTIONS AND WOMEN'S COMPREHENSION OF OSTEOPOROSIS.**

Risk and disease are acknowledged as social constructions as well as biological events, mediated by socio-cultural processes of which language is a part. Osteoporosis is defined as a disease, however, it is an invisible risk condition until fractures occur. The aim is to use cognitive metaphor theory to explore women's conception of osteoporosis and the risk of osteoporosis.

The study is based on focus group discussions and in-depth interviews of women (aged 60-63) in Denmark. The analyses used cognitive theories of metaphors, contending that our conception of the physical world is born out of personal bodily experiences. These experiences are constitutive for generating abstract structures of meaning, which through metaphorical projections provide a constructive role in our overall comprehension of the world.

Women described osteoporosis in terms of a physical deviation from the norms of a healthy body. By using a metaphor, the-body-is-a-house, they described this deviation in terms of a building. The osteoporotic body collapses in contrast to what is considered to be a norm for the structure of a building: to have a solid and erect structure. The bones are pillars implying a norm of a bearing structure, and a bone-fracture is a collapse of the pillars.

The study supports the hypothesis that the understanding of biomedical explanations of disease is organised by a number of structuring metaphors based on experiences from everyday life. Lay people use their personal experience of objects and object-manipulation to make sense of the biomedical explanation of disease and health risks.

**Reventlow, S., Hvas, L., Malterud, K.**

**Research Unit of General Practice in Copenhagen**

*Stream: Health Technologies*

*Thursday the 16 September 2004 at 16.00 - 16.30*

**THE VISIBILITY OF THE INVISIBLE. THE BONE SCAN, OSTEOPOROSIS AND WOMEN'S BODILY EXPERIENCES**

**Introduction**

Osteoporosis is a condition detectable by medical technology through a bone scan, which can show whether a person has a low bone-mass and thereby an increased risk of fractures. This paper contributes to the discussion of what happens when medical technology makes hidden bodily processes visible and the biomedical perception of the body meets that of the lay person. This paper aimed at exploring women's bodily experience after a bone scan.

**Method**

Qualitative study with in-depth interviews of 16 women (aged 61-63) who had had a bone scan of osteoporosis. The analysis was based on Merleau-Ponty's phenomenological perspective of embodiment. Bodily experience is understood to be the existential ground of culture and self.

**Result**

The women appreciated the visual knowledge of their bodies. The information supplied by the scan fostered a new body image. A mark on a curve was transformed to a comprehension that their bodies were fragile. Embodiment of this new body image resulted in new symptom interpretations and a new body discipline in which they were more caution with their bodies.

**Discussion**

It becomes increasingly important to understand people's perception of health in the context of medical technology. Osteoporosis is regarded invisible, however, when a bone scan indicates the occurrence of osteoporosis, osteoporosis is associated with visible and perceptible signs of illness. Statistical risk of osteoporosis as a probability of a bone fracture is transformed into a bodily experience through technological intervention (visualisation by a bone scan) and cultural imaginations (metaphors of osteoporosis and people's understanding of what this means).

**Richardson, J.C., Ong, B.N., Sim, J.**

**Keele University**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 15.45 - 16.15*

### **EXPERIENCING CHRONIC WIDESPREAD PAIN IN A FAMILY CONTEXT**

Studies of chronic illnesses, for example, fibromyalgia, back pain, and MS, have shown the dramatic ways in which these conditions can affect the family, in terms of changed relationships, roles and responsibilities. Concepts from these studies can be applied to the condition of chronic widespread pain (CWP) to provide insight into its impact on the family. However, it is important to look not just at the impact that pain has on the family, but at the influence of the family on the experience of living with pain. Sufferers of CWP attempt to make sense of and manage their condition within the contexts in which it is experienced, which may include the family.

The data presented in this paper is part of a broader, ongoing project exploring the lives of people living with CWP. It uses data collected from interviews with eight people with CWP, and five of their family members (four spouses and one daughter) to explore the ways in which the pain affects, and may also be affected by, family life. Results presented in this paper will focus on the ways in which family responsibilities are managed in conjunction with pain; changes and stability in identity in a family context; and the concept of biographical disruption in a family context. The ways in which interviews with family members were conducted varied and the methodological and ethical implications of this will also be discussed.

**Richman, J.**

**Manchester Metropolitan University**

*Stream: Mental Health*

*Thursday the 16 September 2004 at 16.40 - 17.10*

### **LISTENERS: INMATE CARE WORKER IN HMP AND SUICIDE POLICIES**

The article reviews the rise of public interest in prison suicides. After the first publication (1880) of national prison suicides, interest was revived in the topic from the 1980s. Prison suicides also became a catalyst for stimulating health policies 'behind walls'. The prison population has a greater frequency of morbidity than the general population. Prison suicides are reviewed in terms of locating indicators, especially 'overcrowding'.

Listeners, prisoners trained by the Samaritans, are on the front line of prisoners' troubles. A group of 23 Listeners were surveyed at HMP Manchester. Their roles and identities were explored. Issues of their marginality, bestraddling the two cultures - that of the official custodianship emphasising security and the more covert, inmate culture in opposition - are discussed. Their views on mental illness and the location of its treatment are also noted.

Recent policy issues concerning the 'normalisation' of prison health delivery by NHS mergers is outlined. Primary Care Trusts are given responsibilities for prior health centres and listeners should be incorporated into these future health policies. Scepticism about the possibility of 'healthy prisons' is aired. Ethical issues of researching prisons are also noted.

**Riska, E., Yrjälä, A.**

**University of Helsinki, Finland**

*Stream: Health Service Delivery*

*Saturday the 18 September 2004 at 10.20 - 10.50*

### **DIVERGENT PATHS IN U.S. AND FINNISH CHILD AND MATERNAL HEALTH: THE IMPACT OF THE ROCKEFELLER FOUNDATION**

This paper looks at the history of the maternal and child health policies in Finland and the United States between WW I and WW II, particularly the role of organized medicine and the Rockefeller Foundation in the development of the public health center system and of public health nursing in the two settings. The question is: why did Rockefeller Foundation venture abroad rather than strengthen public health nursing and child and maternal health services at home? The data constitute editorials in JAMA from 1917 to 1933 and material collected at the Rockefeller Archive Center, North Tarrytown, New York. The paper shows that the narrow view of biomedicine and the engineering approach constituted the approach exported from the U.S. setting. The engineering approach strengthened the social reformist endeavors still vibrant in the Finnish setting.

**Romano, V.**

**University "La Sapienza" of Rome**

*Stream: Cancer*

*Friday the 17 September 2004 at 14.00 - 14.30*

**A COMPARATIVE CASE-STUDY BETWEEN ITALIAN AND ENGLISH HOSPICES: CULTURES FACING EACH OTHER**

The reported research explores the way national cultures can affect daily routines in hospices and influence their value-oriented choices on both everyday activities and problem solving at critical moments. It represents the half-way stage of a PhD study that uses palliative care, and the way it is organized and delivered, as a powerful tool to compare and contrast national cultures. England and Italy represent two meaningful stages in the evolution of how terminal illness is conceived and appropriate care delivered. England being a 'mature' system with a longer and more settled tradition while Italy being a new born one still developing. This comparative case-study research of two hospices investigates the relationship between cultural environment and the way terminal care is conceived and delivered. Statistical data from both countries is used to set the scene and then qualitative data from a focus group in the Italian hospice is used to explore the understanding of palliative care in this country.

Particular attention is given to the way the staff organize their jobs and their relationships with patients and carers. Further, a particular social construction of the family is apparent in their management within the hospice setting. The development of palliative care in Italy has looked to the UK for guidance but has been shaped by distinct cultural factors. The study closes with the hypotheses of the main differences that could be found in a parallel focus group from the English hospice drawing in part on an observation phase that is already complete.

**Rosenfeld, D., Faircloth, C.**

**Colorado College, USA**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**A BODY AT REST REMAINS AT REST: MOVEMENT AND MORALITY IN ARTHRITIS NARRATIVES**

While bio-medical research reifies bodily movement in the lives of people with chronic illness into "functional mobility," our analysis of biographical osteoarthritis narratives uncovers a moral commitment to movement as both a moral imperative and a technique to preserve a self threatened by the limits arthritis places on daily life. A content analysis of twelve interviews with arthritis sufferers shows that, in addition to the practical and emotional challenges of living with arthritis, these actors face the daily challenge of displaying their understanding of embodied fluidity - the timely and fluid movement through time and space - as a virtuous practice. Our informants use the "movement mandate" - the commitment to move despite the pain it may cause - to produce themselves as competent social and moral actors sacrificing the demands of their bodies to meet social expectations, and they conduct this performance in front of several audiences: the self, and specific and generalized others. For these informants, in both private and public realms, the experience and the management of pain and physical limitation are profoundly social and accountable matters, as they affect interactions with others, their own social identities and moral integrity, and their relations with self as they seek to balance their arthritic pain with their past, present, and future self-concepts.

**Ruston, A.**

**University of Greenwich**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**VOLUNTARY AND STATUTORY SECTOR PARTNERSHIPS IN THE PREVENTION OF CHD: CAN 'COMPACTS' ADDRESS THE BARRIERS TO JOINT WORKING**

At the beginning of the twentieth century key health and social services were provided by voluntary organisations but with the establishment of the welfare state they became relegated to a relatively minor role in respect of welfare provision. Given the increasing pressure on NHS resources, an ageing population, growing numbers of people with chronic illnesses and the redistribution of services from hospital to community settings successive governments have attempted to implement policies to harness the voluntary sectors' contribution to health and social care. This culminated in 1998 in the establishment of a 'Compact' signed by the Home Secretary and representatives of the voluntary sector in which the importance of the voluntary organisations in the provision of health and social care was reiterated. Local 'Compacts' are expected to provide a means of enabling the voluntary and statutory sectors to work together more effectively.

This poster reports on a study which examined partnership working between the voluntary and statutory sector in the prevention of coronary heart disease (CHD). Partnership working has been identified as an essential element in achieving a reduction in social inequalities and in reducing social exclusion.

Representatives from seventy-five voluntary sector organisations, with a health or social care function, were interviewed. The data suggests that before the voluntary sector can fully contribute to a systematic, coherent overall public health strategy for the prevention of CHD a number of specific barriers to effective partnership working will need to be addressed. Local 'Compacts' may go some way to addressing these barriers.

**Ryan, S.S.**

**University of Warwick**

*Stream: Theory*

*Friday the 17 September 2004 at 15.10 - 15.40*

**THE 'OWN', THE 'WISE' AND THE NOT SO WISE: MOTHERS OF LEARNING DISABLED CHILDREN AND GOFFMAN'S 'SYMPATHETIC OTHERS'**

Within Stigma, Goffman identifies two sets of 'sympathetic others' from whom the stigmatised person can expect support; the 'own' are those who share the individual's stigma and the 'wise' are divided into those who are related to the stigmatised person and those who are intimately privy to the life of the stigmatised person.

This analysis is an underdeveloped area within Stigma and this paper will extend Goffman's analysis by focusing upon mothers of learning disabled children. The experiences of this group of women, whose children's learning impairments may not be immediately apparent and yet whose behaviour may be socially unacceptable, demonstrate the complex and shifting nature of stigma. In public encounters, the mother may acquire the stigma of being an incompetent mother of a disobedient child. However, if she chooses to disclose her child's learning impairment, she will lose the 'primary' stigma but instead acquire a courtesy stigma and, in turn, her own set of sympathetic others.

This paper will demonstrate the salience of the category of 'own' within the mothers' lives and the significance of the mothers' role as 'wise' in their children's lives. It will further suggest that, outside of close family members, there are few individuals who assume the role of wise. The space and the potential for this role, however, is implicit within the data and this can be illustrated by the mothers' responses to negative experiences with those who could be considered as either type of wise, including extended family members and general practitioners.

**Sanders, T., Harrison, S.**

**The University of Manchester**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 10.10 - 10.40*

**USE OF SCIENTIFIC EVIDENCE IN HEART FAILURE: ASSESSING THE IMPACT ON PATIENT PARTICIPATION**

**Background**

The emergence of evidence-based medicine has led to a greater reliance by clinicians on research evidence to inform their clinical decisions. However, there are also signs that scientific evidence is being used more widely by clinicians to provide patients with greater information and in some cases to demonstrate (to the patient) the rationale behind the treatment recommendation. This paper reports findings from a two-year study of the way that clinical information is communicated to heart failure patients during the consultation, and illustrates the views of healthcare professionals in facilitating patient engagement in treatment decision-making.

**Methods**

35 semi-structured qualitative interviews were conducted with healthcare professionals working in heart failure. Also 65 taped observations of cardiologist/patient interactions were carried out at two separate heart failure clinics in the north west of England. The interviews were organised using Atlas-ti and the data were analysed using a variation of grounded theory, to compare and contrast emergent themes across separate data sets.

**Conclusion**

Despite the recent recognition of the need for greater patient participation in treatment decision-making, the findings show that cardiologists and specialist nurses consider there to be limited choice for patients in the selection of treatment and negotiation in heart failure. The 'presentation' of scientific evidence by clinicians, and the expectation of patient conformity to prescribed treatment and lifestyle advice, is an 'emerging' strategy used to secure patient consent. This often limits the patient's ability to participate actively in 'problem-solving' and decision-making.

**Savy, P.**

**La Trobe University, Australia**

*Stream: Methods*

*Friday the 17 September 2004 at 10.45 - 11.15*

**BETWEEN LYLA AND I: WRITING A WORDLESS OTHER**

My PhD pursues questions about identity and experience in dementia. I did fieldwork in three care settings where I became close to several quite impaired old individuals. My aim to capture and make something of their lives landed me deep into methodological arguments about representation of an other's world. My last informant, Lyla took the problem of representation and meaning further for she did not speak other than to echo words of others. For long periods, Lyla paced agitatedly. Her remoteness made her a disturbing but compelling informant.

In this presentation I will lay out the problems I faced and my approaches to write ambiguous experiences more usually left in the settings. I will present ethnographic material from my thesis to explore arguments about referentiality (fact-claiming, realism) and evocation (fact-disclaiming, poetic form) and the shifting relationship between these methodological positions. I consider the value and weight of the words and the dual tasks of ethnographic representation - to make the familiar strange and vice versa.

To capture the disorder and the plight of self conceptually I draw from the ideas of Douglas (1966) and Kristeva (1982), notably abjection, danger, and suffering. Theoretically, these authors demonstrate the possibility of making meaning from conditions of life that seem to be meaningless. Importantly, for my work and connectedness to my informants, their conceptualisations give me the language to talk about the silence, horror and compassion as I witnessed and experienced these and to include my disordered, marginal and lost informants as exquisitely human.

**Schlueter, E., Krones, T.**

**Phillips University Margurg, Germany**

*Stream: Health Technologies*

*Thursday the 16 September 2004 at 14.00 - 14.30*

### **INTENTION TO USE PRENATAL DIAGNOSIS: TESTING AN INTERGATED MODEL**

Individuals facing the personal decision whether or not use prenatal diagnosis are confronted with the conflicting influences of moral attitudes, perceived value, perceived social pressure and external constraints. However, there is a lack of empirical research comparing the effects of these factors simultaneously.

On this background our study assesses the impact of different factors on the individual intention to undertake prenatal diagnosis. A questionnaire concerning several questions on the intention to use prenatal diagnosis was filled out in 2003 by a subgroup (N = 370) of a representative German population sample, aged 18-50 years, with a persisting desire for a child.

Based upon the classical sociological actor models of the homo sociologicus and homo oeconomicus, the theoretical framework used seeks to integrate the different assumptions underlying the constructs of moral attitudes, perceived value, perceived social pressure and external constraints.

The empirical results in regard to the impact of these factors are in line with the theoretical assumptions. Moral reservations as well as perceived constraints show negative effects on the intention to use prenatal diagnosis, while perceived value and social pressure have positive effects. However, considerable differences occur when analysis is conducted separately for both sexes. Moral reservations and social pressure seem to be much more important predictors for women compared to men.

The results of the current study confirm the explanative power of the underlying theoretical model for a general population sample and allow to draw important conclusions e.g. for genetic counselling.

**Seale, C.**

**Brunel University**

*Stream: Cancer*

*Friday the 17 September 2004 at 16.55 - 17.25*

### **NEW DIRECTIONS FOR CRITICAL INTERNET HEALTH STUDIES: REPRESENTING CANCER EXPERIENCE ON THE WEB**

Studies of health representations on the internet have been preoccupied with the assessment of their (medically-defined) accuracy and quality. This contrasts with studies of health representations in 'old' media, where critical sociological analyses are common. Medical sociologists have been concerned to establish the potential of web information in transforming professional-client relations. A case study of breast and prostate cancer web sites provides evidence of the increasing convergence of the 'new' medium of the internet and old media such as newspapers and television. Large institutions are now consolidating their presence on the web so that users experience increasingly similar messages across media platforms. Search engines and links to the web from old media sources direct people to heavily resourced, mainstream health sites where, in the case of cancer, representations of gender are strikingly similar to those found in studies of 'old' media sources. The media convergence thesis contrasts with earlier celebrations of the internet as a new medium that would promote a diversity of perspectives on health. Using existing methods for analysing media texts and developing new methods where appropriate, sociologists and media analysts interested in health need to develop more critical perspectives on this important new medium.

**Secker, J., Bowers, H., Webb, D., Llanes, M.**

**Anglia Polytechnic University**

*Stream: Health Technologies*

*Thursday the 16 September 2004 at 16.40 - 17.10*

### **THEORIES OF CHANGE: WHAT WORKS IN IMPROVING HEALTH IN MID LIFE**

The need to promote healthy active aging in order to offset the impact of an aging population on national resources and ensure a high quality of life in older age is well recognised. In 2001 the English Department of Health established a national pre retirement health initiative involving the development of eight pilot projects. A national evaluation using a theories of change approach embedded within a realistic evaluation design was commissioned to draw out the lessons from across the projects. This paper describes the methods used to identify and test out the projects' theories of change, and the results obtained. The theories of change identified revolved mainly around engaging clients and empowering them to take action through the provision of information. Two projects also saw providing opportunities for social interaction as a means to engaging and empowering clients. Theory testing indicated that health improvement services could be effectively targeted at people in mid life and that service settings played an important part in engagement. In particular contexts, combining free health checks with financial advice was a significant motivator for engagement, as was perceived health need in two deprived areas. Gains in knowledge were also important for empowerment in some contexts, but validation of existing knowledge could be more important in others. Opportunities to engage in social activities were a potent mechanism for empowerment amongst women living in two deprived areas. Further work is required to test these conclusions in other contexts.

**Seymour, J.**

**University of Sheffield**

*Stream: Health Technologies*

*Thursday the 16 September 2004 at 15.20 - 15.50*

### **TECHNOLOGY AND NATURAL DEATH: OLDER ADULTS' ACCOUNTS OF HEALTH PRACTICES DURING END OF LIFE CARE**

There has been little empirical focus on public views about end of life care, particularly those of the very old. This paper examines the views of 12 very old (aged over 85) adults, six men and six women, gathered during a larger study of 77 older adults' beliefs and accounts about technologies and styles of care during dying. This paper reports findings relating to;

Views about home as a place to die: home was the preferred place of care in ideal circumstances because of its symbolic meanings, and its association with important memories. There was agreement that it was right that spouses cared for each other, and that pride could be gained from giving care. For those who were still married, a major concern was how to manage care giving and practical housekeeping in the face of illness.

Dying at the 'right' time: for most female interviewees, death should happen at a pre-ordained time, and was prepared for. Religious imagery was interwoven closely with secular reflections on the possibility of choosing the time of one's own death and using care technologies such as 'do not resuscitate' orders.

Life is precious: In contrast to the women most of the very old men that emphasised their wish to hang on to life for as long as possible.

Natural death: An overwhelming concern for all interviewees was the importance of pain relief and comfort during dying. A 'natural death' was characterized by dying in one's sleep and in comfort.

**Shaw, M.**

**University of Bristol**

*Stream: Methods*

*Friday the 17 September 2004 at 09.00 - 09.30*

**PHOTOGRAPHING LIFE IN BRITAIN: A WORK IN PROGRESS**

This presentation is based on one component of a project funded by the Joseph Rowntree Foundation entitled 'Patterns and Processes of Poverty and Place: New Evidence from the Millennial Census'. That project uses spatial data from the 2001 census to document various dimensions of inequalities of life in Britain, showing a series of 'inverse care laws', such that where there is most need, there is often least provision. Project output will include five posters which depict 'life in Britain', combining text, statistical data, maps, cartograms, and photographs on five different topics - illness/health, education, employment, housing and goods/wealth. This paper relates to the process of producing the photographs for the poster on health and illness.

First, background research into the history of documentary photography and the use of photographs within sociology will be reviewed. Next, the aims of the current project will be described and various options for how this can be photographically visualised will be presented. For both of these elements a range of images will be shown and discussed. In summary, particular attention will be paid to the combination of the empirical, the graphical and the photographic, and the effectiveness of this form of communication

**Sheaff, M.**

**University of Plymouth**

*Stream: Primary Care*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**STIMULATING A SOCIOLOGICAL IMAGINATION AMONG HEALTH CARE PROFESSIONALS**

Clinical training can encourage a predominantly individual level of analysis, and while the influence of society and social groups may be acknowledged, many problems are approached from the perspective of a one-to-one clinical relationship. This paper considers ways of developing the teaching of sociology to health professionals that addresses the potential tension this may create with sociological accounts.

Starting with C Wright Mills conception of the relationship between 'personal troubles' and 'public issues', the aim is to encourage sociological thinking by introducing and working through more concrete examples. Focusing on health care, as well as health, creates opportunities for reviewing contemporary issues from a sociological perspective. These include recent initiatives such as the 'Expert Patient Programme' (the role of lay knowledge and experience), and inquiries, as at Bristol and Alder Hey (raising issues around hierarchy and authority, and professional and lay discourses respectively), as well as long-standing concerns such as inequalities and access to health care.

The paper considers ways in which topics and issues of this kind can be used to stimulate thinking and discussion, encouraging the development of a 'sociological imagination' among health professionals. Examples will be drawn from experiences of creating teaching and learning resources for a range of professional groups, including nurses, midwives, Operating Department Practitioners, Allied Health Professionals and others, at the University of Plymouth.

**Simms, M.**

**St George's Hospital Medical School**

*Stream: Inequalities*

*Saturday the 18 September 2004 at 11.00 - 11.30*

**AGE EXCLUSION THROUGH CLOSURE: OLD POOR LAW TO NEW LABOUR**

Adopting a neo-Weberian 'closure' approach to the division of labour, and drawing from historical research, I outline a theory of age exclusion describing the exclusion of older people, from the workforce, and from hospital based continuing care in Britain. In the nineteenth century socio-economic changes - the introduction of workplace technology, social surveys, the New Poor Law, and workhouse isolation, culminated in workforce exclusion on the grounds of chronological age. In the twentieth century, the Poor Law 'therapy'/'succour' divide, has been recast in the Welfare State 'health'/'social care' divide. At this interface, through the medium of clinical need, age has become a formidable force of exclusion and exploitation perpetuating Poor law closure between those people who are 'able' and 'unable' to work.

**Singh, I.**

**London School of Economics**

*Stream: Mental Health*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**MORAL DILEMMAS AND RITALIN RIDDLES**

In America, methylphenidate, marketed by Novartis under the name Ritalin, is the most common treatment for Attention Deficit/Hyperactivity Disorder (ADHD). Between 6 and 10% of American school children are thought to have ADHD. Approximately 75% of these children are boys.

Communication to parents about Ritalin treatment for their children with ADHD often represents a simultaneous attempt to medicalise behaviour problems and to normalise psychotropic treatment. Thus parents are told that ADHD is a health problem just like diabetes, and Ritalin is as necessary as insulin. Because clinicians are also aware of Ritalin's potential use as a tool for behaviour improvement or enhancement, however, they do not talk about Ritalin's treatment targets in terms of the child's behaviour. Rather they often use the phrase, "Ritalin will allow your child to be successful."

In this paper I examine the interrelation between "health" and "success" in relation to Ritalin treatment for American boys with ADHD. I explore the meanings of 'success' in terms of American ideals of masculine behaviour, and I consider the implications of these ideals for the medicalisation of young boys' behaviour. At the centre of the paper is an examination of data from qualitative interviews with mothers and fathers of boys who take Ritalin for ADHD. I will argue that this data demonstrates the gendered nature of 'health' and 'success' and the extent to which a medicalised understanding of boys' behaviour is contingent upon the desire for success in competitive local contexts.

**Sointu, E.**

**Lancaster University**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 09.35 - 10.05*

**IN SEARCH OF WELLBEING**

This paper theorises the rise of alternative and complementary health practices as related to the wider social context and argues that it is a desire for experiences of wellbeing that prompts many of the quests into alternative and complementary health scene. This wellbeing searched for appears to denote agency, activity and mobility, all seen to spring from developing a sense of awareness of truths located within. Wellbeing like this reflects and reproduces many prevalent (western) social ideals, particularly, understandings of what constitutes appropriate personhood. Wellbeing is a thoroughly contemporary concern that pertains to wider social values, and in particular, to ideals such as self-responsibility and authenticity: wellbeing has come to imply and demand the ability to discover and follow one's own and individually specific path. Here, practices geared to the production of wellbeing help individuals to manage and produce appropriate emotions in relation to wider social ideals, but also in relation to their embodied and gendered identities. As such, the notion of wellbeing can also be thought of as a tool for governance that is significant in shaping and producing subjects who are willing to actively take on the responsibility for personal health. However, wellbeing is also a tactical category allowing individuals to challenge biomedical definitions of health especially when these definitions are felt to misrecognise personal experiences and understandings of illness. This paper is based on qualitative interviews with both practitioners and clients of varying forms of alternative and complementary medicine.

**Solbjør, M., Østerlie, W.**

**Norwegian University of Science & Technology**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 15.20 - 15.50*

**CONSTRUCTIONS OF MAMMOGRAPHY SCREENING AMONG LAY FOCUS GROUP PARTICIPANTS: REASONS FOR ACCEPTANCE OF SCREENING PRACTICES**

Norwegian women aged 50-69 are invited biannually to participate in a national screening program for breast cancer. Each woman receives a personal letter with a pre-set date for a mammography examination.

In a screening program a whole segment of the population is examined for the occurrence of a particular disease. In order to succeed, the screening program is dependent on a high rate of participation. During the first four years, the Norwegian mammography program had a participation rate of 80%. This makes it proper to ask why participants accept the screening invitations and how they construct their understandings of mammography screening.

The research group have conducted a series of focus group interviews among sixty screened women in order to outline how a group of Norwegian women understand mammography screening and their own participation in it. All of the interviewed women had a mammogram taken between the first and second focus group session.

The first analysis indicates that the women feel obliged to join the public screening program. Their articulated reasons are multifaceted and their knowledge about the screening program likewise. They receive a letter with their name on, and see it as an offer they can't refuse. The obedience towards the program seems to be based on the notion of the invitation letter as a call up. Some participants support the program but are sure they don't need mammography themselves. They use mammography to consolidate their feeling of good health or participate in solidarity with women who have breast cancer.

**Solvang, P.**

**University of Bergen, Norway**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 09.35 - 10.05*

**THE SOCIAL SIGNIFICANCE OF MEDICALISATION: CASE DYSLEXIA**

When pupils have difficulties when learning to read and write, one of the responses from the educational system is the diagnosis of dyslexia. This diagnosis is based on neurological psychology and learning theory. However, it is reason to believe that the occurrence of dyslexia is highly sensitive to the requirements for performance the pupils experience.

There are several groups of actors involved in the process of constructing the social meaning of dyslexia; i.e. parents, teachers, educational authorities and organizations representing the interests. Some of these emphasize the constructive social powers related to dyslexia, while others perceive diagnostic reasoning as counter productive to the learning processes. The discussion of this paradox is the main focus of the paper.

Empirically, the discussion is based on four studies of the construction of dyslexia in different social settings, such as individual life stories, parent's stories, educational politics and the legal system. Theoretically, the analysis is founded on an understanding of medicalisation as a two-faced social phenomenon. On the one side there are positive effects such as de-stigmatisation, prestige and easy access to special education resources. On the other side we find such undesirable effects as de-contextualisation, self-fulfilling prophecies and pathologisation. The positive side seems to have the greater contemporary social significance. The paper suggests that the preference for medicalisation is related to the social invisibility of the alternatives to medicalisation, the redistributive power of diagnostic reasoning and the construction of dyslexia as difference rather than pathology.

**Somerville, C., Featherstone, K., Feder, G.**

**Queen Mary's School of Medicine and Dentistry**

*Stream: Lay/Professional Interface*

*Friday the 17 September 2004 at 10.45 - 11.15*

**PATHWAYS TO DIAGNOSIS: MAKING SENSE OF PATIENTS' DESCRIPTIONS OF CHEST PAIN**

The specialism of cardiology within biomedicine is dominated by technological advances in surgical techniques, therapeutics and diagnostics. Despite these technological advances the patient pain narratives remain one of the oldest and most effective, non-invasive diagnostic tests.

This paper highlights the highly narrative based diagnostic process in heart-related chest pain classifications. Drawing on pain narratives collected at a Rapid Access Chest Pain Clinic in East London, the paper demonstrates the processes of preliminary diagnosis and subsequent decision-making for further investigation and treatment of cardiac chest pain. The paper further argues how in clinical practice, the ways in which a patient describes their pain is often considered the most sensitive test to distinguish between cardiac and non-cardiac chest pain. In so doing, the paper considers how such narratives produce a well established diagnostic tool.

**Speed, E.**

**University of Essex**

*Stream: Mental Health*

*Friday the 17 September 2004 at 10.45 - 11.15*

**DISCOURSES OF MENTAL HEALTH AND AGENCY**

This paper will address discourses of mental health. Drawing from a discursive analytic frame, it will investigate the different types of discourses, used by mental health service users, to talk about different aspects of their social situations. The discursive frame is founded on notions of repertoires and contexts. These repertoires and contexts will be employed to primarily address issues of agency.

There is a symbiotic relationship between the repertoire a person utilises and the context in which they are speaking. For example, service users when talking about health professionals may draw from more passive discourses, whilst when talking about themselves may utilise more active discourses. Drawing from empirical interview material collected from service users, the relationship between repertoires and contexts will be explored more fully, in order to identify the social processes at work both in the construction and utilisation of discourses of mental health. In particular, the paper will consider the discursive construction of the 'psychiatric patient', the 'consumer of psychiatric services' and the 'survivor of psychiatric treatment' and how service users utilise these discourses interchangeably in their talk. It is proposed that these different repertoires operate or afford the service user different levels of agency and these different levels are reflected in the context in which they are employed, for example, the patient discourse may primarily be used in relation to talk about mental health professionals. An exploration of these different repertoires and contexts allows for a sociological understanding of the social processes surrounding notions of mental health.

**Stevenson, F.**

**Royal Free and University College School of Medicine**

*Stream: Mental Health*

*Thursday the 16 September 2004 at 14.00 - 14.30*

**AGENCY IN RELATION TO MOOD MODIFYING MEDICINES**

Despite the dominance of the biomedical model, the literature on non-adherence (or non-compliance), lay beliefs about medicines and the extent to which people self-regulate in relation to their treatment indicates that people are active decision makers and their behaviour does not indicate unthinking acceptance of the biomedical model. The starting point of this paper is that even when people are suffering distress such that they may be considered suitable candidates by the medical profession for the prescription of mood modifying medicines they do not necessarily either seek such treatment, and even if such treatment is offered then they may not use it as prescribed. Thus even when feeling that they lack control over their environment, people still act in an agentic way.

Drawing on interview data, the paper explores the complexity that surrounds the decision to seek help and accounts of the results of such help seeking in relation to the use of mood modifying medicines. Specifically, the paper investigates how actions are perceived in relation to taking control. The focus is not on demonstrating agency but rather how the same action may be judged differently by different actors.

In order to situate the arguments the literature relating to chronic illness and concepts such as biographical disruption, loss of self and narrative reconstruction are drawn upon. Arguments in relation to stigma and the divide that exists in people's understandings and beliefs about mental and physical illness are also considered.

**Stewart, M.**

**University of the West of England, Bristol**

*Stream: Reproductive and Sexual Health*

*Friday the 17 September 2004 at 09.35 - 10.05*

**SANITISED THROUGH WORD AND DEED: VAGINAL EXAMINATION AND MIDWIVES' DISCOMFORT**

Vaginal examination (VE) is a common procedure in labour, carried out by both midwives and obstetricians, that provides information about cervical dilatation as well as the position and presentation of the fetus. This, in turn, gives some indication as to how long labour will last.

This paper will present observational and interview data from an ethnographic study exploring the ritual of the vaginal examination, describing the techniques used by midwives to prepare for the procedure, including the use of sterile packs, and washing of the woman's genitalia. It will be argued that labouring women's vaginas are perceived as 'dirty' and that midwifery practice acts as a signifier of this. Midwives use the ritual of the vaginal examination as one strategy for demonstrating their considerable power over women and as a means of separating themselves, as 'clean', from the women, who are 'dirty'.

Data will also be presented to show that, whilst attempting to sanitise women's bodies, midwives use verbal asepsis when discussing the procedure, referring to vaginal examination as 'VE' in discussion with other professionals, and as 'an internal' in discussions with women. I will argue that this demonstrates midwives considerable ambivalence and discomfort when required to touch and talk about women's genitals.

Midwives need to re-examine the rituals associated with vaginal examination and to re-consider both their practice and the words and language they use when preparing women for this intimate examination.

**Stewart, S.**

**Otago Polytechnic, New Zealand**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**THE NEW ZEALAND MIDWIVES' EMAIL GROUP: HOW AN EMAIL DISCUSSION GROUP WORKS FOR HEALTH PROFESSIONALS**

The development of the Internet has been revolutionary, with far reaching effects that impact on all of our lives in one way or another. The Internet has a lot to offer health professionals, in particular, the facility of e-mail. E-mail enables people to be able to communicate with each other, at any given time, from anywhere in the world. One e-mail device is the discussion list or group. There are numerous e-mail lists or groups that were specific to health professionals. An e-mail group is a group of people with a similar interest who use list servers or programs that automatically deliver messages to the whole group. One member of the group produces a message and it is automatically sent to the whole group. By joining such a list health professionals can 'talk' with each other, generating scholarly debate, exchanging information, offering professional support and opportunities for reflection on practice (Spender, 1995; Sudweeks & Simoff, 1999). This is particularly desirable for health professionals who live in remote and rural areas, who are unable to keep in touch with col leagues as much as they would like (Stewart, 2003). This paper describes how the New Zealand Midwives' E-mail Group provides a forum for disseminating knowledge and providing social support, and suggests that e-mail groups are valuable tools for health professionals in developing their practice.

**Stewart, S.**

**Otago Polytechnic, New Zealand**

*Stream: Ethics*

*Saturday the 18 September 2004 at 11.00 - 11.30*

**CONDUCTING SOCIOLOGICAL RESEARCH ON THE INTERNET: ETHICAL ISSUES FOR HEALTH RESEARCHERS**

The Internet has become an integral part of every day life in the developed world as an avenue for disseminating information, as well as a means of communication. Alongside these developments has been the growth of the Internet as a tool for research. The Internet creates phenomenon that can be investigated such as web sites, e-mail discussion groups and bulletin boards. The Internet can also be used as a tool for gathering data, for instance e-mail focus groups, real time interviews and web-based surveys, as well as recruiting participants to a study (Eysenbach & Till, 2001).

This paper is a review of the ethical principles of informed consent, anonymity, confidentiality and intellectual property that are vital to consider when conducting Internet research. These principles have to be systematically considered so that there is no risk to the research participant. The ethical principles of Internet research are the same as traditional research. Nevertheless, it is important to remember that the Internet is a relatively new tool and source for research, and many Ethics Committees or Institutional Review Boards are unfamiliar with the issues of Internet research. Thus, this paper will also suggest some strategies for health researchers as they prepare their research proposals such as providing evidence that they have carefully considered all ethical aspects of their research; are familiar with computer and Internet technologies; access the expertise of Internet scholars and utilize international Internet ethics guidelines.

**Summerville, L.M.**

**University of Newcastle**

*Stream: Methods*

*Saturday the 18 September 2004 at 11.00 - 11.30*

**PARTICIPANTS' VOICES: EXPERIENCES OF 'BEING RESEARCHED'**

Examinations of the ethical issues involved in 'doing' ethnographic research are commonly centred on discussions of the processes of recruitment and access, interrogations of the relationships that develop between the researcher and participants in the field and the processes and implications of exchanging information.

However, the underlying desire within ethnographic research to justify the critical position of the researcher in the generation of data, orientates these discussions towards the researcher's perception of the field at a particular point in time; the researcher's identity within the field and the researcher's relationship with those with whom she works.

This paper attempts to address this imbalance in ethical reflection by shifting the perceptual focus from the researcher towards the researched. It does this by introducing an account of the research experience from the point of view of the participants.

The data that informs this paper was generated from a group interview with six older women held at the end of their participation in a two-year ethnographic study designed to explore their experiences of everyday ageing and the impact this experience has on social relationships, health and well-being.

Using the participants' words to generate questions and issues for debate, it suggests that as part of our ethical considerations we, as researchers, need to concentrate in greater depth on participants' initial perceptions of the researcher and the research process when obtaining consent and also to investigate periodically throughout the research process, the impact of participation on participants' sense of self and social identity.

**Thomas, H., Christie, N., Storey, L.**

**University of Surrey**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 14.00 - 14.30*

### **RECOVERY FROM SPORTS INJURY**

It is estimated that some 29 million incidents of exercise related morbidity occur per year in the UK, of which 9.8 million are sufficiently serious to result in treatment and disruption to the participants' ability to resume usual activities (Nicholl et al 1995). Despite an extensive literature on sports injury comparatively little is known about the meanings such injuries and recoveries have for sufferers. Medical sociology has paid extensive attention the process of becoming a patient but has left largely unexplored the process of emergence from patienthood and re-engagement with normal social roles.

This paper reports the results of an exploratory, qualitative interview study of recovery from injury amongst 20 men and women who have experienced a sports injury sustained in either a professional or leisure context sufficient to disrupt their usual activities, particularly work. The paper considers: the nature, circumstances and meaning that the injury has for the participant; the sources of medical or other healthcare treatment and advice; the processes and experience of recovery, both medical repair and social re-engagement; responses by others to the injury e.g. family, friends and work colleagues; and the process of negotiating return to work. The implications of recovery from sports injury for a wider sociology of recovery are explored. Potential conflicts between health promotion and prevention policy priorities that aim to increase physical exercise to help combat cardiac disease and diabetes with those that aim to reduce accidental injury and its outcomes are noted.

**Timmons, S., Harrison-Paul, R. ; Dirkse Van Schalwyk, W.**

**University of Nottingham**

*Stream: Health Technologies*

*Saturday the 18 September 2004 at 11.00 - 11.30*

### **AUTOMATIC EXTERNAL DEFIBRILLATION: LAY PEOPLES' EXPERIENCE AND UNDERSTANDINGS OF BEING TRAINED TO USE MEDICAL TECHNOLOGY**

Automatic External Defibrillation (AED) is a development of defibrillation technology which can be used by anyone. The AED has been shown to be safe and effective, and has increasingly been deployed in public places. The AED gives audible instructions on how to use it, and will 'diagnose' someone who has collapsed and then, if appropriate, deliver the correct electric shock to 'treat' their heart attack. If the person has not had a heart attack, the machine will not do anything, so there is no danger of giving a shock to someone who does not need it.

We have studied a wide range of settings, including railway stations, airports, leisure centres and large commercial organisations where AED has been purchased and implemented, and will discuss:

How people who have been trained to use the defibrillators feel about them: would they be prepared to use them in a real cardiac arrest, and do they think they have been prepared for the (potential) psychological impact of such an incident?

How 'lay' users of this technology make sense of it: how do they think the machine works, and what expertise does it embody?

How do users think about responsibility and risk in connection with this technology?

We have interviewed the people who have purchased the AEDs, the people who have been trained to use them, and the people who have provided the training, a total of 60-80 qualitative, semi-structured interviews. Data have been analysed thematically.

**Tjora, A.H.**

**Norwegian University of Science and Technology, Norway**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 14.35 - 15.05*

**CONTINUOUS COMPETENCIES: INFORMATION AND KNOWLEDGE IN TELEPHONE-BASED HEALTH ADVICE SERVICES**

Various strategies have been chosen to develop reliable telephone-based health advice services. Whereas the NHS in the UK has developed a separate advice service, NHS Direct, similar health advice service is in Norway integrated with the ambulance dispatch. In this paper, a study of the knowledge base of Norwegian advice service is presented and contrasted with other variations, such as the British.

Six Norwegian advice services (so-called AMK centres) were observed in the period March-July 2001 and 38 (of 43) AMK centres responded to a survey focusing on the knowledge base for responding to callers. During observation, interaction in the AMK centres was recorded using video and by taking notes on a laptop computer.

One important finding of the study is the varied knowledge base for the AMK centres, which includes nurses' experience, protocols, collegial consultation, local knowledge, general knowledge, consultation with other health personnel, using encyclopaedias, and so on. Especially interesting is local knowledge, which includes knowledge about geographical details, overview of local emergency resources, knowledge of local people's behaviour and special social problems, and knowledge about local professional behaviour.

Conclusively, the variation within the knowledge base for the AMK centres result of the centres' embeddedness in local and regional networks of health service providers, in a decentralised overall structure. By contrasting the Norwegian system with the British, the question of knowledge base for telephone-based advice services becomes a question about integration with other providers and structural centralisation.

**Tritter, J**

**University of Warwick**

*Stream: Cancer*

*Friday the 17 September 2004 at 09.35 - 10.05*

**MORE SOCIAL THAN PSYCHO: TENSIONS IN THE DEVELOPMENT OF A SOCIOLOGY OF CANCER**

Increasingly sociological theories and methods are being adopted in the study of cancer. Primarily these focus on the impact of the condition on patients, carers and relatives but also on the social organisation of care delivery and the social construction and meaning of cancer in society. Such research is at odds with more traditional biomedical approaches to the study of cancer and often conflicts with dominant psychological models that hold sway in cancer services. Central to this conflict are the conceptualisation of the cancer patient as passive, static and with very little agency which is dominant in the biomedical and psycho-oncology literature and in cancer services (at least in the UK). The growing stress on patient and public involvement in the NHS and internationally and pressure for greater patient decision-making and choice of treatment fits uncomfortably within such a framework. This paper will identify emerging strands in the sociology of cancer literature and suggest key points of conflict with both biomedicine and psycho-oncology. I will go on to propose key sociological contributions and insights to the study of cancer and conclude with some of the implications for service delivery and organisation that sociology of cancer illuminates.

**Underland, G.**

**Norwegian University of Science and Technology, Norway**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 09.35 - 10.05*

**TO USE, OR NOT TO USE... HEALTH PROFESSIONS ATTITUDES TOWARDS HEALTH INFORMATICS**

In hospitals there is an ever increasing amount of medical knowledge and information which the various health professions will adapt, mediate, discuss and use in treatment and care of patients. Today this information can be found in the paper-based medical patient record, which is used for sharing information about the patients. In recent years, electronic patient records (EPR) have been implemented at Norwegian hospitals in order to replace the paper-based record, to increase efficiency, rationalise medical work and increase security for patient data by improved access to medical information.

Healthcare is a knowledge-intensive arena. It is important that medical information is available and this principle should benefit the EPR. The study, on which this paper is based, indicates, that the EPR is not used to the extent that we should expect it to be. The study also documents, that health professions do not exploit the inherent potential of the EPR. Some professions show very little interest in how the EPR can contribute to their work practise, it is under-utilised, and some do not see any advantages of the IT- system. A hospital ward has its rules, routines and practises, which are produced and reproduced through practises and negotiations. New technology will feed into this process and will result in new and reinforced negotiations and produce new structures. This implicates that it is crucial to take practise into consideration when an IT- system is implemented, to be able to achieve optimal understanding and use of the new technology.

**Vivat, B.**

**King's College London**

*Stream: Experiences of Health and Illness*

*Thursday the 16 September 2004 at 14.40 - 15.10*

**"MY CARERS HELP ME KEEP INDEPENDENT"**

As part of a study to develop a palliative care service for people with advanced multiple sclerosis (MS), I conducted individual interviews with 23 people with MS. Many of these people identified independence as an important issue, but their understandings of independence varied. In this paper I will discuss my interviewees' understandings of independence and highlight how, although they all valorised the concept of independence, some redefined it. Many said that independence was important either because they felt that they were no longer independent, or because they felt that their independence was reduced, and that it was important to them to retain what independence they still had. These interviewees thus subscribed to an understanding of independence stemming from Enlightenment views of the subject and of personal autonomy, such that, to them, independence meant isolated, individual self-sufficiency. However, other interviewees, while still valorising the concept of independence, understood it in a different way. These people, although living in what to an outsider might appear to be highly dependent situations, perceived themselves to be independent. Reindal (1999) argues that independence should be redefined in terms of an understanding of the subject that recognises all humans as interdependent. I will suggest that this is precisely how these interviewees were defining independence, and will conclude by pointing to wider debates concerning individualism, 'dependency,' and the social model of disability.

**Vivat, B.**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**CONTROLLING CARING**

Allopathic medical systems are often characterised as opposing "care" and "control," in association with the oft-made opposition between "care" and "cure". From this perspective allopathic medical professionals are defined as seeking to cure and/or control disease or illness, an aim which is often constructed as opposed to care. Since nobody is "cured" in a hospice, hospices are often identified as typifying the "caring" approach, even when aiming to provide symptom and pain control. In 1999 I conducted an ethnographic study of a hospice in the West of Scotland in which I sought to explore the spiritual aspects of care. During this study I became aware of how issues of care and control arose relating to how, or whether, patients responded as workers wanted to the care which patients received from workers. These issues related to other interactions and evaluations, such as (i) how workers interacted with patients whom they had identified as "going downhill" - that is, as more likely to die; (ii) how, and with whom, workers discussed death and dying; and (iii) how workers mutually evaluated some patients' deaths as "good" or particular patients as having "done well." I will outline these issues, and indicate how, in this particular hospice, they seemed to me to illustrate an interweaving, rather than an opposition or a tension, between care and control.

**Vrecko, S.**

**London School of Economics**

*Stream: Mental Health*

*Friday the 17 September 2004 at 09.35 - 10.05*

**ADDICTION IS A DISEASE OF THE BRAIN -- ISN'T IT?**

This paper investigates how the contemporary brain science of addiction has developed over the last half century within biomolecular and neurobiological 'styles of thought' (cf. Fleck 1977). The analysis, based upon historical and archival research, is organized around the shift from conceptualizations of addiction as an organic or molar disease - that is, a disease that was thought to affect the brain and other organs in some general, but unspecified way - to those conceptualizations which moved beyond tissues and organs to the molecular structures of receptors, neurotransmitters, and nerve cells. It brings into question the assumption that changes in styles of thinking about addiction occur as a consequence of the discovery of 'natural' neurochemical truths of the brain and its molecular structures, independent of political rationalities, material considerations and realities, and scientific entrepreneurship. Instead, it suggests that the interplay between cultural, political, economic, and technological factors have often influenced which particular ways of going about studying, thinking about, and researching dependence have been pursued most actively. After examining how these factors have influenced the formation of new experimental methods and new criteria of objectivity which determine what scientific facts about addiction are found in the laboratory, in the clinic, and in the human body, the paper concludes by examining the implications of these new understandings of addiction for how compulsive desires are governed in contemporary societies of the West.

**Ward, K.J., Fox, N.F., O'Rourke, A.**

**Northern General Hospital**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 09.00 - 09.30*

**'EXPERT PATIENTS', PHARMACEUTICALS AND THE MEDICAL MODEL OF WEIGHT LOSS: THE CASE OF XENICAL AND THE INTERNET**

Do 'informed' or 'expert' patients challenge dominant traditions in biomedicine or simply adopt these conventional ways of thinking about body shape and size, and health? This paper examines this question in relation to the use of the weight loss drug - Xenical, and an internet forum that discusses perceptions and treatment of overweight-ness and obesity. Using data collected from the 'X-Online' forum, it is argued that users are highly insightful and reflexive in their thinking about overweight-ness and obesity and through extensive internet use, they become 'experts' in overweight-ness its treatments. However, it is argued that while the 'expert patient' can be perceived as a desirable state, as it allows a democratisation of health care, it can also be perceived constraining. The exchanges between the users in the X-Online forum perpetuate the biomedical perception that overweight-ness is a treatable condition, or an undesirable state that can be eradicated through embarking on precise diets, exercise regimes, and the consumption of drugs. Users of this forum become 'experts' in traditional and dominant biomedical thinking about obesity, rather than challenging biomedical ideas and the social meanings attached to the thin and fat body.

**Waring, J.**

**University of Manchester**

*Stream: Health Technologies*

*Friday the 17 September 2004 at 10.45 - 11.15*

**THE TRANSIENT CONSTRUCTION OF MEDICAL ERROR**

Errors in the delivery of health care have been identified as a major threat to quality. The NHS is currently introducing new systems to learn from and manage these 'adverse events'. This is premised on the Human Factors approach which draws from social psychology and ergonomic to highlight the individual and systemic dimensions of error. It is argued, however, that this perspective fails to account for the negotiated, cultural and social aspects of error, in particular the social construction of error. Data taken from 32 qualitative interviews with consultant grade doctors reveals important socio-cultural and discursive influences on error perception and interpretation. It was found that, drawing on bio-medical knowledge, doctors strive to make sense of mistakes in terms of causality and often identify error 'types', such as decision-making and treatment. However, it appears that the discursive field that informs these error constructs frequently becomes destabilised by the uncertainties inherent in medical knowledge and practice. In consequence, doctors seem to re-construct notions of error with reference to other socio-cultural parameters that accommodate this uncertainty. Specifically, the meaning of error is filtered or accentuated with consideration to issues such as perception, expectation, severity and complexity. As such it is argued that the medical construction of error is transient or fluid, and frequently divergent from the concept promoted policy. The paper argues that is necessary to appreciate the distinct discourses and socio-cultural fields that influence the construction of error and importantly how these present different methods of error control.

**Warr, D., Russell, E.**

**University of Melbourne**

*Stream: Inequalities*

*Friday the 17 September 2004 at 14.00 - 14.30*

### **NATURE-STRIPS AND POWER-LINES: THE SIGNIFICANCE OF PLACE IN HEALTH RESEARCH**

There is compelling evidence that living in socioeconomically disadvantaged places is associated with poorer levels of health and well-being. There are many difficulties in untangling the association between place and health and research has relied heavily on data collected for other purposes. The indicators that are used may not capture current conceptualisations of why place is likely to be significant for health, or people's experiential understanding of the places where they live. These methodological problems are compounded by a concomitant neglect in theorising the concept of 'place', and how it is relevant for understanding subjective experiences of neighbourhood and community. The interrelationships between these theoretical and methodological issues are twin concerns in this paper, which understands neighbourhood as providing both objective and subjective conditions in which people conduct everyday life.

Neighbourhoods represent complex experiences because they can be mapped and observed as exterior public spaces, but they also host the qualified and privatised interior spaces of people's homes. These indeterminate meanings of neighbourhood as furnishing both objective and subjective conditions for existence, physical and social environments, and public and private spaces, led anthropologist De Certeau and colleagues (1998) to describe neighbourhoods as thresholds between public and private spaces. In this paper, we use these theoretical ideas to consider the practical and social significance of place in health research, and then illustrate how these concepts were applied in a small empirical study of two socio-economically contrasting suburbs in Melbourne, Australia, that have divergent health outcomes.

**Watson, E., Barbour, R.S., Smith, K., Hendry, C.**

**University of Dundee**

*Stream: Experiences of Health and Illness*

*Friday the 17 September 2004 at 16.55 - 17.25*

### **"HOPE VERSUS PROGNOSIS". THE PARTNERS EXPERIENCES OF LIVING WITH HEART FAILURE**

#### Background

Heart failure is a growing global health problem characterised by impaired quality of life, high mortality within 6 months following hospitalisation and numerous hospital admissions. The chronic nature of this condition alongside current trends to reduce hospital stay, and a move to care in the community has resulted in greater impact on partners. This is the focus of an ongoing PhD study, exploring the experiences and perceived needs of partners of people diagnosed with heart failure.

#### Methods

The study involved undertaking semi-structured interviews over a 6 month period. A purposive sample of partners of people admitted with a diagnosis of heart failure to a large North-East of Scotland Teaching Hospital, were invited to participate.

#### Focus and preliminary findings

Interviews have explored issues around the conceptualisation of the diagnosis of heart failure. They have sought to illuminate the processes involved in dealing with the disease, and how strategies have been implemented by the partners to accommodate the illness in their every-day life. This study has revealed an unexpected gap between clinical prognosis and lay understandings.

An exploration of how individuals construct their identities in relation to their past, present and future within the context of living with this chronic illness has been undertaken. Issues regarding the nature of the couple's relationships involving the gendered role expectations have been highlighted. But it has to be asked within these preliminary findings, is hope misplaced by these partners?

**Weiner, K.**

**University of Nottingham**

*Stream: Genetics*

*Friday the 17 September 2004 at 16.20 - 16.50*

**WHAT HAPPENS WHEN A GENETIC CONDITION LEADS TO A COMMON AND TREATABLE DISEASE?  
PATIENT CONSTRUCTIONS OF FH**

Existing studies on the social and cultural implications of testing for genetic disease have tended to focus on rare or relatively untreatable conditions such as Huntington's Disease or heritable breast cancer. Nevertheless, a genomic model for managing and treating common conditions is emerging within biomedical discourses and this includes the idea of predictive or susceptibility testing. There is, however, little evidence about how lay people might respond to developments in this area.

This paper is concerned with patient discourses about familial hypercholesterolaemia (FH). This is a relatively common inherited condition which, untreated, leads to high cholesterol levels and is therefore associated with early and severe coronary heart disease. FH is monitored by measuring blood cholesterol levels and treated with cholesterol lowering drugs (mainly statins). Dietary and behavioural modifications are also advised. It is, therefore, managed in a similar way to all high cholesterol and it is by no means self-evident that patients will understand FH as a distinct category of genetic disorder.

The paper presents the preliminary analysis of my doctoral research, which asks in what ways patients construct FH as genetic. The analysis focuses on patients' accounts of FH, for example, the way they explain FH, their ideas about health responsibilities (to themselves and to their kin) and their ideas about their future health. The research is based on interviews with adults with FH undertaken at a lipid clinic (a specialist out-patient clinic) in the north of England.

**Welch, N.**

**University of Melbourne**

*Stream: RG15 and International Health*

*Friday the 17 September 2004 at 15.10 - 15.40*

**THERE'S NO PLACE LIKE WORK**

Research has consistently shown that work is better for health than unemployment, and the Whitehall studies concluded that some jobs are better for health than others. This paper examines the nexus of health, work and place to explore the complexities of call centre work in rural Australia, where unemployment is high, wages standard, and health outcomes are relatively poor. In these circumstances, for many call centre workers, the benefits of work seem only marginally better than being unemployed.

Ethnographic methods were utilised to research the call centre industry in Bendigo, a rural Australian city. Call centre work is repetitive, sedentary and highly monitored. These structural issues have implications for health, in particular, emotional stress and physical health problems. These issues are analysed in the context of the changing nature of work in a post-modern context, and the economic reality of limited rural opportunities. Yet, this is only part of the story. Auge (1995) and Ritzer (2004) theorised that non-places have no distinctive nature, and lack substantive features. I use a call centre as an example of a non-place to elaborate on the tension of working in a place like Bendigo, which is imbued with cultural and historical richness, whilst employed in a featureless, highly monitored call centre. I conclude that when considering occupational health and safety issues in call centre work practice, and practical outcomes for health generally, that it is important to appreciate the compounding effects of broader social and economic contexts on the structure and meaning of work.

**Wiles, R., Charles, V., Crow, G., Heath, S.**

**University of Southampton**

*Stream: Ethics*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**RESEARCHING RESEARCHERS: LESSONS FOR RESEARCH ETHICS**

There is widespread debate about ethical practice in social research. Research practice in medical sociology is constrained, to some extent, by the need for approval by NHS Research Ethics Committees and, increasingly, University Ethics Committees as well as professional guidelines. However, these constraints do not address all the ethical decisions researchers have to resolve during the process of research. In this presentation, we draw on research conducted on an ESRC-funded study of informed consent in social research. The study involved conducting focus groups and telephone interviews with researchers working in the broad areas of health and childhood research to explore how issues of informed consent are managed by researchers working with groups commonly identified as 'vulnerable'.

Researchers' knowledge of the 'tricks of the trade' and our wish to demonstrate respect for our peers raised a number of ethical issues in the process of the research. Conducting research amongst our peers on the topic of ethics made us, and our study participants, particularly sensitive to these issues and we explore them here to highlight the implications they have for research with other groups. We report on three interrelated issues. The first relates to issues of confidentiality and the desirability of study participants amending their interview/focus group transcripts. The second relates to issues of anonymity and the advantages and disadvantages of study participants being identified in research publications. The third relates to issues of ownership of data and consent. The responses of participants and the management of these issues will be discussed.

**Wilkinson, C.**

**University of Plymouth**

*Stream: Lay/Professional Interface*

*Saturday the 18 September 2004 at 09.00 - 09.30*

**'DIALOGUE MATTERS?' HOW SCIENTISTS, MEDICAL PROFESSIONALS AND JOURNALISTS VIEW COMMUNICATION TO BROADER PUBLICS**

Examinations of the practitioner-client relationship suggest an increasingly active lay knowledge, supported by non-directive ethical stances. Social studies of science and technology have further emphasised the validity of lay local knowledge, while extending social constructionist perspectives to include the nature of scientific facts and knowledge claims. The public's knowledge of science and medicine are thus validated placing an increased emphasis on personal responsibility for health. However in light of recent scientific and medical 'crises' and media coverage of issues such as MMR, genetic technologies and nanotechnology, 'public understanders', scientific and medical professionals and politicians say 'science matters'. While publicly supporting dialogue to navigate these crises, there remains a link to public education of scientific and medical facts, and a concern regarding media misrepresentation. This paper casts light on the relationships between the public, journalists, medical and scientific professionals through a series of interviews, supported by survey data, carried out in the course of PhD research examining discourses regarding new genetics. By exploring the attitudes and experiences of members of the public, media, scientific and medical communities, the research reveals a surprising number of convergences in the attitudes of these groups. While also highlighting certain points of conflict; this suggests dialogue creates a complex, insightful and far from ambivalent perspective on the significant relationship between practitioner and public.

**Williams, C.**

**King's College London**

*Stream: Poster*

*Friday the 17 September 2004 at 16.00 - 17.00*

**FRAMING THE FETUS IN MEDICAL WORK: REPRESENTATIONS AND PRACTICES**

Are perceptions of the fetus shifting with new reproductive and genetic technologies? How is the fetus envisaged, imagined, defined, and by whom? For a number of years, the contested status of the fetus has lain at the intersection of reproductive, abortion and disability politics. Arguably, the use of images, visualisation techniques and innovative medical procedures have focused our attention more firmly on the fetus than ever before. Though factors affecting the attribution of personhood are not fixed, it could be argued that the practices and rituals which impact on notions of personhood are increasingly being extended to the fetus - for example, they are 'seen', sexed, named, spoken to and about, and treated.

This poster explores perceptions of the fetus primarily through the perspectives of health practitioners, because of their powerful role in constructing the present and future fetus. Practitioners will be seen to have contrasting, sometimes conflicting ways of thinking about the fetus, depending on, for example, their professional background or their stake in this area. Rather than explore the concept of fetal personhood from a philosophical perspective, I hope to highlight the contexts out of which such questions arise, and just as importantly, those from which they do not.

**Williams, S.J.**

**University of Warwick**

*Stream: Theory*

*Friday the 17 September 2004 at 14.35 - 15.05*

### **THE MEDICALIZATION OF SLEEP? SOME FURTHER THOUGHTS AND REFLECTIONS**

This paper revisits the question of whether or not sleep is the 'latest chapter in the medicalization story' in the light of further evidence, both past and present, concerning these developments and debates. Theoretical and conceptual issues regarding the 'doing' and 'undoing' of sleep are also elaborated in this context. Medicalization, it is argued, is not an either/or state but a matter of degree, which may be more or less advanced depending on the case in question. The medicalization of sleep, moreover, may well be a late twentieth century development, but important historical precursors can nonetheless be found, particularly in the nineteenth century. The paper concludes with some further speculations on broader processes of 'sleepicization' (i.e. a heightened awareness and sensitivity to sleep matters in all spheres of society), including calls for 'well-slept' citizens and a 'well-slept' society.

**Wong, Y.F., You, S.F.**

**I-Shou University, Taiwan**

*Stream: Health Policy*

*Friday the 17 September 2004 at 16.20 - 16.50*

### **SARS, QUARANTINE AND CIVIL DISOBEDIENCE: A CASE STUDY OF THE SHUTDOWN OF HEPING HOSPITAL OF 2003**

On April 24th 2003, Taipei Municipal Heping Hospital, where the first Taiwanese SARS (serious acute respiration syndrome) hospital infection occurred, was shut down abruptly to halt the outbreak of SARS infections in Taiwan. Being compelled to work and without necessary protection against SARS, some hospital staff broke the quarantine order by getting through the blockade. Through an occupational health and safety approach, this research investigates the social construction of the medical professionals' disobedience, with the intention of evaluating the operation of the state's emergency health powers.

In the light of critical debates on civil disobedience together with some interview data about those directly involved in the Heping case, we explore the reasons for the healthcare workers' acting in self-defence, with a concern about the lack of an occupational hygiene perspective in the quarantining. The social right meanings of "occupational health and safety" and "public health" are addressed in an attempt to explore the "conflict" between them in the case under consideration. The discussion also draws upon John Rawls's (1971) argument on the justification for civil disobedience, leading to supplementing Rawls' brief assertion relating to the so-called "extreme conditions".

We argue that Taiwanese public health policy-making represents a dictatorial regime relying on experts, in that the values of front-line medical workers are by and large excluded in the formation of the nation's epidemic prevention and control measures. Thus, the effects of the state's regulation have detracted significantly from the resistance of the medical professionals in the Heping case.

**Wood, F., Prior, L., Scott, S., Gray, J.**

**University of Wales College of Medicine**

*Stream: Genetics*

*Friday the 17 September 2004 at 14.35 - 15.05*

### **REPOSITIONING THE PATIENT: THE IMPLICATIONS OF BEING AT RISK**

#### Introduction

Medical discourse has displayed a shift away from terms of illness and disease to terms of health and risk. Increasing numbers of individuals are seeking advice regarding the risk associated with their family history of cancer. This paper explores, from the patients' perspectives, the re-definition of what it means to be 'a patient' and how the social world of 'being at risk' is to be structured.

#### Methods

We conducted interviews with 39 patients referred to a regional cancer genetics service. Interviews were analysed for talk about the impact of the risk assessment on everyday life.

#### Results

Patients struggled to comprehend their status within the health care system. Many expressed uncertain feelings about their identity as neither a patient nor 'healthy'. Patients were required to confront the possibility of their future self as suffering from a bodily pathology that is probable rather than actual, and to incorporate this tentative knowledge into their 'lifeworld'. Respondents reported strategies that they had devised to resolve their ambiguous status, which we describe as 'normalisation' and 'seeking surveillance'.

#### Conclusion

The process of risk assessment brings together two distinct social worlds: that of the medical professional and that of the lay person. Patients appear to be less concerned with their genetic status than with what this means for them in terms of access to health care and their family relationships. Health professionals need to be aware of how patients manage this new identity between healthy and afflicted.

**Woodward, L.**

**Nottinghamshire Healthcare Trust**

*Stream: Mental Health*

*Friday the 17 September 2004 at 11.55 - 12.25*

### **THE NEED TO BE RECOGNISED: LOCATING IDENTITY THROUGH DIAGNOSIS?**

Depression is becoming an increasing aspect of daily living and a complex yet, interesting, phenomenon. Patients with psycho-social distress represent 30% of all GP consultations and around 50% of all consecutive attendees at GP surgery (Kessler et al 1999). Goldberg and Huxley (1992) highlight that of 250,000 patients seeking help from their GP annually, approximately 150,000 of these fail to be identified as a 'case' and thereby fail to have their self diagnosis ratified by the GP. These patients constitute an interesting group of which little is known concerning their decision to seek help in the first place. This paper explores the idea that there exists a need to be recognised and esteemed within an illness diagnosis which may partly explain the rise in 'therapeutic' demand within general practice and the increasing incidence of depression in society. Western society is seemingly moving towards a more consumer culture, 'as the relevance of more traditional anchors and support of the community - the family, church, and religion - have eroded over the past 50 years' (Shaw and Woodward, 2004). Society therefore may be experiencing a cultural shift towards an intense 'therapeutic sensibility, a demand for meaning, and an unprecedented concern with the question of identity' (Furedi, 2003). One manifestation of this is perhaps a 'continual search for psychological diagnosis in an attempt to find some meaning in confusion' (Bracken, 2002).

**Wrede, S.**

**Åbo Akademi University, Finland**

*Stream: Health Service Delivery*

*Friday the 17 September 2004 at 14.00 - 14.30*

**HOW THE FINNISH HEALTH CARE DIVISION OF LABOUR RESPONDS TO THE NEW PRACTICAL NURSE: CONTESTED PROFESSIONALISM OLD AND NEW**

In the early 1990s, the training for health care assistants, social service assistants, paramedics, child care workers and few other occupations occupying similar occupational roles was renewed in Finland. Nine previously separate curricula were merged into one new degree called practical nursing in social and health care. An important idea in combining health and social care orientation in the educational reform was to make the new practical nurses more flexible. Furthermore, professional expertise and autonomous practice were emphasized. In health care, the new rhetoric emphasis in policy challenges the earlier confinement of practical nursing to basic bedside care.

On the basis of the analysis of professional journals for practical nurses, registered nurses, public health nurses and doctors this paper looks at the views of the different health care occupations and professions on the ongoing reform of practical nursing. What constitutes practical nursing for the different groups? How is the health care division of labour renewed as a result of changes in practical nursing?

The paper suggests that the reform aiming at the creation of a new type of practical nurse challenges traditional elitist versions of professionalism in health care. Professionalism and autonomy are encouraged also at the lower levels of professional hierarchies. However, the reform is linked to the institutional restructuring in the welfare state and the neo-liberal ideals of flexibility and effectiveness. The emphasis on leadership and productivity support traditional versions of professionalism and are obstacles for the emergence of a truly new kind of practical nurse.

**You, S.F.**

**I-Shou University, Taiwan**

*Stream: Health Policy*

*Friday the 17 September 2004 at 15.45 - 16.15*

**HEALTH UNDER GLOBALISATION: GLOBAL INFLUENCES AND LESSONS IN THE TAIWANESE CASE**

This paper addresses the on-going debate about globalisation in the context of health, with a view to comprehending the political-economic dimension of policy formulation and the social consequences of globalisation in the case of Taiwan. We explore how a Taiwanese 'health miracle' was created alongside an 'economic miracle' at considerable social cost. In short, the development of deepening economic liberalisation together with the recent National Health Insurance (NHI) reform have added negative effects to existing health variations, in terms of constituting new barriers preventing access to NHI care for the economically disadvantaged. Other damaging effects brought about by Taiwan's economic globalisation are also identified, leading to structured health inequalities among disadvantaged groups, particularly the indigenous population and foreign workers.

With a view to seeking an explanation for the divergent trends in global health, the social impacts of the Asian Financial Crisis of 1997 on Taiwan are examined, in relation to their implications for health. There has been observed a worsening tendency that may enlarge existing health inequalities, since rising unemployment plus a general decrease in educational expenditure have appeared in the post-crisis era. Equally important is the fact that the changes in Taiwan's health expenditure as a percentage of GDP after the crisis have not been consistent with economic development. As regards the reason for this, we argue for a 'structured divergence' approach (Ginsburg, 1992) to the explanation of Taiwan's health expenditure, referring to the determinants of Taiwan's health policy being highly related to the operation of party politics.

**Yu, J., Murphy-Black, T.**

**University of Stirling**

*Stream: Ethnicity*

*Friday the 17 September 2004 at 14.00 - 14.30*

### **SEXUAL ATTITUDES OF BRITISH BORN CHINESE TEENAGERS**

Health promotion and sexual behaviour counselling should be sensitive to cultural and family norms, values, beliefs and attitudes. There are few systematic studies of attitudes towards sexual behaviour among British born Chinese teenagers in Britain, and thus need to explore these issues. This ethnographic study aims to investigate the sexual attitudes and behaviour among these teenagers and what factors influence them. The qualitative design contributes substantially to greater understanding of individuals' experiences. Including both teenagers and parents overcomes the limitation of inconsistent reports between generations, and the recruitment of mothers and fathers provides a better perspective on family influences.

In-depth interviews were carried out with 20 unmarried teenagers, aged 16 to 19, born in Britain or moving to Britain before age 5 and 20 Chinese parents. NUD\*IST 6 was used to manage the data. By examining the influences on teenage sexual attitudes and behaviour in a social framework, three thematic areas were developed - peer influences, family influences and sex education at school. Differences between genders and between generations were discussed.

This paper will concentrate on sexual attitudes of these teenagers. The majority of them expressed a conservative view of sex. They believed that sex was something special and related to love, trust, commitment and/or marriage. However, they were tolerant to others having sex. When a few teenagers did express a permissive view, they were concerned about the safety and readiness for sex.