HEALTH | TECHNOLOGY | SOCIETY RESEARCH GROUP
Bridging the Gaps Between the Sociologies of Diagnosis and Intervention
SYMPOSIUM REPORT
Rapporteur: Dr Michael Morrison

Event funding: Foundation for the Sociology of Health and Illness
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FOREWORD

Welcome to this comprehensive report of the inaugural workshop of the Health, Technology and Society (HTS) Research Group at the University of Exeter! The report provides background information concerning the HTS Research Group and the workshop, in which we sought to ‘bridge gaps’ in theory and scholarship between the recently robustly developing sociology of diagnosis, and the more nascent development of a sociology of intervention (an area I am myself concerned to theorise and develop as an empirical programme). I am grateful to the scholars whose fascinating and deeply substantive presentations formed the core of the workshop - Professors Sarah Nettleton, Celia Roberts, and Oonagh Corrigan. The report contains synopses of each speaker’s presentation with bibliography, and these make very interesting and thought provoking reading indeed. The workshop was organised such that the second half of the programme involved discussion in small breakout sessions, in which ‘themes arising’ were identified and developed. The report summarises these thoroughly and thoughtfully; these summaries also make stimulating reading. The workshop was funded by a grant from the Foundation for Sociology of Health and Illness, for which we are grateful, with the objective of making a contribution to the field of sociology of health and illness. This report is one aspect of our effort to make such a contribution. Another is participation in an ESRC-funded Seminar Series entitled ‘The role of diagnosis in health and wellbeing: A social science perspective on the social, economic and political costs and consequences of diagnosis.’ The HTS Research Group is organizing the first of five seminars in this series, to be held in Exeter on January 28th 2013. This will be a relatively small, interactive seminar focusing on the role of technological innovations in diagnostic practices, structures and experiences. Information about the series is available at the following website: http://www.sociologyofdiagnosis.com/.

Finally, the report provides further information about the HTS Research Group and its members. We actively seek collaboration with academic, user group, and professional partners, and hope that this report will provide a useful guide to our work and our vision. More information is available on our website, http://socialsciences.exeter.ac.uk/sociology/research/healthtechnologyandsociety/. I am deeply grateful to Dr. Michael Morrison for his hard work in developing this report, in organizing workshops and seminars, and for engaging so productively in the work of the HTS Group. I am also grateful to the other group members who provided input into the report, and to the ESRC Centre for Genomics in Society for housing the HTS Group and providing the infrastructure for our development.

Enjoy reading! We welcome feedback!

Susan Kelly
OVERVIEW OF THE SYMPOSIUM

The one day symposium ‘Bridging the gaps between the sociologies of diagnosis and intervention’ was held on the 10th May 2012 at the University of Exeter. The event served to inaugurate the Health Technology and Society (HTS) research group, which is based in Exeter’s Streatham Campus.

Headed by Dr Susan Kelly, the HTS group focuses on social aspects of technological innovation in the life sciences, health and medicine, with a particular focus on sociological understandings of diagnosis. Diagnosis is understood broadly to be a social process defining the boundary between sickness and wellness, the normal and the pathological. As such, diagnostic practices and categories have profound implications for the social experience, self-understanding, health outcomes and behaviour of individuals and families. The processes and categories of diagnosis are also sensitive to context, including the contexts of technological innovation. Research undertaken by the HTS group examines how emerging diagnostic technologies contribute to shaping social processes of diagnosis; providing new – or reinforcing existing – classifications of disease and illness, identities and experiences. Current topics of HTS research include the development and deployment of non-invasive prenatal diagnostic testing, the implications and consequences of early childhood diagnosis, direct-to-consumer genetic testing in the domain of mental health and investigating patient understanding and behaviour in response to ‘pre-disease’ states such as ‘pre-diabetes’.

Growing out of the ESRC Centre for Genomics in Society (Egenis), the HTS group has considerable expertise studying the role of genetics/genomics in diagnosis, health systems, and experiences of patients, consumers, families and health care professionals. The HTS group also aims to develop a wider role as a focus for interdisciplinary research involving social aspects of emerging medical technologies across the University of Exeter and beyond.

The themes and focus of the one day symposium were chosen to reflect the group’s interests, and especially the sociological understanding of diagnosis, while also addressing a pertinent topic for contemporary sociology of medicine, health and illness. While the sociology of diagnosis has seen a resurgence of interest, as exemplified by the recent special issue of Social Science and Medicine (Volume 73 (6) September 2011) dedicated to the topic, the theoretical and practical linkage between diagnosis and clinical intervention remains comparatively under-researched and under-theorised. If diagnostic technologies are understood to act by drawing on specific indices of measurement and methods of visualisation to frame disease categories in a particular way, then the introduction of a novel set of diagnostic technologies can reconfigure the practical and conceptual understandings of disease categories. While identity-related aspects of such changes for patients and wider publics have received some attention, less is understood about how these changes impact on the processes of medical intervention and the roles of healthcare practitioners subsequent to diagnosis. At present, a number of novel diagnostic technologies, including post-genomic technologies such as cell-free foetal DNA testing in prenatal screening and whole genome sequencing in oncology and idiopathic childhood disorders, are moving from research applications into clinical
practice, driven by logics of earlier, more detailed, and more efficient detection of disease. There is thus both a historical gap in sociological understanding and a set of contemporary, high profile developments with implications for sociologists of health and illness, healthcare policymakers and practitioners, governments, ethicists, patients and other implicated publics.

These developments raise a number of pertinent questions such as:

- Do new diagnostic technologies affect existing organisational practices and if so how and with what outcomes? For example, if a new diagnostic technology allows diagnosis earlier in the life-course or earlier in the medical management of a life event such as pregnancy, does this give new responsibilities to particular professional groups (e.g. nurses, midwives, lab technicians), and does it reduce or alter the role of other groups (e.g. genetic counsellors)?

- If changing diagnostic methodologies can reframe the boundaries and meaning of disease categories how does this affect the meaning and choice of available interventions, and the subsequent trajectories of disease management, for patients and physicians?

This list is not intended to be exhaustive, but rather to be indicative – to open up the domain of inquiry, not to close it off. The aim of the HTS symposium was to provide a platform to bring together scholars working in a range of relevant domains within the sociology of health and illness, including the sociologies of diagnosis, the body, the profession(s) of medicine, and healthcare technologies, with the purpose of stimulating wider discussion, allowing room for experience, research and insights beyond the HTS group itself, to test ideas and stimulate new conversations.

To this end the symposium was widely advertised, with a restricted number of places in order to keep a productive group discussion manageable. Four travel and accommodation bursaries were also available to facilitate the participation of postgraduate students and early career researchers. Three speakers were invited with a view to bringing relevant expertise and insight to the event from a range of perspectives including the sociology of diagnosis, Science and Technology Studies (STS) and the sociology of medical practice, education and research. The symposium was organised into morning and afternoon sessions, with the morning session involving an introduction by Dr Kelly and presentations from each of the three invited speakers. Rather than present on a specific, delimiting topic, each of the key speakers was invited to draw on their own experience and expertise (and not just their most recent work) to address the topic(s) of technology, diagnosis and intervention. Post-presentation discussion was deliberately kept brief in the morning session as the afternoon session was specifically designated for this function.

The afternoon workshop session was split into two parts; participants were first split into smaller groups to facilitate discussion. Each group had one of the morning's presenters and one HTS group member assigned, to lead the discussion and take notes respectively. Participants were then regrouped for the final hour of the event to report back on the main points (ideas, theoretical issues, recommendations for topics, and methodologies for future study etc.) from each group discussion. This generated a lively and interactive discussion which also provides us with a body of data from which to develop our report summarising the key findings and recommendations arising from the event. The aim of the afternoon session was to
develop and set out a more detailed research agenda for further social research into the links between technology, diagnosis and intervention. This report constitutes one of the major outputs from that discussion.

We are pleased to report that the event was well attended and that participants other than the invited speakers came from the Universities of Cardiff, East Anglia, Exeter, Lancaster, and Plymouth as well as from the Peninsula College of Medicine and Dentistry (PCMD) and the Foundation for Genomics and Population Health (PHG). Three travel/accommodation bursaries were also awarded to facilitate the participation of postgraduate students and early career researchers. The symposium generated a lively and collegial debate and we consider the event to have been a success in terms of addressing the topic of the sociologies of diagnosis and intervention and formally launching the Health technology and Society research group.

The remainder of this report provides further information from the symposium including details of the key speakers, a report on the main points from their presentations, a bibliography of useful material on the sociologies of diagnosis and intervention, and a detailed discussion of the issues and ideas for future work arising from the workshop session. PowerPoint slides from each of the morning session presentations and other information on the event is also being made available through the HTS website: http://socialsciences.exeter.ac.uk/sociology/research/healthtechnologyandsociety/

This event was supported by a grant from the Foundation for the Sociology of Health and Illness [http://www.shifoundation.org.uk]
SPEAKER BIOGRAPHIES

Susan Kelly

Senior Research Fellow, ESRC Centre for Genomics in Society (Egenis) & Senior Lecturer, Department of Sociology & Philosophy, University of Exeter

Director of the Health, Technology & Society (HTS) research group at Egenis, Dr Kelly's research interests focus on the development of new biomedical forms of investigation and intervention into human bodies and beings, especially in the arenas of reproduction (prenatal testing and diagnosis), psychiatric genetics, childhood disorders, and complex diseases. Current work examines the implications of next generation sequencing and post-genomic science for biomedical understanding and clinical practice; for example, applications of post-genomic technologies to understanding and intervening in human reproduction.

In her role as director of the HTS group, Dr Kelly co-ordinates the activities of staff and student HTS members. Current work with other HTS members addresses the introduction of non-invasive prenatal genetic diagnosis and includes a survey of public attitudes and further investigations of the regulatory, ethical and implementation impacts of this emerging technology.

Recent works include:

Kelly, S.E., (manuscript in process) Parenting in the Genetic Age: Parents, impairment and dilemmas of responsibility.


Sarah Nettleton

Reader in Sociology, Department of Sociology, University of York

Dr Nettleton is a medical sociologist with a broad range of interests, whose research has covered health promotion; medically unexplained symptoms; lay people's use of e-health resources; food allergies; the working lives of medical doctors; running; and recovering heroin users. Theoretically and conceptually, Dr Nettleton’s work focuses on the following areas: sociology of the body and embodiment and the contested nature of medical and health knowledge. She has also worked closely with Dr Annemarie Jutel (Victoria University of Wellington, New Zealand) in reinvigorating diagnosis as a topic of sociological attention.

Recent publications include:


Celia Roberts
Senior Lecturer, Department of Sociology, and Co-Director, Centre for Gender and Women’s Studies, Lancaster University

Dr Roberts’ research interests centre on the body, health, reproduction, sexuality and aging. She is based at the University of Lancaster where she is closely affiliated with the Centre for Science Studies, the Division of Health Research, the ESRC Centre for the Economic and Social Aspects of Genomics (CESAGen) and the Centre for Gender and Women’s Studies.

Much of Dr Roberts work has brought her into contact with issues of novel and emerging biotechnologies; she is currently writing a book, provisionally entitled *Puberty in Crisis: a bio-social account*, which tracks a variety of discourses constituting contemporary puberty, coming from biomedicine, technoscience, environmentalist movements and popular media. *Born and Made: An ethnography of preimplantation genetic diagnosis* (with Sarah Franklin) is based on ethnographic research of the so-called ‘designer baby technique’ (preimplantation genetic diagnosis, or PGD). Further work, with Franklin and Karen Throsby has also studied the donation of embryos to stem cell research within the PGD clinic.

Dr Roberts also teaches on the courses, ‘Research Projects in Practice’ and ‘Feminist Technoscience Studies’ is an editor of *Feminist Theory* and recently co-edited, with Myra Hird, a special issue of *Feminist Theory* on ‘non-human feminisms’.

Recent publications include:


Oonagh Corrigan
Associate Professor, Sociology and Ethics of Medicine, Plymouth University Peninsula School of Medicine

Dr Corrigan is a medical sociologist specialising in the social and ethical aspects of medical practice, medical education, health policy, and clinical research. Her research areas include clinical trials, genetic databases, personalized medicine, consent, trust, professionalism and the emotional work of doctors. Her work also contributes to policy development and debate by revealing the disjuncture between policy, organisational structure and the experiences of those on whom the policy is intended to effect. She leads the ‘researching professionalism hub’ at Peninsula Medical School and is currently interested in the subject of values in medicine and health care as well as the use of ethnography and visual methods.

Recent publications include:


1) Susan Kelly: The Sociology of Intervention

What is the sociology of intervention?

Or rather, where should we look to find existing sociological literature that addresses and characterises medical intervention?

Dr Kelly suggests a number of relevant concepts (and texts) that offer useful starting points for investigation, including:

- The phenomenology of impairment (Hughes & Patterson, 1997)
- The social production of childhood impairment (Leiter, 2007)
- The socio-historical contexts of research on families and disability (Ferguson et al. 2000).

There is also a wider literature on individual decision making and behaviour in relation to health, and on parental decision making about children’s’ healthcare – especially with regards to long-term, chronic and ‘genetic’ conditions. However, much of this literature is dominated by concepts of risk, individual autonomy and responsibility, and deals less directly with understanding the nature, impact and practices of medical intervention itself.

One of the defining features of contemporary intervention is the drive towards ever earlier intervention, and especially childhood intervention. This is not an entirely new phenomenon. Child health has been a significant issue for public health since the beginning of the twentieth century. As David Armstrong reports ‘The significance of the child was that it underwent growth and development: there was therefore a constant threat that the proper stages might not be negotiated that in turn justified close medical observation’ (1995, p396). State responses included the setting-up of infant welfare clinics, milk depots, health visitors and school-based assessments of children’s development such as height (and/or weight) surveys.

Drawing on the US example, Dr Kelly lists some milestones in the expansion of childhood surveillance and intervention programs over the course of the previous century, beginning with the ‘well child’ visits in the 1920s (Halpern 1988).

- In 1986 the Early Intervention (EI) programme was created by the US Congress under the Individuals with Disabilities Education Act (IDEA) and fully implemented in the 1990s
- In 2001 an American Academy of Pediatrics policy statement recommended paediatricians regularly screen children for referral for early intervention services

Childhood and early intervention programs do not develop through medical rationality alone – they are linked to wider issues of public health, social organisation of healthcare and allocation of healthcare resources. In this instance we can see that US early intervention programs have been closely linked to the provision of care and support services for people categorised as disabled.
The ‘Ashley X’ case gives a clear illustration of how childhood intervention can generate complex, even controversial entanglements of parental decision making, responsibility, autonomy, medical ethics, the social organisation and provision of healthcare services and conflicting understandings of individual identity and wellbeing. The case involved an American child, ‘Ashley X’, with severe learning difficulties whose parents opted to stall her growth and maturation by means of a series of interventions (including surgery and pharmaceutical interventions) to keep her body in a ‘childlike’ state. The rationale for intervention was that Ashley’s parents feared they would not be able to look after her by themselves if she grew to full adult height and went through pubertal maturation, and that the adult Ashley would require continuous institutional care. The intervention was intended to open up an alternative future, where Ashley could continue to be looked after by her parents at home, at the cost of her not developing into a physically adult form. Following media coverage, the case generated significant, often heated public debate and raised considerable concern from disability activists and spokespeople (Adams-Spink 2007).

Much of this discussion invoked the contrasting medical and social models of disability (see Hughes & Patterson 1997) which respectively locate disability within the individual body or as a product of a society’s physical and attitudinal barriers to people with particular conditions. The two contrasting models illustrate how different understandings or ways of thinking about a condition can lead to very different kinds of intervention being considered appropriate. In the medical model, impairment is located in the body, which then becomes the appropriate site for (‘corrective’) intervention such as surgery, whereas the social model looks to change external societal arrangements which as seen as limiting the choices and possibilities for people with impairments. In the ‘Ashley X’ case, part of the reason the child’s parents wanted to make the medical intervention was because they felt they could not afford to pay for additional home-based carers to help them look after a ‘fully grown’ Ashley, which can be seen as a social, economic and organisational failure to provide adequate resources for people with difficult or long-term medical conditions. The case is also a pertinent, high-profile example of the social complexity of intervention.

Dr Kelly then turns to her own research with parents of children with genetic conditions, geneticists and genetic counsellors (Kelly, 2002; 2003; 2005; 2009) to provide further examples of the way medical interventions are understood and given meaning in particular social contexts, by looking at:

- Parents’ narratives of decisions concerning biomedical, rehabilitative and social interventions into childhood impairment
- Trajectories and stories of impairment, intervention decisions and outcomes

These narratives reflect many aspects of Ashley X intervention decisions – the social contexts of care and care provision, the blurring of ‘medical’ and ‘social’ justifications, parental responsibility and negotiations of authority and the public/private nature of intervention decisions.

- Themes of parental guilt, need and desire to take action as a response (and a reaction) to their children’s status as impaired, disabled or developmentally delayed are evident and recurring.
- The need to take action includes conventional medical interventions (pharmaceuticals, corrective surgery etc.) but also involves seeking out
information, services etc. and is not necessarily limited to the realm of orthodox medicine but can also involve investigating alternative practices (such as 'magnetic therapy').

• Phenomenologically, impairment is understood as malleable and ‘unique’ (and embodied), prognoses are not certain but frequently contested, and contexts of intervention (therapeutic, medical, developmental) suggest that the ‘will to health’ (Rose 2001) is translatable to a ‘will to change’ - an imperative to intervene?

• Parents of children with impairments find themselves at intersections of biology and culture, particularly at the social, cultural and technological boundaries of human variation, normality and pathology, capacity, and plasticity.

Impairment and disability related to genetic (and other) conditions appear to evoke a parental imperative to intervene. Recourse to medical intervention and the sense that impaired bodies are ‘malleable’ and open to being changed by medical intervention can be linked to the hope and belief in the transformative nature of what Clarke et al (2003) have described as ‘biomedicalisation’. Clarke et al’s highly cited paper characterises modern medicine as highly technological, scientific, pervading all (or most) aspects of life, concerned with risk and possibility, and able to interact with bodies at the molecular and cellular level. In this view ‘biomedicine’ goes beyond merely controlling symptoms of disease, its power is understood as reconfiguring bodies and identities through its interventions (see also Shim et al, 2006).

References


2) Sarah Nettleton: Towards A Sociology of Diagnosis

Issues of diagnosis are discussed in a great deal of sociological literature on medicine, health and illness, but the idea of a specific sociology of diagnosis puts diagnosis itself as the major object for sociological analysis. Recent work by Sarah Nettleton and Annemarie Jutel (Victoria University of Wellington, New Zealand) in advancing a sociology of diagnosis illustrates the potential appeal of this approach: Dr Nettleton reports that they received over 80 submissions for their 2011 special issue of Social Science & Medicine on the topic.

To explain more about the emerging sociology of diagnosis, two questions are presented:

• What is a diagnosis?
• What is and why develop a sociology of diagnosis?

What is a diagnosis?

Outwardly, diagnosis seems relatively straightforward. It is something familiar to anyone who has visited their GP, been admitted to hospital or seen a medical specialist. However having a diagnosis is something that can also affect our social identity – how we understand ourselves and how others understand us. The effects of having a diagnostic ‘label’ can be beneficial – for example as a means of getting access to medical and social resources, but they can also be stigmatising and even dehumanising. A recent newspaper article about the death, in institutional care, of mental health campaigner and schizophrenia patient Janey Antoniou was titled “Janey Antoniou: ‘She was a person, not a diagnosis’” (Roberts, 2012). As illness and disease can disrupt the routines of everyday life, receiving a diagnosis can also disrupt identities, causing the diagnosed individual to reinterpret or reconfigure their self-biography (Bury, 1982).

• Diagnostic categories themselves are not fixed, atemporal units – they change over time as old categories are dropped and new categories introduced. It is argued that diagnostic categories appear to be getting more sub-divided, more fragmented over time.
• Diagnostic categories are also linked to (the production of) medical knowledge – the ability to diagnose is the traditional source of doctors authority – over patients but also over other healthcare professions such as nursing, pharmacy etc.
• At the same time, diagnoses also exist outside the clinic. Individuals self-diagnose or discuss potential health problems with other members of their social circle every-day, in acts of lay diagnosis.

What is, and why develop a sociology of diagnosis?

Two papers, both by Mildred Blaxter, but published over 30 years apart illustrate the development of sociological interest in diagnosis. Blaxter is generally credited with drawing sociological attention to the issue of diagnosis in her 1978 paper on ‘Diagnosis as category and process’, where she stated:

‘The activity known as ‘diagnosis’ is central to the practice of medicine but is studied less than its importance warrants’ (1978, p9).
The term ‘sociology of diagnosis’ itself was not coined by Blaxter, but first appeared in a 1995 paper by Phil Brown, which also called for renewed sociological attention to the topic of diagnosis. Despite the efforts of Blaxter and Brown, it has not been until the more recent work of Annemarie Jutel (2009; 2011) that diagnosis has begun to be more widely taken up as a specific topic of sociological enquiry.

Mildred Blaxter’s second paper, ‘The case of the vanishing patient’, published in 2009 deals with her own experiences as a patient whilst being treated for cancer. In this work, Blaxter reported that the often complex diagnostic technologies involved were not themselves alienating or distressing; instead the most alienating, troubling aspect of the process was the patient record:

‘in modern medicine it is much more important for sociology to study what Cussins (1998) called the ‘ontological choreography’ of these ever more complex systems, including the way in which images and records appear to create and control both medical practice and the patient’s medical experience. This is what actually counts’ (2009, p776).

As well as being of academic interest, issues of diagnosis attract considerable media attention. Dr Nettleton presents several recent examples of diagnosis-related news stories from mainstream media:

- A discussion on tightening up the rules for diagnosing and compensating whiplash injuries
- A story titled ‘ways to spot breast cancer years in advance’
- News of classificatory changes to recognise ‘breast cancer’ as comprising up to 10 different, discrete disease categories
- Parents demanding an enquiry into the death of a child while in hospital, possibly as a result of not receiving the correct treatment.

These stories illustrate narratives of hope and fear around diagnosis and disease, the movement towards earlier screening, ‘pre-disease’ and risk, the shifting, atemporal nature of disease categories and issues of trust, expertise and proof in making diagnoses, or misdiagnosis (see Bloor, 2000 for an in-depth case study on issues of expertise, proof and contested disease categories). These news stories also show how issues of diagnosis are not confined to some notional realm of medicine but have significant social and legal consequences.

Another example of both the complexity of diagnosis and its situatedness in particular contexts is Halpin’s (2011) work on Huntington Disease. Huntington Disease (HD) is considered relatively easy to diagnose, but is still routinely misdiagnosed in everyday practice. Why is this? Halpin’s study points to the context of the patient’s interaction with medical services – their behaviour, their medical history and their ‘location’ – which of medicine’s many sub-specialities end up in charge of their diagnosis and management.

In the case of HD, being ‘located’ in neurology or psychiatry can have significantly different consequences for the way an individual is evaluated and treated. Neurology and psychiatry ‘see’ the brain differently – they evaluate disease based on different criteria and describe symptoms, behaviours, interventions and outcomes in different ‘languages’. Here Halpin draws on Bakhtin’s (1986) concept
of ‘speech genres’; distinct language styles that can actually hamper communication between different professional groups, to expand on this point.

‘It is not that the psychiatrists are inept, but rather are framing HD symptoms through a psychiatric, rather than a neurological or neuropsychiatric, diagnostic genre’ (Halpin, 2011 p863).

These different disciplinary standards also extend to the different classification schemes for disease used in different contexts. Problems evaluated as ‘mental health issues’ are more likely to be evaluated by psychologists and psychiatrists using the Diagnostic and Statistical Manual of Mental Disorders, currently in its fourth edition (DSM-IV). In other areas of medical practice the main classificatory guide is the International Statistical Classification of Diseases and Related Health Problems (The ICD, currently in its 10th edition). The DSM-IV does not flag up Huntingdon Disease as a significant part of mental health evaluation while the ICD-10 does, but is less commonly used by psychologists and psychiatrists, meaning they are more likely to misdiagnose possible HD cases as other types of disease.

Further examples of the context-dependency of diagnostic practice and diagnostic categories include:

• Institutional proximity of legal, insurance and medical systems where diagnosis is a resource for patients, professionals, industry, administrative regimens and governments

• Technologies and technical data which are locally mediated by perception, interpretation and communication between different groups

• Fragmentation: between different disciplines and indeed between different ‘models’ or ways of interpreting the body (see Mol 2002 – ‘The body multiple)

These complex socio-technological processes speak to epistemological and ontological issues and debates.

To return to the attempt to develop a contemporary sociology of diagnosis, Jutel and Nettleton (2011) address the complexity and contingency of diagnosis in a number of ways: Firstly, the power of diagnosis as a tool with many functions is addressed by building on Blaxter’s classic formulation of diagnosis as both process and classificatory system, to add a third component – diagnosis as consequence. Diagnosis should be considered sociologically as:

• **Category** - official label that classifies and names a disease or medically-related problem.

• **Process** – activity that identifies a disease – either in the clinic or institutional politicised arena

• **Consequence** – administrative (access and distribution of resources health care); legitimates sickness/deviance; cultural expressions of (ab)normality, guides research, treatment; evidence base etc.

Secondly, diagnosis needs to be analysed and understood as working at multiple levels:

• **Individual** – biographical, experiential, self, identity, sick role
• **Institutional/social** – negotiated in the clinic; political arena, social movements

• **Societal** - classificatory/administrative/bureaucratic systems, statistics, planning; framing, models and ideologies of disease (allopathic, pathological medicine)

In discussing diagnosis (and its sociology) we are primarily dealing with the biomedical model of the body which dominates Western medicine. Rosenberg (2002) has analysed some of the particular characteristics of contemporary biomedicine, and especially the diagnostic classificatory system of disease that gives medicine its particular character (see also Clarke et al 2003 cited above). Rosenberg identifies specificity, standardisation and ‘generalisability’ as important aspects of modern, Western biomedicine.

• **Specificity** – the recognition of diseases as specific entities, characterised by particular aetiologies

• **Standardisation** – the employment of instrumental measurement of the body allowing images and readings of the body that appear objective – not reliant on a patient's description of symptoms – and can be rendered in standard units

• **Generalisability** – the creation of medical records etc. allows standardised accounts of individual cases to be linked into the collective understanding and classification of disease.

In turn, medical classificatory systems like the ICD and the DSM become ‘social actors, real inasmuch as we have believed in them and acted individually and collectively on those beliefs’ (Rosenberg, 2002 p240). These classification systems and diagnostic categories serve a multitude of surveillance, ordering and planning purposes (the societal level of diagnosis identified by Jutel and Nettleton); generating mortality statistics, monitoring flow of diseases, planning services and resource allocation in clinical practice. In this, Bowker and Star’s (1999) ‘Sorting things out: Classification and its consequences’ is highly relevant to understanding the formation, operation and contingency inherent to systems of classification as attempts to stabilize particular orderings of the material and social worlds.

Diagnostic classificatory systems and categories also represent unique histories as ‘a museum of past and present concepts of disease’ (Blaxter, 1978).

The converse effect of the dominance of diagnostic classification systems is that those without an accepted diagnosis, but with a self-identified medical need become marginalized – their needs are much less likely to be recognized by medical practitioners. In many cases phenotypic symptoms are not sufficient to support individuals’ claims of being entitled to medical management or intervention. They may be ill but not have a disease (i.e. belong to a recognized category of disease). Diagnosis is thus also a site for contested claims and negotiations of entitlement between lay actors and medical professionals (Nettleton, 2006).

At the same time, the rise of risk-based assessments and concepts of ‘pre-disease’, early intervention and preventative intervention threaten to collapse the
boundaries between health and disease. Dr Nettleton draws on David Aaronowitz’ work on risk and chronic disease to illustrate this point:

‘Chronic disease has become a kind of risk state in which diagnosis, treatment, and “disease management” are directed at reducing the changes of anticipated, feared developments’ (Aaronowitz, 2009a p419).

Aaronowitz identifies five factors which have made chronic disease ‘more risky’

1. Clinical interventions altered natural history of disease  
2. Greater biological, clinical, epidemiological knowledge of chronic disease risk  
3. Increased numbers with diagnosis due to screening, diagnostic technologies and disease definitions  
4. New ways of conceptualizing efficiency  
5. Intense diagnostic testing and medical intervention

Some disease categories are now understood as risk factors for other diseases. Adding to this, more screening tests applied to greater segments of the population and broadening disease categories are bringing ever more people into the ‘net’ of medical management and medical control.

In trying to take account of all of these factors and levels of analysis in developing a sociology of diagnosis, Annemarie Jutel (2011) has produced a model for understanding the social processes, practices and consequences of diagnosis.

**Social Understanding of Diagnosis**

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**Implications of a sociological model**

A focus on the context(s) in which screening and diagnostic testing take place can draw attention to the culture of routinized testing in medicine. A number of recent scientific papers and articles have questioned the assumption that screening / testing is an unquestioned benefit to all patients or that more screening is always better (Aaronowitz, 2009b; Bach, 2012; Quaseem et al, 2012). Routine testing has implications for healthcare efficiency, cost and resource management and patient safety and wellbeing:
‘You need to screen 1,900 women in their 40s for 10 years in order to prevent on death from breast cancer, and in the process you will have generated more than 1,000 false-positive screens and all the overtreatment they entail’ (Aaronowitz, 2009b).

Beyond this, sociologically-informed studies can treat questions of when and why particular tests are ordered or not for particular patient groups or individuals as a site for empirical investigation. What drives the deployment of mass testing programs and which factors are involved at the level of individual physicians, institutions and at the societal level? How have these circumstances been historically produced and what can they tell us about the culture(s) of contemporary medicine – e.g. how does the popularity of routine screening and diagnostic testing in broad patient populations relate to ideas of evidence-based medicine?

References


3) Celia Roberts: Articulating Transitions Between Diagnosis and Intervention

Complementing the previous two presentations, Dr Roberts draws upon examples from current and prior projects that illustrate how issues of diagnosis pervade much sociological and science and technology studies (STS) work on medicine and medical technologies.

The presentation focuses on two of the key questions identified as part of the rationale for this symposium:

1. If changing diagnostic methodologies can reframe the boundaries and meaning of disease categories how does this affect the meaning and choice of available interventions, and the subsequent trajectories of disease management for patients and physicians?

2. Do new diagnostic technologies affect existing organisational practices and if so how and with what outcomes?

*New diagnoses, new modes of life*

Question 1 can be formulated thus:

Changing diagnoses → new enactments of conditions → new interventions → new modes of living with a condition (for Drs and patients)?

Although the framing of the question is relatively straightforward it is important to realise that each of the arrows is actually doing a lot of ‘work’ in presenting a series of causal links between diagnostic innovation and lived experiences of disease. Each arrow stands in for complex transitions/chains of connection that require empirical exploration and mapping. These processes should not be taken for granted but are themselves targets for empirical sociological investigation.

Case study 1: Early onset puberty

Diagnoses should not be taken as *a priori* categories but as socially negotiated and contestable arrangements. This is true both at lay-medical boundaries and between healthcare professions and professionals. In the case of early onset puberty there is both widespread concern about increasing rates of early onset puberty globally and contestations over how to diagnose the condition and what counts as ‘early’ or ‘pathological’.

In the 1960s and 70s, only about 1% of girls were thought to start puberty before the age of 8 or 9. Today, in some populations, more than 1/3 of girls now do so. This is true in many countries: the US, the UK, Scandinavia, India, China etc. Explanations of this phenomenon are wide-ranging and unstable: scientists look to obesity, endocrine disrupting chemicals, early childhood stress and absent fathers as potentially important factors.

But what counts as early onset puberty? This is a contentious field – puberty is a fluid process, which has multiple paths and flows (breast growth, pubic hair growth, a growth spurt in height, changes in teeth and bones, hormonal changes, behavioural changes, menstruation, skin changes...). Some of these are difficult to measure; many are difficult to talk about. Even something as seemingly straightforward as breast growth is complex to assess: although the practices used to assess growth are ‘old fashioned’ (visual inspection and palpation) they rely on
fine-tuned skills (it is difficult, for example to distinguish visually between fat and breast tissue) and ‘feeling the difference’ requires training and experience.

Beyond these practical questions of measurement come more theoretical questions about where to draw boundaries: these are statistical and political issues, with serious implications for medical practice and health systems. If the boundary of ‘normal’ puberty is shifted from 8 to 7, as some scientists have proposed (following studies indicating that large numbers of children are maturing this early) then fewer children will be referred for specialist assessment (which will save money) but some with serious pathologies (early puberty can be caused by brain tumours) may be missed. If an event is statistically normal, it may still be pathological (unhealthy).

Assessments of pubertal development are made using standards of ‘normal’ age-related development such as the orchidometer, which are derived from previous cohort studies of children’s development. The foundations of most UK standards lie in work carried out by Tanner and Whitehouse working with a cohort of children at the Harpenden children’s home in the 1950s and 1960s. While these are ‘old’ techniques they now raise some very contemporary ethical issues linked to the categorisation and assessment of children’s bodies:

- Ethical issues around embarrassment etc. raise the alternative of getting kids to self-assess – but self-assessment is also seen as less scientific.
- There is a need to consider the effects of assessment and diagnosis (tall girls, early puberty, intersexuality), which links to Jutel’s concept of ‘diagnosis as consequence’.
- Visual diagnosis very important in this debate, e.g. the role of photography in producing a ‘snapshot’ of individual cases for future reference can clash with contemporary ideas about the acceptability of photographing (unclothed) children.
- Another example is ‘race’ (see Braun et al – doctors need to make fast judgements, but these are risky!). How do you ‘just look’ to evaluate? The practice requires a lot of tacit knowledge and experience.

Early puberty is also interesting because, as the boundaries of the diagnostic category are contested a space is created for negotiation between clinicians and parents about when intervention is warranted. A number of leading clinicians in this field have reported that informing parents in order to change their view of ‘normal’ usually reduces a demand for treatment (Kaplowitz & Oberfield, 1999, Hermann-Giddens et al, 2004). At the same time other sources of information, such as promotional material about hormone drugs designed to slow down pubertal development disseminated by pharmaceutical companies may promote intervention by emphasising the abnormality of ‘early’ puberty.

**New diagnoses, new responsibilities**

Question 2 asks:

Do new diagnostic technologies → new organisational practices, i.e. new responsibilities and roles?
Case study 2: Pre-implantation genetic diagnosis (PGD)

Pre-implantation genetic diagnosis is a procedure by which a single cell can be extracted from an embryo and tested for known chromosomal or monogenetic diseases such as Cystic Fibrosis. The procedure requires the embryo to be outside the body and so is primarily used in the context of IVF, to screen embryos created ‘in vitro’ in order to avoid implanting unsuitable (diseased) embryos back into the body.

Novel technologies such as PGD can radically change the whole experience of medical management and intervention for a condition, or in the case of PGD, of pregnancy. PGD produces new responsibilities in certain couples (particularly those with histories of having an existing child with a particular condition) especially an imperative to engage to some extent with these diagnostic technologies in order to avoid producing suffering. This in effect creates a new type of patient; the pregnant woman at risk of giving birth to a child with a genetic abnormality, and who must therefore try to understand the science and the practices of PGD. This can be illustrated with interview data from Dr Roberts work on PGD with Sarah Franklin (Roberts and Franklin, 2004; 2006):

‘And it was interesting meeting the geneticists, ... who explained things ...in more detail and, and actually, you know, sort of made us aware of the pitfalls... They had all these em-, pictures of embryos to show us and because, I mean it’s taken me a long time to try and understand FISH, [...] but, you know what was really good was to be shown examples of how something can be just hiding behind something else and those are things that you just, you know ... When I first sort of discovered it, I thought it would be so easy, so clear cut, ‘cause it seems so clear cut, and it was very good to have it explained to us that it’s not. And that um, some things are very difficult to detect’ (Liz).

While much discussion of PGD has highlighted issues of choice, interview data shows that theses of responsibility (and guilt) are also significant:

‘We just couldn’t go through with another baby with SMA Type 1, we just couldn’t do it. We couldn’t do it to ourselves, but we couldn’t do it to another of our children, or our family. It would just be a definite no’ (Anne).

In the extract, the participant, Anne, constructs her decision to undergo PGD as a responsibility, moving away from the language of choice. In this quote she lists those to whom she feels responsible: herself and her partner, her family, and her potential child. Producing a second child who will become seriously ill and die before its first birthday is, for Anne, ‘a definite no’. Significantly this ‘definite no’ is based on the genetic knowledge she and her partner now have, which they did not have when they gave birth to their first child (SMA = spinal muscular atrophy and, an incurable condition caused by a mutation in the SMA1 gene). Like most SMA parents, they had no idea that they were at risk of having a child with SMA until it happened. It is having this genetic information that renders PGD more of a responsibility than a choice.

In this case it is not the genetic information per se which justifies intervention. Instead the participants emphasise the nature of a potentially fatal, incurable disorder as a justification for PGD:

‘I mean if we was to find out that we was carriers of something else, and we were just going to produce a child that would inevitably be disabled, or
whatever, we wouldn’t use PGD. You know, we see it as something that can…

prevent children dying, basically, that’s why we’re using PGD’ (Anne).

Here, then, is a distinction between the problem of disability in general, and
terminal childhood diseases in particular, is emphasised – this couple clearly
separate the use of PGD from the pursuit of desirable traits by choosy parents
implied in the media concept of the designer baby. For Anne, this did not mean
that she was unaware of the difficulties of making decisions about which genetic
conditions were serious enough for PGD.

The availability of PGD creates new experiences and responsibilities for patients,
but also for patient groups, clinicians, laboratory scientists and genetic
counsellors. New roles emerge in response to these changed configurations – and
new industries too. Such novel technologies also place new demands on NHS;
balancing needs, benefits, costs and the contribution to ‘science’ as well as
clinical outcomes. Finally, PGD can also generate new forms of suffering; parents
wanting to have an unaffected child now face the same odds as any couple
depending on IVF to have a child, they become effectively infertile (Boardman,
2010).

Case study 3: Pre-natal ultrasound screening

Here Dr Roberts draws on the work of one of her PhD students, Li-Wen Shih, who
is studying the uptake and use of pre-natal ultrasound screening (PST) in Taiwan.
A combination of a strong desire for a healthy baby and a healthcare system that
facilitates ‘shopping around’ for services has led to a high investment in
ultrasound screening. As a consequence women in Taiwan spend significant
amounts of time engaging repeatedly with PST in an attempt to get the answer
they want (i.e. a confirmation that their baby is and will be healthy). As with PGD,
the produces new experiences of pregnancy; both increased anxiety about getting
tested, and finding pleasure when a good result is achieved. Shih’s work also
highlights how these new lived experiences of pregnancy are not wholly sui
generis but combine older experiences and cultural attitudes such as (women’s)
family responsibilities, along with the technological reframing of pre-natal health
created by PST, to create novel ‘foldings of old and new’.

Case study 4: Pregnancy biosensors

This final example derives from a recently initiated project looking at pregnancy
biosensors. Ovulation monitoring is a good example of what pregnancy
biosensors are and do; OvWatch and Duo Fertility devices can be worn on the
body, with sensors and computers doing diagnostic work ‘in real time’. This
technology is already available – for example the Duo Fertility monitor is available
from the high-street chemist Boots. Biosensors monitor and record ‘bio-data’ such
as body temperature; used to make predictions about the timing of ovulation, and
then indicate this status to the wearer.

These devices are controlled by consumers, but their data is often willingly shared
online. Biosensor technology allows potentially continuous self-monitoring, aligned
with ideas of people buying into new diagnostic technologies as a way to ‘get to
know themselves’. Similar logics are visible in genetic and genomic testing,
especially online-based direct-to-consumer testing such as that offered by
companies like 23&Me. After buying genetic testing kits and sending the company
a saliva sample, customers can access genetic information about their past
(ancestry), present (genetic traits) and future (disease susceptibility) as well as connecting with relatives and strangers who share similar DNA as part of virtual ‘genetic’ communities. Users can also access their own raw genomic sequencing data, ostensibly to help them gain more information about the meaning of their own genetic markers from the scientific literature. However the massive amounts of data involved raise questions about the ability to actually derive useful, meaningful information from the potential ‘data overload’.

The biosensor project at Lancaster University is funded by the Intel Corporation. The project aim is to better understand the ways in which people use their own diagnostic tools and technologies and share results with others. The impact of this novel monitoring technology will almost certainly have implications for Dr/patient relations, for health systems and indeed for corporations wanting to develop new technologies.

Questions and areas for research

- Folding of old and new – topological rather than linear approach to historical developments
- Iatrogenesis
- Significance of failure (vs. hope)
- Changing relations between patients/consumers/clinicians/health bureaucracies/corporations
- Role of internet and related technologies of measurement, recording and statistical analysis

Lastly a reminder about ethical (‘who lives and dies and how’) questions from Donna Haraway:

‘These questions cannot have simple, single or final answers. However, a serious commitment to refusing both the culture of no culture and the nature of no nature means these questions have to be asked, as a constitutive part of technoscientific practice’ (Haraway, 1997 p113).

References


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Work of PhD student Li-Wen Shih on how pregnant women experience prenatal genetic screening and testing, and how that experience affects their relations to the foetus, family, medical practices and technologies (such as ultrasound screening, genetic testing, amniocentesis, and chorionic villus sampling etc..).

[http://www.lancs.ac.uk/fass/sociology/pgrprofiles/185/](http://www.lancs.ac.uk/fass/sociology/pgrprofiles/185/)

Living data project at Lancaster – Intel supported project on pregnancy biosensors. No project website as yet.
4) Oonagh Corrigan: From Bench to Bedside: Diagnosis and Medical Uncertainty

Uncertainty, medical or otherwise, is omnipresent in life. The struggle is whether to embrace uncertainty or try to exert control.

Diagnosis, by contrast, is a powerful tool for exerting control by ordering and organising knowledge about health and disease. Its power is illustrated in this quote from Annemarie Jutel:

‘Diagnosis guides medical care. It organizes the clinical picture, determines intervention, and provides a framework for medical education. … it also defines professional medicine‘(Jutel, 2009)

Dr Corrigan then presents a range of previous and current research projects, and the theoretical links that can be drawn between them, to further explore this tension between uncertainty and the medical ordering of disease and health. These ‘reflections from the field’ can be visually represented thus:

This model illustrates the links between novel technologies such as pharmacogenetics/pharmacogenomics, the expectations that are produced about how these new technologies will operate in clinical practice (and how they will change clinical practice), the process of evaluating new technologies in clinical trials (which involves sociological investigation of how clinical trials act as sites for the production of ‘gold standard’ knowledge about interventions and how bioethics is manifested at these sites through ‘ethical’ technologies such as informed consent) and medical practice and medical education (which in turn can shape directions for medical research).
Important aspects for sociological study are:

1) The moves from highly technical to ‘everyday’ medical practice (and back again?) at different sites from the clinical trial to the lecture theatre.

2) The need to think about how physicians themselves are shaped- what happens to them and what is done by them at different stages in the cycle.

Case study 1: Medical education

In regards to the call to look at how physicians themselves are shaped, medical teaching and training is a good site to look for relevant shaping processes and factors, especially in relation to the central dichotomy of certainty (or order) vs. uncertainty. In this vein it is also useful to consider some of the other dualisms that pervade contemporary medical practice and training:

- Research and Practice
- Cure and Care – most funding goes into research on cures, care is seen as a secondary priority
- Science and Art – moves towards evidence based medicine clash with tacit skills and physician judgement
- More medical knowledge and more uncertainty – the apparent paradox that evermore data can actually produce less certainty about what to do (especially with risk factors)
- Diagnosis and Uncertainty - Diagnosis Imposes categorisation and order on the disorder of illness, representing a denial (but not necessarily a conquering) of uncertainty.

This prevalence of dualisms in medical work – and especially their inculcation in medical students during their training and education was recognised by medical sociologist Renee Fox (1957; 2011) who drew attention to embedded dichotomies including:

- Body vs. mind
- Thought vs. feeling
- Objective vs. subjective
- Explanation vs. understanding
- Material vs. spiritual
- Self vs. other
- Individual vs. social, communal & societal

In our medical curriculum, such polarities have been reified in the split conceptions of health and illness, in their "biomedical" as opposed to "psychosocial" components, and in the sharp distinctions maintained between basic science and the clinical aspects of medicine.

At the same time, medical students and junior doctors do learn about medical uncertainty in particular ways:

- Impossibility of amassing all medical knowledge –uncertainty associated with these gaps.
• The uncertainty in distinguishing between personal ignorance and ineptitude.

• The limitations and inadequacies that exist in medicine.

Bleakley et al (2008; 2011) have addressed the issue if uncertainty from the point of view of medical education, arguing for the need to tolerate uncertainty in medical training and indeed of teaching medical students to tolerate uncertainty in practice.

However this goal is problematic. As Light (1979) has pointed out: the foundation of professionalism itself lies (at least partly) in the public’s belief that professionals know what they are doing and can act correctly.

‘Socialization for uncertainty takes on particular significance in professional training, because the professions depend on the public believing that they know what they are doing. Their license and mandate rest on the claim that they have mastered esoteric knowledge and can apply effective techniques to manage other people’s problems and uncertainties’ (Light 1979).

This creates the paradox that uncertainties arise relatively commonly in professional practice, but the basis of professional authority lies in their perceived ability to overcome uncertainty, to act as a problem solving resource by converting uncertain ‘illness’ into authoritative ‘disease’. Thus a tension is created between what is expected and what is encountered in diagnosis.

Case study 2: Clinical trials

Clinical trials are considered the ‘gold standard’ for evidence-based evaluation of the safety and efficacy of pharmaceuticals and other interventions. A sociologically-informed perspective can try to unpack these ‘certainty-making techniques’ to reveal the inherent uncertainties. In a Science and Technology Studies sense clinical trials are a ‘black box’ where information, techniques, pharmaceuticals, patients and/or volunteers and healthcare professionals are ‘fed in’ and authoritative judgements about interventions are produced at the other end. The term ‘black box’ refers to the hidden or occluded practices that happen within clinical trials. To open the ‘black box’ through empirical investigation is to examine how certainties about medicine and diseases are socially constructed.

One reason why clinical trials are ‘black boxed’ is because the majority of trials are sponsored by pharmaceutical companies who prefer to keep information on their products confidential.

Ways in which clinical trials performed to produce certainties include the ‘cleaning’ of patient populations involved in the trial by excluding those with multiple conditions or other characteristics (excluding paediatric or geriatric patients etc.) and by using certain pre-specified biomarkers as indicators of the ‘right type’ of disease to be included. Such strict inclusion/exclusion criteria look ‘clean’ on paper but often contrast with the messiness of clinical trials in practice – for example individuals may fall in and out of the criteria during the trial.

Using ‘cleaned’ patient populations can fail to detect adverse drug reactions that will occur when the drug is used in a wider, messier ‘real world’ population (Corrigan, 2002). Many drugs shown to be successful in trials turn out not to be in clinical practice, illustrating how uncertainties can be hidden by some types of
certainty production in medical practice, as part of the feedback loop model described at the start of this presentation.

Case study 3: Diagnosis in practice

*How do physicians view diagnosis?*

‘We general practitioners are mainly interested in the utility of diagnoses: we take a pragmatic approach. We welcome a diagnosis as an opportunity for reducing the complexities of the problems that our patients present, a means of creating or imposing order and understanding in the midst of confusion and chaos, a defence against confusion and uncertainty. (Dowrick, 2009a)’

As this quote from Dowrick (2009a) illustrates, physicians view of diagnosis is more pragmatic then dogmatic (see also Dowrick 2009b, for an extension of this approach to issues of mental health).

Marc Berg’s work on the construction of medical disposals (1992) argues that sociologists have paid too much attention to social influences on (diagnostic) decision making and too little attention to the *context* of decision making. Patient narratives are important, but it should be remembered that doctors largely control the questions in a diagnostic encounter, positioning and interpreting patient’s replies in relation to possible diagnostic categories. Berg shows how the physician’s use of directed questioning ‘transforms patient’s problems into solvable problems’. Using this approach is a way to overcome what Berg sees as the dualism in the sociology of diagnosis itself—the cognitive versus the social.

Drawing on observational study of work in oncology clinics, Dr Corrigan also highlights the role of sub-categorisations of disease in understanding the likely outcome and treatment choices.

This combination of nuanced questioning, looking for an utilisable diagnostic category or sub-category and drawing on additional observations of a patient in forming a diagnosis are captured in Linda Adams’ doctoral study of diagnostic decision making in emergency settings, which proposes the following model:
In emergency settings, diagnoses are made under significant time constraints and must be based on available information to give a pragmatically useful guide to immediate intervention. Interview data carried out as part of Adams PhD work suggests physicians in this setting treat diagnosis as a ‘puzzle solving’ activity or a piece of ‘detective work’ based on making best use of all the information available in that limited temporal space for decision making – driven by the need to ‘do something’.

Case study 4: Pharmacogenetics and other technologies of ‘personalised medicine’

Pharmacogenetics tests, which are intended to identify possible genetic markers of susceptibility to adverse drug reactions associated with particular pharmaceutical regimes, involve a move away from testing for disease per se to testing for ‘normal’ genetic variation. Work in the sociology of expectations has illustrated how the promise of pharmacogenetics draws upon ideas of resolving the complexity of variable responses to pharmaceuticals through the certainties of genetic data (Hedgecoe and Martin, 2003). This promise invokes the belief that the authoritative knowledge produced by genetic information will transform the ‘art’ of diagnosis and patient management into an evidence-based science.

The reality, however, is very different as is the case with other genetic tests. While genetic or biomarker tests are becoming increasingly common, their results are often uncertain and their clinical utility variable. They do not necessarily offer any resolution to medically unexplained symptoms, and the problems of false positive and false negative results complicate their use in routine practice. Furthermore the use of genetic tests does not meet the demands or expectations of patients in a number of cases (see Badger, 2009 on genetic diagnosis of obesity and Statham et al, 2010 on genetic diagnosis for intellectual disability).

A final example of the ways in which novel diagnostic technologies can actually increase uncertainty rather than simplifying the process of diagnosis comes from the BBC 2 series ‘Great Ormond Street’ which follows the daily work and experience of London’s Great Ormond St hospital for sick children. The first episode of series 2 (‘a difficult line’ http://www.bbc.co.uk/programmes/b01hn6rf) follows physicians in the oncology ward and features a scene where doctors are looking at the image of the child’s brain on the scanner, as one of them (probably a clinical oncologist) upon realising that a tumour mass is still in the brain despite a surgical intervention comments to the attending surgeons “We are treating the scan, not the tumour”. This episode illustrates a paradox between the concrete and the abstract, between the material disease and the imagined disease, between the actual source/embodied disease and the measure/image/detection of the disease, between the diagnosis and the treatment.

References

Adams, L. (ongoing) PhD study on medical decision making in emergency situations. Based at PCMD, supervisor Oonagh Corrigan.


FINDINGS FROM THE WORKSHOP SESSION

Introduction

This section reports on the discussion carried out in the afternoon workshop component of the symposium. Where appropriate, major points raised during the workshop have been augmented with additional sociological detail to create a fuller account of the issues at stake. The purpose of the workshop component, and of this report, is not to try to ‘solve’ issues of diagnosis and intervention, but to provide a coherent and useful platform to guide future sociological work.

Perhaps the most immediate impact of the symposium was the recognition of the utility of the emergent sociology of diagnosis. The resurgence of interest in diagnosis as a topic of sociological study is relatively recent and is mainly captured in a series of papers and a book produced by Dr Annemarie Jutel of the Victoria University of Wellington in New Zealand (Jutel, 2009; Jutel 2011; Jutel & Nettleton, 2011). Many participants reported that adopting a ‘diagnostic lens’ allowed them to find new relevance in work they had not previously considered to be primarily ‘about diagnosis’ and enabled them to productively bring together insights from a range of existing theoretical and empirical studies. This resonates both with Mildred Baxter’s claim that diagnosis is ‘central to the practice of medicine’ (1978, p9) and Annemarie Jutel’s framing of diagnosis as an ‘absent presence’ in much sociological work to date, that is, a topic which is present in the literature and could be, but rarely has been, brought to the fore as the primary focus of attention.

The topic of diagnosis also played a prominent role in much of the workshop session discussions. The key themes arising from that discussion are presented below under the following headings:

1. **Contemporary landscapes of healthcare** – aspects of the wider landscape of medicine which seem likely to have an impact on diagnosis and intervention, including ‘big data’ driven medicine and the contemporary drivers of diagnosis and screening.

2. **Spaces and places of diagnosis** – examines the multiple sites where diagnosis can occur; the clinic, the lab, medical specialities, lay diagnosis etc. and raises the issues of the boundaries of our investigation.

3. **Time and timing in diagnosis and intervention** – introduces the concepts of scheduling, rhythm and timing as important factors shaping diagnosis and intervention.

4. **Theorising the links between diagnosis and intervention** – brings together the concerns of the workshop discussants and examples of relevant research in trying to understand and conceptualise the relationship between intervention and diagnosis.

5. **Summary of future research directions** – the final section will bring together all of the suggested topics and directions for future research raised in the preceding sections.

As with most of the section headings in this part of the report, this categorisation is mainly intended to facilitate clarity of presentation and analysis rather than claiming
to represent some fundamental division in what is a highly connected and interlinked domain of human activity.

A note on screening: Recent calls for greater sociological investigation of medical screening and the development of a dedicated sociology of screening (Armstrong & Eborall, 2012) raise the question of the relationship between screening, diagnosis and their respective sociologies. Armstrong and Eborall advocate a sociology of screening that deals specifically and exclusively with population-based screening defined as:

the purposeful application of tests to an asymptomatic population in order to classify people into those who are unlikely to have or develop a disease and those who are likely to have or develop a disease (Armstrong & Eborall 2012, p162 italics in original).

In this model of population screening, it is the use of entirely probability-based categories and the accompanying potential for generating false-positives and false-negatives in a ‘normal’ population that make it practically and sociologically distinct from diagnosis. At the recent launch of the Sociology of Health and Illness monograph on the sociology of screening1, (based on the prior special issue of the journal Vol. 34, no.2 2012) a number of participants from both academic and clinical backgrounds reinforced this separation of diagnosis and screening as also being understood and experienced as very different phenomena in everyday medical practice.

Nonetheless, there are potential ways in which the studies of diagnosis and screening can be complementary. Screening, after all, can often lead to diagnosis as one of the consequences of being identified as ‘at risk’ is often to be targeted for further medical follow up and investigation. Additionally, both screening and diagnosis involve assigning people to particular categories of health and illness (see Timmermans & Buchbinder, 2010 on the ways in which routine screening tests can produce ambiguous, intermediate or liminal states between health and disease creating a category of ‘patients-in-waiting) suggesting an overlap at the level of theories of labelling and categorisation. Finally, there are broader issues concerning the moral and normative discourses which attend screening, diagnosis and ‘responsible’ health-orientated behaviour in general. These are most clearly brought out in the workshop discussions on the contemporary healthcare landscape which follows.

1) The contemporary healthcare landscape

The workshop discussion was wide-ranging and often invoked topics that, while raised as potential influences on diagnosis and intervention, are better considered part of the wider landscape of healthcare and the socio-economic, political and cultural forces that shape it. In many instances these aspects are already the subject of significant literatures within the social sciences and other disciplines (e.g. bioethics) and it is beyond the scope of this report to explore these topics in anything like a comprehensive fashion. Nonetheless, they formed an important part of the discussion, and will therefore be sketched out here on as background issues to be kept in mind when considering the subsequent sections.

1 http://www2.le.ac.uk/departments/health-sciences/about/seminars-2012
These wider influences on diagnosis and intervention can roughly be grouped in terms of two themes:

1. The drivers of an expanding medical domain and the proliferation of diagnosis and diagnostic categories

2. The increasing availability of large data sets of biomedical (including genetic/genomic) data and the potential ‘data deluge’ of information available to healthcare professionals and (sometimes) patients

**Drivers of diagnosis and intervention**

There was a clear feeling among participants that the trend in contemporary medicine was towards more: more screening, more tests, more technology, more areas of human life coming under diagnostic labels, more information and more intervention. The addition (and sometimes subtraction) of particular diagnostic categories has been the mainstay of sociological engagement with medical classification through medicalisation, labelling theory and prior work on sociology of diagnosis such as Brown (1995) (Armstrong 2011). This sense of medical expansion, however, is not simply a matter of broadening classification systems; it is closer in tone to that described by Clarke et al (2003) who argue that (western) culture itself is becoming increasingly pervaded by biomedical concepts and understandings. In turn, more aspects of life become understood as having a (bio)medical component:

Biomedicine [becomes] a potent lens through which we culturally interpret, understand, and seek to transform bodies and lives (Clarke et al, 2003 p163).

Public demand was thus suggested as one potential driver of greater engagement with, and claims for access to, medicine through the actions of patient groups, lobbyists, and also ordinary members of the public. Certainly, there is evidence that this does occur in particular instances:

It is widely acknowledged that some national screening programmes have been introduced largely due to organised patient and citizen advocacy rather than scientific, clinical and epidemiological evidence (Faulkner, 2012 p221).

This form of public demand has been associated with concepts of the ‘informed patient’, the patient-as-health-consumer, the modern ‘rational, reflexive self’ who acts to secure their own health as a personal good and with the ‘beliefs, behaviour and expectations of the articulate, health-aware and information-rich middle classes’ (Greenhalgh & Wessely, 2004 p197). Here medicine is seen as a gateway to individual wellbeing, a resource for self-maintenance, and potentially as a way of escaping culpability for challenging or anti-social behaviours by seeking a diagnostic label to reframe them as biomedical rather than moral actions. Similarly, Nikolas Rose (with Carlos Novas and others) has developed the concept of ‘biological citizenship’ to describe how individuals and groups increasingly define themselves in terms of genetic and other kinds of medical knowledge to make claims and take action in a world dominated by the discourses of science and medicine (Novas & Rose 2000; Rose 2004).

This model of individualist, health-seeking behaviour also ties in with another proposed driver of medical expansion: the commercial healthcare industry, including private healthcare providers, the pharmaceutical and diagnostic industries and especially internet-based providers of direct-to-consumer testing and diagnostic kits.
Pharmaceutical firms have previously been accused of ‘selling sickness’ and ‘disease mongering’ by promoting pharmaceutical treatments for so-called lifestyle ailments, as for example with the promotion of Prozac for unhappiness as well as depression, Paxil for ‘excessive shyness’ or Viagra as a ‘sexual enhancer’ as well as a drug for clinical ED (Conrad & Potter, 2004; Moynihan, Health & Henry, 2002; see also John Abrahams work on pharmaceuticalisation). Beyond this, the direct-to-consumer sale of genetic and other bio-molecular testing kits via the internet feeds more directly into the idea of a market for personal diagnostic information. Firms can ‘cut out the middle man’ of healthcare providers and sell testing kits straight to members of the public – with the proviso that the company remains both provider and ‘owner’ of the data produced by the test (Harris, Wyatt & Kelly, 2012; Pálsson & Prainsack, 2011). In this account the industry-led marketisation of health, accompanied by discourses of self-knowledge, empowerment and individual risk and responsibility, both creates the desire for individual testing and supplies the product to meet this demand.

A third proposed driving force was medical culture itself. In the morning session, Sarah Nettleton directed attention to Robert Aaronowitz’ work on the culture of routinized testing in medicine and the apparently ingrained belief that more testing is always better (Aaronowitz, 2009a; 2009b). Increased monitoring and testing also feature prominently in technology-laden visions of the future of healthcare. One such vision – by no means the only one, but a useful illustration of significant issues raised by workshop participants nonetheless - is ‘P4’ medicine (Sobradillo, Pozo & Agusti, 2011; European Commission, 2012). ‘P4’ refers to the four key elements of this programme:

1. **Personalisation;** especially in relation to the potentially immanent individual “digital genome”.

2. **Predictivness;** due to the anticipated ability to predict the risk of certain diseases based on “personal genome” information in combination with lifestyle data, age, sex, occupation etc.

3. **Preventiveness;** early, pre-symptomatic intervention based on individualized risk prediction.

4. **Participation;** the requirement for the active involvement of the individual concerned in proactively maintaining their health.

This type of ‘personalised’ medicine links the move towards massive data-driven healthcare (discussed in more detail below) with an emphasis on ‘targeted’ pre-emptive intervention at the level of individuals. This form of data-driven preventative medical intervention (“prevention is the new intervention”) is seen as particularly desirable from certain policy perspectives. As with childhood intervention (see Susan Kelly’s presentation), preventative intervention offers a promising route for governments to secure desirable (biological) citizens (healthy, productive, actively engaging with the market for health) and avoid, or reduce undesirable outcomes (e.g. ‘deviant’ unhealthy, non-productive, or dependant individuals) by pre-empting episodes of sickness and ill-health, perhaps even in chronic as well as acute disease (OECD 2004; Penn 2002). These biopolitical manoeuvres are accompanied by moral discourses of the responsibility to secure future health on the part of individuals, families, children and healthcare professionals (see e.g. Hertzman et al, 2011 on the public health duty to early childhood monitoring and intervention).
A major concern raised in conjunction with the combination of all three potential drivers of medical expansion is that medical authority can potentially extend through mandatory or routine screening programmes to include, not only those ‘engaged’ health consumers, but other more reticent members of the public leading to unsought, and potentially unwanted diagnoses.

The ‘data deluge’

Technologies including whole genome sequencing, population-scale genetic epidemiology and biobanks of linked tissue samples, genomic data and medical records all draw on the promise of information communication technologies (ICTs) to collect, sort and make available larger quantities of health-related data than ever before. Combine this with the input from multiple diagnostic and screening tests, imaging devices and bio-sensors and there is a potential ‘deluge’ of biomedical information for any given patient and physician to draw on. Unsurprisingly, accounts of ‘big data’-driven medicine raise a range of novel (and not so novel) ethical, governance, technical and social issues. However, workshop participants were mainly concerned with two particular aspects: how ‘big data’ might change, or already be changing, the nature of the work of doctors, and the potential for increased social control mediated through data-driven ‘personalised’ medicine (as touched upon above).

On the first point, the major query was whether doctors or patients might be able to make sense of the potentially vast amounts of data on hand and if so how? Will the role of the GP or family doctor increasingly be one of ‘sorting through the noise’ of big data to find appropriate answers? Oonagh Corrigan’s direction to pay attention to the ways in which uncertainty is framed and managed in medical practice is highly relevant here. Despite the promises of more ‘precise’ diagnosis, large amounts of data are likely to require a significant amount of interpretation and will not always present a simple, coherent picture. As Armstrong (2011) has argued ‘there are no diseases waiting in nature to be discovered; there are no diagnoses which capture an immutable illness state’ (p806). Instead, different classification systems bring into being different understandings of what disease ‘really is’. What kinds of illness and disease will a mass-data approach to classification produce? In the task of sorting through the noise of mass data who will decide what is important and what is not, or how to resolve conflicting pieces of information? Decisions about what is ‘important’ and to whom (patients, physicians, families) are highly context dependant evaluations. Thus much of the impact of this approach to medicine, if it comes to pass, will depend on how uncertainty is managed in practice. This in turn raises questions about how the emergence of big-data driven medicine will affect the training needs, competencies and skills base of healthcare professionals throughout the health system (and not just in specific high-tech laboratories or IT facilities). Large amounts of potentially highly technical data could also make it more difficult for patients to understand, let alone express a preference about, their conditions and treatment options.

The other major focus on systems of massive data handling involves the large amount of personal data (including lifestyle information and demographic data on age, gender, race, class etc.) being collected and shared. This raises not only privacy concerns, but also the potential requirement for continuous monitoring and ‘real-time’ updating of relevant information. The potential scope of medical surveillance already extends beyond an individual lifetime, from prenatal screening
to predicted risk of passing on genetic traits on to future descendants. The more the collection of ‘total’ data on individuals becomes part of routine practice the more difficult it may become to resist constant surveillance as a prerequisite for anyone wanting to access medical services. Ideas of big-data driven medicine imply that a total knowledge of individuals will yield the possibility of full (medical) control over the instance of illness and disease. As social scientists, wanting to resist technological determinism, there is an inherent scepticism about such claims. But it is important to look beyond this immediate reaction to reveal the specific problems of such ideas of control.

One obvious point is the probable unpleasantness of living in a society where health is raised to a ‘super value’ and the requirement for self-monitoring is all pervasive; where every decision made during a day from how to travel to work in the morning to what to eat at lunch becomes a locus for informed health-conscious decision making which is then duly recorded and added to a lifetime repository of health information and used to calculate future health outcomes. A further concern is that such technological regimes could be used to pursue political agendas, such as creating more efficient, more productive workforces, families and individuals using the rhetoric of informed choice to diminish, in practice, the range of socially acceptable forms of living. An example of this argument can be found in relation to prenatal screening where the choice of whether or not to access information about a pregnancy is presented in the context of ‘pregnancy as a risky event’ in which women are required to take personal moral responsibility for the outcomes (Grob, 2006).

This version of choice privatizes responsibilities for preventing disability, or, should the test be declined, facing up to the future of living with a disabled child’ (Kerr, 2004 p82 cited in Williams et al, 2005 p1990).

In this reading, the act of facilitating choice fulfils any moral duty of the state or the medical establishment and positions a disabled child, and any associated financial and emotional costs, as solely a matter for maternal or familial responsibility. By moving away from the social model of disability and from concepts of health and wellbeing as a matter of communal responsibility, disability is tacitly presented as an undesirable category of personhood and giving birth to a disabled child as an immoral, or at best irresponsible, act.

However, it is important to note that all of these potential forces of medical expansion and control have their limitations and sites of resistance. There is evidence to suggest that the case for medical consumerism is overstated. Lupton (1995) and Mechanic (2002) have found that even when individuals position themselves as ‘medical consumers’ choice is mainly restricted to selecting between personal physicians and access to specialists and tends to disappear when individuals are confronted with episodes of serious illness or disease. There are also limits on the extent to which people are able, or want, to take responsibility for their own health by becoming ‘informed patients’ both in terms of searching for information online or elsewhere and in the context of the patient-practitioner encounter (Greenhalgh & Wessely, 2004; Henwood et al, 2006). Ethical discourses of screening and testing can be countered by alternative accounts of moral behaviour; in a series of interviews with parents of children with genetic conditions or impairments, Kelly (2009) found the majority of respondents opted not to engage with prenatal screening for further pregnancies, “choosing not to choose”. These decisions did not
reflect a simple rejection of medical intervention, opposition to abortion, or affirmation of a positive parenting experience with an affected child. Rather, opting to avoid the condition of choice ‘appears to be a strategy of responsible parenting’ that emerges from ambivalence towards the options presented by reproductive technologies’ (Kelly 2009, p81 emphasis added). Further, Plows & Boddington (2006) have highlighted significant problems with the concept of biocitizenship, finding that issues of identity construction are more complex than simply accepting or rejecting a ‘biological’ perspective and that many social movements act in ways that contradict Rose’s model.

Foucauldian analyses of healthcare have long ago revealed the (bio)political role of all public health programs in attempting to create and manage orderly populations and the story of public health to date is as much about resistance as it is about control. Questions of utility and cost effectiveness are paramount. It is highly unlikely, for example, that the massive infrastructural commitments needed for big-data driven medicine could ever be cost-effective in dealing with the many minor ailments which make up the majority of the workload of many primary care practitioners. It does not require a multi-billion pound data network to recognise the common cold. Furthermore, as Mol & Elsman (1996) observe:

Diagnostic procedures that give more and more detail but do not have an effect on therapy, may be an unnecessary burden, or even risk, for the patient. They moreover waste scarce resources. Thus, to be rigorous: diagnostic techniques should be appropriate to what is done with their results (p612).

It is more likely that big-data driven techniques will be unevenly introduced across the range of medical services, potentially colonising areas such as oncology and idiopathic childhood disorders (two areas where whole genome sequencing is most rapidly moving from research into practice) while remaining relatively unused in others. It is these specific sites to which sociological attention should be directed in order to empirically investigate the impact of big data technologies on practices of diagnosis and intervention.

Finally, technological visions are just that – hopeful anticipatory statements about what future technological systems might be capable of, usually in a best case scenario. The early stages of novel technological projects are usually characterised by significant hype (Brown, 2003) and contain their own, often implicit, commitments to political-economic ideologies which shape the way in which their benefits are framed². Even the proliferation of commercial tests from the diagnostic industry is held to some sort of account by healthcare governance agencies concerned about the often unproven clinical utility of such tests and the costs of reimbursement (Faulkner, 2012). The importance of noting these limitations is because, as social scientists, we have a duty not only to subject social phenomena, such as ‘high tech medicine’ to a critical gaze, but also to be reflexive in producing our own accounts of these phenomena and ensure that they are not themselves overly deterministic, inflexible or dogmatic (Dingwall & Goulden, 2012). The geneticisation thesis can be considered a case in point; social scientists have theorised that the reframing of many common illnesses in terms of their genetic causes promotes a reductionist and determinist view of human health and disease (Nelkin & Lindee 1995; ten Have 2001). However, empirical investigation of genetic diseases and practices provides a

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² See http://www.genomicsnetwork.ac.uk/egenis/news/comment/title,25415,en.html for more discussion of this theme in relation to personalised medicine.
more equivocal account of the influence of ‘genetic absolutism’ in disease categories and lay responses to genetic illness (see Pavone & Arias, 2012 p237-9 for a discussion and list of references on the geneticisation debate).

2) Spaces and places of diagnosis

*Who makes diagnoses and where are they made?*

Contemporary western biomedicine is systemic; it exists in distributed networks of healthcare institutions, practices, professions, locations etc. If diagnosis is central to the practice of all medicine, then the sociological gaze must extend beyond the traditional site of the doctor-patient interaction in general practice. The landscape of diagnostic practice includes among its sites the laboratory and the clinic, the various medical specialisms and, potentially, acts of diagnosis by non-physicians and even diagnosis outside formal healthcare settings.

There is often a physical separation of such sites; different units or wards within a hospital, different hospitals and clinics within a city or region etc. and they are often spaces associated with particular types of technical expertise as with biochemists or geneticists in the laboratory, radiologists in x-ray facilities, or GPs in their surgeries. These sites are important because they represent separate ‘social worlds’ with different institutional settings, professional norms, and forms of knowledge. They are often places which favour particular ways of ‘seeing’ and conceptualising bodies and disease aided and mediated by specific technologies of measurement and visualisation. It is important to consider the effects for patients, disease identities etc. of this fragmented landscape, but perhaps even more important to understand how the different sites connect and interact.

*Medical specialisms*

The many medical specialisms and sub-fields constitute one such set of sites where diagnoses are produced in different ways. In her presentation, Sarah Nettleton used Halpin’s work on Huntington’s Disease as an example of how being diagnosed by physicians belonging to one specialism or another, in this case either neurology or psychiatry, can have significant consequences for the way an individual is evaluated, how their condition is presented and understood and, importantly, the types of treatment that will be offered. Conditions can sometimes find a ‘home’ in a particular medical specialism for a variety of social, professional, organisational and historical reasons. Girls with Turner Syndrome (TS), for example, are often evaluated and treated by paediatric endocrinologists (at least in the UK and the US), even though TS is a genetic (chromosomal) condition (Morrison, 2008).

One reason for this is that TS is most commonly associated with the symptom of abnormal short stature. The short stature of TS is treatable with human growth hormone, which as a hormone drug for paediatric use, comes under the disciplinary authority of paediatric endocrinologists. The reasons why short stature came to be seen as the defining medical ‘problem’ associated with TS are complex, but can be traced back to the use of statistical measures of height and weight as tools to assess the health of populations that emerged in the late nineteenth century (Tanner, 1981). Children became especially subject to public health surveillance at this time, as they were seen to be at risk of failing to develop ‘properly’ (Armstrong, 1995). Childhood height became a useful and widespread marker of potential underlying ill health and cause for referral to a paediatrician, and indeed this remains the case today. As
academic paediatricians turned to study biochemical aspects of childhood disease in the early twentieth century, many cases of short stature were linked to abnormal functioning of particular endocrine (hormone producing) glands (Fisher, 2004). By the late 1930s both the sub-discipline of paediatric endocrinology and the idea of short stature as resulting from hormone deficiencies had become established in medical practice.

When human growth hormone (hGH) was first isolated in 1956 it was initially regarded as a potential panacea for all childhood growth deficiencies (Morrison, 2008). As experimental application revealed this was not the case in practice, paediatric endocrinologists then began the task of working out which types of short children did and did not respond to growth hormone, in the process reclassifying children with poor growth into new diagnostic categories of hGH-resistant and hGH-responsive short stature. Turner Syndrome fell into the latter category and so found a ‘home’ in paediatric endocrinology and a primary therapeutic approach in treatment with hGH. As a consequence, other aspects of TS, such as the propensity for developmental / learning delays, can be downplayed in the clinical management of the condition because they are not ‘endocrine issues’ even though they may affect patients’ quality of life as much as, or more than, being short (ibid).

Conversely, other conditions may struggle to find a disciplinary home and patients can find themselves continually passed around between consultants from different specialities. One such example is neurofibromatosis type 1 (NF-1), as illustrated by the work of HTS affiliate Daniele Carrieri. NF-1 is a genetic condition, but has a highly variable set of symptoms where variation occurs not only between affected individuals but also over the lifetime of an affected individual. As a result, people with NF-1 tend not to identify with or internalise their diagnostic label and NF-1 is rarely the focus of biosocial activities such as patient advocacy or support groups. Instead, affected individuals tend to focus on which ever particular symptoms are of most concern to them and may look for support to patient groups associated with that symptom – e.g. cancer-based groups for people with NF-1 related tumours. Alternatively, they may prefer to downplay and ignore the condition as much as possible if symptoms are felt to be minor (Carrieri, 2012). This fragmentation is repeated in the medical management of NF-1 with patients tending to end up with specialists who reflect their individual concerns; again oncologists for tumours etc.

**Distributed diagnoses**

The process of diagnosis itself can be distributed across different types of sites where knowledge about bodies and diseases is produced – for example between the laboratory and the clinic. As noted above, these sites can often overlap with the location of medical specialists and other forms of (often technical) expertise. In Mildred Blaxter’s (2009) account of her own experience as a patient with an ultimate diagnosis of lung cancer, she reports that the ‘diagnostic phase’ of her illness experience required visits to three different hospitals plus GP visits and involved meetings and input from representatives from cardiology, radiology, gastroenterology, surgery and oncology as well as GPs and specialist nurses from imaging and surgery. Unlike the case of NF-1 described above, this spatial and disciplinary fragmentation appears to be routine, guided by externally produced guidelines and standards such as clinical care protocols. The diagnostic process involved was iterative, with each site adding a specific type of diagnostic information;
an x-ray, a scan, a blood test etc. and the outcome, the final diagnostic categorisation, produced in closed-door Multi-Disciplinary Team meetings.

Latimer et al (2006) report a similar situation in their study of the production of genetic diagnoses in childhood dysmorphia. Unlike Blaxter, Latimer and colleagues were able to access and unpack the ‘black box’ of team meetings where diagnostic decisions were made. They highlight the different types of ‘seeing’ work involved in assessing and interpreting the multiple, technologically-mediated inputs such as scans, genetic and molecular test results, patient histories etc. These records, scans etc., along with the representatives on a multi-disciplinary team, are what are circulates between different sites of diagnostic knowledge production, linking and connecting them. These physical artefacts do not ‘speak for themselves’ but are made to speak by actors in the diagnostic team meetings who interpret them. This exercising of clinical judgement requires as much tacit skill, based on experience and practice, as it does recourse to formal assessment and evidence-based guidelines. For Latimer et al these sites illustrate

‘the micropolitics of medical knowledge, whereby the personalized authority of the clinician intersects with and may overrule knowledge invoked on the basis of research and journal science’ (2006, p604).

Diagnostic decisions are shown to be iterative, dynamic processes where decisions are tentative, ‘working diagnoses’ rather than definitive statements of fact. This is a major location of the ‘ontological choreography’, the combining of different representations of the patient (or different models of the body, after Mol, 2002) which Sarah Nettleton highlighted as a key domain for future sociological analysis.

These diagnostic decision meetings are also the location where the patient appears to become most ‘virtual’, with the variety of reports, visualisations etc. presented at the meeting seeming to eclipse the embodied patient in the hospital bed, waiting room or at home. It is this aspect of organisation and management of patient care that Blaxter (2009) found most alienating and discomfiting. This virtual environment also runs the risk of ‘treating the scan not the patient’ as reported by Oonagh Corrigan in her presentation. Yet this type of multi-sited diagnostic process is likely to become ever more common as novel technologies such as whole genome sequencing move from research into routine use as diagnostic tools, adding yet another layer of complex data, and another component in the virtual representation of the patient, to be interpreted.

**Diagnostic classification systems**

Much of the above refers to the process of diagnosis, but the sociology of diagnosis also directs us to consider diagnosis as a classificatory system. Armstrong (2011) argues that this aspect of diagnosis has been largely taken for granted in much previous sociological work on medicine, health and illness such as medicalisation or labelling theory. As Oonagh Corrigan explained in her presentation, medical classification systems also act at multiple sites; in medical education, clinical trials, medical research, resource allocation in healthcare, epidemiology and in public health etc. The various classificatory systems, of which diagnostic categories can be considered the individual cells (Brown, 1995), are themselves located in diagnostic manuals such as the International Statistical Classification of Diseases and Related Health Problems (ICD), the Diagnostic and Statistical Manual of Mental Disorders (DSM), International Classification of Primary Care (ICPC) and other, less-used
works. The creation and development of these systems has its own historical landscape of early innovators, national and international institutions, revised editions and committees (see Armstrong, 2011 for a sociological account of the development of the ICD. Grob, 1991 provides a historical account of the origins of the DSM).

**Lay diagnosis**

Physicians may be the dominant source of diagnostic authority within medicine, but before ever going to see a doctor a person must first categorise themselves as being in need of medical help. The general assumption is often that a person goes to the doctor when they are sick, but as Zola observes ‘this term “sick”, is much clearer to those who use it, namely the health practitioners and the researchers, than it is to those upon whom we apply it – the patients’ (1973, p677). How, when and why people categorise themselves as sick, and sufficiently sick to seek medical advice, is a complex, highly-contextual and thoroughly social affair. The concept of lay diagnosis refers to the full range of (self) assessments of personal health and help-seeking behaviour including, symptom assessment, self-medication, alternative therapies, religious and faith-based action, behaviour modification and lifestyle changes, seeking psychiatric help, talking to family and friends about health issues, looking for health information on the internet and simply ignoring possible symptoms and hoping they will go away.

Healthcare research in this area has primarily focused on help-seeking behaviours for particular diseases, especially cancer, with a view to identifying and remedying the social factors which cause individuals to delay going to physician (Zola, 1973; Smith, Pope & Botha, 2005). However, in many of these studies ‘the reasons for delay are a list of faults’ – the patients have no time, no money, do not trust physicians, have low educational attainment etc. (Zola, 1973 p678). Such studies implicitly adopt a medical framing whereby a rational person, on realising they are ‘really’ sick, will then directly seek medical help. Instead, Zola suggests that physical ‘symptoms’, aches, pains, minor deficits in functioning etc. are common in everyday life but that there is ‘an accommodation both physical, personal, and social to the symptoms and it is when this accommodation breaks down that the person seeks, or is forced to seek medical aid’ (Zola, 1973 p679). Sociologically, lay diagnosis describes complex ways of making sense of embodied experience of illness which do not rely on the formal aetiologies and disease categories of contemporary western biomedicine. This is not to infer that lay understandings have nothing to do with orthodox medicine. Rather they often draw on biomedical understandings of the body, health and illness but do not necessarily use only this information or interpret it in the same way a healthcare practitioner would. The sociology of lay diagnosis is complemented by extant sociological studies of lay pharmacology (Cohen et al, 2001; Webster, Douglas & Lewis, 2009), lay epidemiology (Russell & Kelly, 2011) and lay aetiology (Russell, Kelly & Golding, 2010).

The concept of self-diagnosis has a much narrower remit and refers to individuals who explicitly identify themselves as belonging to a particular orthodox diagnostic category and present themselves to healthcare professionals looking for confirmation of diagnosis and/or appropriate treatment (Jutel, 2010). Self-diagnosis, as with the ‘informed patient’ who is likely to display self-diagnosing behaviour, represents something of a paradox for the medical establishment; on the one hand it constitutes a challenge to medical authority as the appropriate source of diagnostic decision making, but at the same time reliable self-diagnosis offers a route to more self-care
(reducing the workload of physicians) and patient compliance with prescribed remedies (ibid). Self-diagnosis is also the preferred course of action from a public health perspective in the case of outbreaks of infectious disease. Both phenomena are of sociological interest, but lay diagnosis seems to offer a richer domain for investigating the interplay between formal, scientific and public understandings of health, illness and disease.

The variety of diagnostic behaviour and the limits of inquiry

What do we mean when we talk of diagnosis? The question is not as clear cut as it might initially appear. In their edited collection ‘Ethnographies of diagnostic work,’ Büscher, Goodwin and Mesman (2010) proffer a broad definition of diagnostic activity as “identifying and categorising problems (or opportunities) and defining scope for action” (p1). Following this definition, they find diagnostic activity in the practices of engineers, designers and technical support helpline operators, in police work, military planning, business strategy, and in a host of mundane everyday assessments made by experts and non-experts alike. In contrast, the sociology of diagnosis, from the pioneering insights of Mildred Blaxter to the recent work of Jutel & Nettleton, has located diagnosis solely and firmly within the domain of medicine. However, even within medicine and healthcare, decision making about bodies and diseases is not strictly limited to physicians. Health-related assessments and judgements are also made by nurses, midwives, pharmacists, paramedics, coroners, pathologists (Rees, 2011) and social workers. During the workshop it was suggested that more sociological attention ought to be given to these ‘other’ spaces as (potential) sites of (medical) diagnostic activity. At the same time, the very pervasiveness and adaptability of a diagnosis-focused approach also raises questions about how to delimit the frame of sociological enquiry. Should a sociology of diagnosis incorporate what we might term ‘diagnostic behaviours’ among lay persons and healthcare professionals other than physicians? What about alternative and non-western medicines? Or practices that use biomedical language, tools and practices but are deemed outside the boundaries of orthodox medical practice such as private clinics using off-label prescribing of medicines for anti-ageing purposes? If not, can we specify what it is about physician-led diagnostic practices that warrant special sociological attention above and beyond these other considerations?

There is a danger of having too broad a scope of investigation and the attendant risk of losing coherence, but it is also important to recognise the situatedness and interconnectedness of much medical decision making. Biomedicine itself is not a homogeneous or monolithic entity; rather it is localised; adapted and shaped by regional, national and international factors such as the nature and organisation of various healthcare systems, economic models of healthcare, resource availability, levels of techno-scientific development, infrastructure, historical, political and cultural circumstances etc. One approach which, although it does not specify a clear boundary to the study of diagnosis, was mooted and received significant support during the workshop was to put greater emphasis on comparative studies as a basis of future research. Additionally, instead of rejecting broader conceptualisations of diagnosis, it may be more productive to ask what a sociology of diagnosis focusing on the domain of medicine can learn from studies such as those reported by Büscher, Goodwin and Mesman (2010).

3) Time and timing in diagnosis and intervention
Time is deeply implicated in health and illness; certain diseases are known to occur predominantly in particular seasons, at particular stages of life such as childhood or old age and even at particular times of day; they have specific durations and rhythms and also affect the experienced time of the person undergoing a period of illness (Adam, 1995). Medicine, and its component processes, systems and outcomes also have their own timeframes, rhythms, periodicities, durations and schedules, although these have historically received less attention than they perhaps warrant. This section provides a guide to some of the time-related aspects of diagnosis and intervention that came out of the symposium.

Time and diagnostic categories

Some diagnostic labels contain their own time codes; acute (short term, immediate), chronic (long term, recurring) and terminal (duration to a fixed event in the life-course) illnesses. Benyon-Jones (2012) demonstrates that such codes are not necessarily fixed, but, using the example of ‘early’ and ‘late’ abortions, shows how healthcare practitioners’ own judgements on, and perceptions of, time and timing shape the application of such medical classifications in ways that have significant consequences for practitioners and patients alike. Diagnostic categories themselves are not ahistorical or acultural entities, but are products of particular historic and cultural moments. Blaxter conceptualised diagnostic classificatory systems such as the ICD as ‘museum[s] of past and present concepts of the nature of disease’ (1978 p10). Some diagnostic categories, such as hysteria, fall out of favour or are removed from the sphere of medical authority (homosexuality) and no longer appear as cells in the classificatory systems. In other areas, new approaches or novel technologies can create wholly new cells (e.g. diagnostic categories framed at the molecular level, ‘big data’-driven approaches).

The content of a diagnostic category, including its boundaries and the choice of measurements used to define and assess a disease, can also change over time, impelled by shifts in medical knowledge and practice. Pickersgill (2010) describes this type of dynamic in the history of anti-social personality disorder. Research on the experience of parents of children with ‘genetic’ conditions has also shown that, while a diagnosis of genetic disease may be regarded as an ‘inescapable truth’ about a child, parental engagement with the medical management of these children often changes over time, as many parents begin to assert their own, experiential knowledge in making decisions about how best to care for their individual child; for example, in terms of making decisions about treatment options, locations, access to services etc. (Whitmarch, Davis, Skinner & Bailey, 2007; Kelly, 2009). The diagnostic label may stay the same, but the practical, lay understanding and response to it can be highly dynamic.

Time in practice

The following extended quote from Blaxter (2009) illustrates a number of the temporal aspects of diagnostic practice that were raised in the workshop:

Protocols imply timetables, which are not only crucial to efficiency, but are of particular importance to the patient. Sometimes they are the only way in which chaos and the feeling of lack of control can be kept at bay. High-tech medicine necessarily elongates timetables. Tests take time to be arranged and involve specialised staff; images take time to analyse and involve intermediary experts. Roth first showed, in his classic book (1963), how in any case the medical
profession may use timetables to structure the patient’s career in the way that
best fits their own organisation, and how the natural rhythm of illness can
become subverted by the timetables imposed by medical practice and the
organisation of hospitals. Dr X might consult at a particular hospital on only one
day a week, tests might be available on equally restricted days, and reporting
their results might take several days. Given that different departments might be
involved, each with their own timetables, the slow progression of this case
history is easily understood (p775).

A number of different temporalities are identifiable in this single extract; the
standardised times of care protocols, the organisational times of particular hospitals,
doctors and departments, the machine time of high-tech diagnostic devices, the
natural rhythm of illness and the personal time of lived experience of sickness. Many
of these temporalities are linked with the different diagnostic spaces discussed
above; particular laboratories or medical specialisms have their own organisational
and technological times, as well as the time involved in co-ordinating the input of
multiple sites, time for the patient to travel between sites etc. Diagnosis is not
necessarily a single event but a series of spatially and temporally discrete (though
interwoven) processes from initial, tentative diagnosis, through a prolonged period of
refinement involving additional tests, scans etc. to produce interim ‘working’
diagnoses until an eventual outcome and treatment are allocated.

*Technologies, timing and experience*

As Celia Roberts demonstrated in the morning session, novel technologies can
reconfigure the meanings and experience of illness and medically-managed events
for both patients and healthcare professionals. Taking her case studies of pre-
implantation genetic diagnosis (PGD) and ultrasound use in Taiwan, it is possible to
see the temporal element in this reconfiguration. The timings and rhythms of ‘regular’
pregnancy are largely displaced by the organisational and technological timing of
clinics, screening technologies, and in the case of PGD the re-ordering of the timing
of ‘conception’ to the schedules of oocyte extraction, in-vitro fertilisation procedures
and embryo implantation. These distinct temporalities are part of the change in how
pregnancy is experienced and understood by all parties involved.

Recent and ongoing work by Susan Kelly, Hannah Farrimond and Michael Morrison
in the HTS group focuses on another novel, pregnancy-related diagnostic technology
where timing is a major issue. Cell-free foetal DNA testing is a technology that allows
tiny amounts of foetal DNA to be extracted from maternal blood and amplified for
genetic analysis (PHG Foundation, 2009; Kelly & Farrimond, 2012). One of the
major posited applications of this technology is as an easier, safer approach to
testing for Down syndrome. The present technologies for confirming DS,
amniocentesis and CVS, carry a 1-2% risk of inducing a miscarriage in an otherwise
healthy pregnancy and so are used only in pregnancies already identified as being at
high risk for DS. Cell-free foetal DNA testing also has the potential to permit testing
much earlier in the pregnancy: cffDNA testing can potentially be performed from 7
weeks post-conception compared to 15 weeks for amniocentesis. This option would
disrupt the current organisation of antenatal care; a DS test could potentially be
offered before women are even expected to have met a midwife for the first time in
the current timeline. Would this mean that the medical management of pregnancy
would have to be pushed back even closer to conception? Alternatively, might
cffDNA testing be administered at the current first (10 week) meeting with the care
team, and if so would there be an opportunity to discuss the test with a genetic counsellor as is currently required before amniocentesis/CVS? A number of blood tests are already collected early in antenatal care to detect sickle cell anaemia, thalassemias etc. Would the cfDNA test be singled out as different or might it get ‘lost’ in the mixture of routine blood tests in early pregnancy? What would this mean for the quality of informed consent obtained? Might earlier testing mean an increase in terminations of DS pregnancies and what effect would this have on the provision of abortion services? These are all questions raised by the simple shift in timing of the diagnosis of a particular condition and illustrate the importance of time and scheduling in structuring diagnosis and intervention.

*Future research directions*

We consider that temporal aspects of diagnosis and intervention would add a valuable extra dimension to comparative studies of, for example, how a particular condition is diagnosed at different sites. Other areas for further investigation include the importance of timing in lay diagnosis and the dynamics of changing diagnostic classificatory systems.

4) Theorising diagnosis and intervention

“Our in an experimental setting, diagnosis is rarely an activity carried out as an abstract puzzle-solving exercise. It is part of the clinician’s continuum of work. After he has made has "made a diagnosis" he then has to do something else” (Blaxter 1978 p13).

If one thing is clear from the symposium and the points set out above, it is that a simple, linear model of:

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symptoms → diagnosis → intervention
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is inadequate to describe the complex realities of the medical encounter. In one sense of course, diagnosis itself represents an intervention of medicine into the everyday life of an individual (especially with unsought diagnoses). It is true that in some cases a particular therapeutic intervention can and does routinely follow on from a particular diagnosis. This is evident, for example, with the diagnostic category of growth hormone deficient (GHD) short stature and therapeutic intervention with human growth hormone, where disease and therapy have historically been co-constructed. The diagnostic label of GHD short stature presents the nature of the disease as a deficit in a particular bodily chemical and renders the treatment – restoration of that missing biochemical element – seemingly self-evident (Morrison, 2008). This, though, is not necessarily the case.

In their study of the diagnosis and treatment of diseased blood vessels in the leg, Mol & Elsman (1996) argued that the processes of diagnosing a disease and designing an appropriate treatment are ‘neither entirely different, nor simply the same’ (p611). Rather they posit that:

Detecting disease and designing treatment are different and interdependent. There are gaps between them and they interweave. The boundary between them is neither simple nor solid. It is not a boundary that can be drawn in time, between this phase and the next, between the first encounter with the patient in the consulting room and the final decision to intervene. For in the first encounter the question is already ‘what to do’ and the final decision may hinge on the question of how severe the patient's complaints are or where exactly a
[symptom] is located. Instead of a difference in phase, there is a difference in accent, in relevance. In dealings with a patient and in the use of diagnostic tools, what is important shifts back and forth between searching for clues for how to react, assessing the severity, determining the site of the disease, and measuring its extent (Mol & Elsman, 1996 p627).

We have already seen that diagnosis is not a single event, but rather a complex process dispersed across time and space. Mol & Elsman’s account adds to this perspective by highlighting the non-linearity of the process, the shifting back and forth between measurement, assessment and planning of interventions.

This is also echoed to an extent by the pragmatic approach to diagnosis on the part of physicians reported by Dowrick (2009a), as cited by Oonagh Corrigan in the morning session:

We general practitioners are mainly interested in the utility of diagnoses: we take a pragmatic approach. We welcome a diagnosis as an opportunity for reducing the complexities of the problems that our patients present, a means of creating or imposing order and understanding in the midst of confusion and chaos, a defence against confusion and uncertainty (Dowrick, 2009a).

In face of the ‘raw illness’ at the coalface of primary care, it is often difficult to translate particular symptoms into a specific diagnostic category. Tests and measurements can be used to rule patients out of a diagnostic category as much as to assign them to one. Many diagnostic categories do not define a specific aetiology for disease meaning there is no seemingly ‘self-evident’ treatment option. In this respect the example of hormone deficiency diseases and corresponding hormone replacement therapies may represent an uncommonly close linkage of diagnosis and intervention compared to wider medical practice. Some diagnostic categories are broad ‘one size fits all’ labels which can accommodate a range of variable symptoms; at other times patients may need to be ‘fitted in’ to a working diagnostic category. In all of these cases the choice of a treatment option may be directed primarily by a desire to manage risk and uncertainty rather than flowing from the ‘correct’ diagnosis of disease.

The multiple roles of diagnosis and intervention

While some workshop participants argued that diagnosis was in itself a form of intervention and that diagnosis and intervention were often tightly linked, others suggested that diagnosis did not necessarily lead to intervention at all, and, similarly, that interventions could occur without being preceded by a diagnostic process. Certainly being assigned to a diagnostic category can have social consequences beyond, or instead of, receiving a course of treatment. Having a diagnostic label can validate claims to additional resources, exceptions from behavioural norms and other requirements of everyday life. These resources do not necessarily belong within the realm of medicine, but can take the form of financial, educational, and social assistance, access to facilities and forms of support not generally available to the non-diagnosed population.

Interventions too need to be considered as involving more than just recourse to pharmaceuticals or surgery. Lifestyle or behavioural changes e.g. diet and exercise, better management of stress etc., psychiatric or psychological therapies, counselling, and access to support services can all count as forms of intervention in a wider sense. Importantly, many of these interventions can result from either formal
diagnosis or lay diagnosis suggesting another site for future comparative studies. In particular circumstances traditional interventions can also occur without a confirmed diagnosis, for example, surgical or pharmaceutical intervention can be used investigatively to produce information about an uncertain or unknown condition; determining whether or not a condition responds to a particular course of therapy is one way of finding out more about that condition. Experimental interventions are also routinized in certain spaces such as clinical trials and hospital research, where the boundaries between research and intervention become blurred. It was suggested that future research could examine further instances of diagnosis which do not lead to conventional intervention and instances of intervention which occur without prior (formal) diagnosis to better clarify the nature of the relationship between these two practices.

This research aim could also be furthered by looking at instances of misdiagnosis – not through the usual frame of assigning blame, but with a view to understanding how and when an event becomes classified as ‘misdiagnosis’ rather than, for example, an appropriate response to uncertainty.

**The influence of technologies on intervention and diagnostic categories**

As well as being complex and non-linear, the relation between diagnosis and intervention is not necessarily uni-directional. In organising the symposium, speakers were asked to consider the extent to which, as tools for determining the boundaries and meaning of disease categories, novel diagnostic technologies can affect the meaning and choice of interventions for patients and physicians. In his historical study of the changing ‘disease identity’ of anaemia throughout the twentieth century, Keith Wailoo (1997) has shown that the reverse is also true; that the availability of a particular intervention can reconfigure the understanding and meaning of a disease category. In the case of ‘pernicious anaemia’ Wailoo reports that ‘[b]y 1934 the disease had been reconstructed around the antidote. Pernicious anaemia [became] a disease curable by liver therapy’ (1997, p128 emphasis in original). Aaronowitz (1998) also makes a similar point about the impact of the availability of steroid therapy on models of ulcerative colitis (see p38-54). Thus technologies of diagnosis and those of intervention both influence the construction of disease categories and change can come from either end of the diagnosis-intervention pathway.

**Cycles of diagnosis and intervention**

Even after an intervention has been selected, this does not necessarily signal an end to testing and assessment of bodily performance. Response to treatment regimens is often monitored and revised subject to assessments of treatment efficacy and prevalence of unwelcome side-effects. Unexpected findings can lead to re-diagnosis and alternative courses of treatment. Thus episodes of diagnosis and intervention may occur multiple times in succession during a single illness experience. The rise in prevalence of chronic illnesses is a particular case in point; with chronic illness the ‘illness episode’ and hence the entanglement of individuals with healthcare systems, remains open-ended as lifetime disease management is often the ‘outcome’ (Varul, 2010 – see also Frank, 1995 on the concept of ‘remission society’). For the chronically, or terminally ill patient, sickness is always immanent and therefore surveillance and monitoring are constantly present too. This may give rise to cycles of testing, intervention, further testing, more intervention etc., which persist until death. It is also possible that this is the kind of location where ‘hard and fast’
sociological distinctions between screening, monitoring and diagnosis may break down.

During the workshop the topic of *prognosis* was raised. Prognosis, the expected course of how an illness will develop over time, was not something we had initially considered when convening the symposium. We consider it, however, an emergent direction for future investigation, especially given the form of the original question as asked during the event: “Does prognosis mediate between diagnosis and intervention?”

5) Summary of future research directions

*Theoretical aspects*

- What are the appropriate boundaries of investigation – especially through a sociology of diagnosis approach?
- Should the social study of diagnosis concentrate on formal medical diagnosis by physicians or should we also look at diagnostic behaviour made by nurses, midwives, pharmacists, paramedics, coroners, pathologists, lay and self-diagnosis using the same theoretical framework?
- What might be lost or gained by either approach?
- Should this framework also extend to alternative, traditional and fringe medical practices?
- What is the role of prognosis? How should we theorise and understand prognosis, and might the concept be useful in understanding the relationship between diagnosis and intervention?

*Sites of investigation*

- In order to understand the impact and nature of ‘big data’ driven approaches to medical classification and diagnosis, social scientists should look at those sites, such as oncology and childhood dysmorphia where technologies like whole genome sequencing are most advanced in moving from research into practice.
- More attention should be paid to the dynamics of changing diagnostic classificatory systems such as the ICD and the DSM and they ways in which they affect diagnostic processes for both patients and healthcare personnel.
- The overlaps (or not) between lay and formal diagnostic processes, categories and consequences.

To further conceptual and practical understanding of diagnosis, intervention and the relationship between them, attention should be directed to cases where:

- Diagnosis occurs without traditional (medical/surgical) intervention
- Intervention occurs without prior (formal) diagnosis
- Instances of ‘misdiagnosis’ – including examination of how and why the term is applied in particular circumstances.

*Types of investigation*
Comparative studies were suggested as a particularly useful approach to future sociological investigation of diagnosis and intervention. Proposed directions for future research included:

- Focusing on a single disease and comparing how it is diagnosed at different sites, including different medical specialisms, different national healthcare systems, and comparing lay and formal diagnostic approaches to the same condition.
- Taking two or more diseases within a broader grouping, e.g. ‘genetic conditions’ or mental health disorders and comparing how they are diagnosed and managed at a single site (i.e. a particular clinic or hospital).
- Comparing the patient experience and physician-patient interaction across different types of diagnostic category; ‘stable’ diagnoses, contested conditions, asymptomatic conditions, risk-based ‘pre-diseases’ etc.
- Comparing the theoretical models of the social/political/economic factors driving the expansion of diagnosis and diagnostic categories with findings from empirical study.

We also suggest that comparative studies of diagnosis and/or intervention would benefit from addressing the temporal aspects of each process as part of the overall investigation.
FUTURE EVENTS

The symposium, and this report, marks the formal launch of the HTS research group. In this final section of the report, we outline our vision for the future of the research group and present some forthcoming HTS events for 2012-13. The majority of the core HTS staff are currently affiliated with the ESRC Centre for Genomics and Society (Egenis) at the University of Exeter. Although the ESRC genomics centres are now being wound down, the HTS research group will continue through the transition of Egenis staff into the School of Sociology and Philosophy. It is a major goal of the HTS group to become a hub for inter- and multi-disciplinary projects involving the social aspects of innovation and (biomedical) technologies at Exeter and beyond. One way in which we plan to achieve this is by building on our existing collaborations; for example with the Science, Culture and the Law at Exeter (SCuLE) research group in the School of Law, and by developing new working partnerships with other research groups, projects and departments. HTS members will also continue to pursue their own research interests through ongoing and novel projects.

ESRC seminar series

The most significant forthcoming event that HTS members are involved with is the ESRC seminar series:

The role of diagnosis in health and wellbeing: A social science perspective on the social, economic and political costs and consequences of diagnosis.

Dr Susan Kelly and Dr Michael Morrison of the HTS group are part of a successful consortium, along with Dr Charlotte Salter and Dr Andrea Stockl (University of East Anglia), Dr Sarah Nettleton (University of York), Dr Simon Cohn (University of Cambridge) and Dr Annemarie Jutel (Victoria University of Wellington, New Zealand) that has been awarded an ESRC grant to hold a series of seminars exploring different aspects of the sociology of diagnosis. The seminars will be hosted by the institutions of consortium members in the UK and are due to run through 2013-14.


Early technological innovations such as the stethoscope, the scalpel and, later, x-rays were not only central to the clinical project of separating the measurable, anatomical body from the self-reported symptoms of the prospective patient, but also became powerful symbols of the practice of modern medicine itself. Recent diagnostic technologies such as genetic tests or MRI scans are scarcely less pervasive. Technological innovations can affect how disease categories are understood by patients, physicians and the public, shift location of diagnosis and related clinical work (e.g., e-health initiatives and self-diagnosis) and even obscure distinctions between risk of disease and the disease itself. **Indicative questions:** What are the drivers and the consequences of innovations in diagnostic technologies? To what extent are predictive, diagnostic and therapeutic technologies interrelated? Can a critical sociology of diagnosis speak to a conventional health technology assessment programmes? **Organisers:** Dr Susan Kelly, Dr Michael Morrison

Diagnosis serves as a prism which absorbs and reflects a panoply of issues central to the experience and practice of medicine and health care. It is the act by which ailments are explained and labeled, but it is also the label itself. Clinicians draw upon a range of nosologies, taxonomies and other authoritative classification systems, such as the DSM and ICD, for diagnostic guidance. But, as Bowker and Starr (1999) elegantly argue, each classification system has its own history and serves its own purposes. It is through diagnostic activity and the processes of applying and negotiating these disease systems that diagnostic categories change, revealing the malleability, instability and fluidity of diagnosis both as a process and as a category.

**Indicative questions:** What constitutes a diagnosis? What socio-economic and political forces contribute to the fabrication of a diagnostic category? Is there a future for discrete diagnoses? **Organisers:** Dr Charlotte Salter, Dr Andrea Stockl

Seminar 3: Diagnosis, politics and collective health movements. University of Cambridge October 2013

This seminar will discuss how diagnoses are contested, challenged and politicised. It will explore the different ways in which diagnoses can affect different social and cultural groups in order to understand the implications for class, age, gender, ethnicity and sexuality. **Organiser:** Dr Simon Cohn


Exploring how diagnostic practices create or challenge territorial boundaries within and between lay and professional as well as between professions. We will consider how diagnosis is undertaken within complementary and alternative health settings. **Organiser:** Dr Sarah Nettleton


This final seminar focuses on the nature of the diagnosis-policy engagement in order to illuminate the policy implications of the sociological perspectives explored in the earlier seminars. Representatives from the policy domains and professional organisations relevant to each of the seminars will be asked to respond to the policy issues identified as a vehicle for maximising the relevance and impact of the analysis. **Organisers:** Dr Charlotte Salter, Dr Andrea Stockl

More information on the seminar series and details of how to register for each of the events can be found at the project website: http://www.sociologyofdiagnosis.com/
Susan Kelly

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