



## Introduction

# Towards a sociology of diagnosis: Reflections and opportunities

## Introduction

In 1978 Mildred Blaxter declared in the pages of *Social Science & Medicine* that: 'The activity known as "diagnosis" is central to the practice of medicine but is studied less than its importance warrants' (p. 9). Thirty-one years later, she published a moving autobiographical article in the journal *Sociology of Health and Illness* recounting her own diagnosis of cancer (Blaxter, 2009). What is striking about this article, "The Case of the Vanishing Patient" is first the sociological impact which she assigned to diagnosis and second, the ways in which she has woven sociological theories through her data to make sense of her personal diagnostic process. She draws upon science and technology studies (STS), cultural sociology, illness narratives, sociology of professions, relations between practitioners and patients, the sociology of knowledge and finishes by offering analytic insight of and pragmatic implications for health care delivery. Diagnosis, she demonstrates, serves as a prism which absorbs and reflects a panoply of issues central to the experience and practice of medicine and health care. It also evokes collective responses, as Robert Aronowitz (1991) has written, providing an insight into the society in which diagnoses occur.

The sociological study of diagnosis both requires, and can contribute to, a diversity of sociological methods and theories, making the development of a sociology of diagnosis as a discrete field of study a viable exercise. The *raison d'être* for this Special Issue is to demonstrate the merits of such a sub-discipline by bringing together a collection of empirical pieces confirming this topic as an innovative vein of research and nudging forward the research agendas that it generates. In so doing, we build on a few isolated claims that a sociology of diagnosis can form a concrete body of work and can both deploy, and contribute to, the sociological understandings of health, illness and health care.

## Calls for a sociology of diagnosis

Nearly two decades on from Blaxter's plea that sociologists should pay more attention to medical diagnosis, Phil Brown (1995) emitted a similar call. It was he who first used the term 'a sociology of diagnosis,' and argued that it should form a central strand of medical sociology's endeavour to articulate the social construction of health, illness and perhaps most crucially disease (more on his current views later in this article). Although the paper itself was influential, any attempt to forge a sociology of diagnosis was lost until the call was taken up in recent times by Annemarie Jutel (2009; 2011b), one of the guest editors of this issue. In her review paper published in *Sociology of Health and Illness* and in

her book *Putting a Name to It: Diagnosis in Contemporary Society*, she argued that diagnosis constitutes a major classification tool for medicine and outlined the work such tools perform. Within the context of Western biomedicine diagnosis: validates what counts as disease; offers explanations and coheres patients' symptoms; legitimates illness, enabling patients to access the sick role; provides a means to access resources and facilitates their allocation; and forms the foundation of medical authority. But close scrutiny reveals that the picture is not a simple one. Medical diagnoses are also contested, socially created, framed and/or enacted. And while diagnosis of disease is 'central to the practice of medicine' as Blaxter put it (see above) and as the context of the practice of medicine has changed, so too has the play of social, political, technological, cultural and economic forces which impinge upon diagnostic categories and diagnostic processes.

In the decades between Blaxter's two papers, post-industrial societies have undergone significant transformation. Most notable has been the rise of neo-liberalism, globalisation and marketisation. This has meant that while diagnosis still forms the foundation of clinical practice, the day-to-day activity of diagnosing has become increasingly porous, permeated by commercial interests, consumerism and commodification. Diagnosis now represents much more than a patient consulting a practitioner with illness symptoms and coming away with confirmation of disease, if indeed it ever did. Diagnostic categories are less bounded, with the dualism of disease and non-disease collapsing in the face of new categorisations of potential disease and risk factors. Patients now bring expertise, knowledge, and expectations to the clinic. Their conceptualisation of cause and consequences of disease classification is taken more seriously by policy makers and care providers. Practitioners in turn, are extolled to position the autonomous lay person at the centre of their care, rather than the acquiescent 'patient.' But even at this micro level, diagnosing constitutes a socio-political process that begs scrutiny. These are some of the themes explored in the papers in this issue and to which we return in our discussion below.

## Diagnosis – an absent presence

We can re-read the literature in the sociology of health and illness and see that diagnosis has not been neglected, and certainly studies of diagnosis as a social process are clearly present. Similarly the contestation and consequences of disease classification are evident. One could argue that diagnosis has had an absent presence in the sociology of health and illness. It figures in a number of important debates and literatures within the field, most obviously

in the history of medicine, medicalisation and the sociology of technology. Here we see illustrative examples of how disease categories are: identified (for example, Alzheimer's disease (P. Fox, 1989), PTSD (Scott, 1990), overweight (Jutel, 2006) and Lyme disease (Aronowitz, 1991)) and enacted (for example, atherosclerosis (Mol, 2002); breast cancer (Klawiter, 1999), and anorexia nervosa (N. Fox, Ward, & O'Rourke, 2005)). We also see, as Allan Horwitz has eloquently demonstrated, how both internal factors (interprofessional dynamics) and external (drug industry and advocacy groups) serve to configure and reshape diagnosis (in this case, Major Depressive Disorder), with dramatic impact on mental health, its practice, treatment, research and epidemiology (Horwitz, 2011).

Diagnosis is also evident in the sociology of illness experience and illness narratives. The naming of a disease can give rise to 'biographical disruption' (Bury, 1982), a 'loss of self' (Charmaz, 1983) and 'narrative reconstruction' (Williams, 1984), or a symbolic transformation (Fleischman, 1999). Diagnosis is the means by which we gain an insight into the biographical and temporal adjustments (cf Bury, 1982 and Williams, 1984). Empirical studies have yielded data demonstrating the impact and consequence of diagnosis on people's lives, producing an important set of concepts to make sense of the diagnostic experience. Diagnosis *organises* disease, providing a name, a treatment, a direction to an ailment (Balint, 1964). It is an *interpretative* project involving a back and forth exchange between lay and professional to find a satisfactory explanation (Leder, 1990). And diagnosis can be a *narrative surrender*, where a lay person's story of embodied experience is re-appropriated, and recast by medicine (Frank, 1995). Diagnosis is a starting point, the foundation from which sense-making and experiences are crafted.

Diagnostic processes are prominent in those studies which examine contested diagnoses; especially those where lay people or activists have contributed to the identification and confirmation of diagnostic categories. Social movements have debunked some medical diagnoses (for example homosexuality (Kirk & Kutchins, 1992), and hysteria (Shorter, 1992)) and contributed to the establishment of others (for example, miner's lung (Bloor, 2000) Lyme Disease (Aronowitz, 1991), Gulf War syndrome (Brown et al., 2001; Zavestoski, Brown, Linder, McCormick, & Mayer, 2002; Zavestoski et al., 2004), RSI (Arksey, 1998) and HIV/AIDS (Epstein, 1996)).

Diagnoses are an important foundation for some forms of medicalisation (Barker, 1998; Conrad, 1975; Lee & Mysyk, 2004; Rosecrance, 1985; Tiefer, 1996): providing a label to which medicine can anchor its authority, and around which it can express its concern and set its agendas. Capturing, in a medical diagnostic label, unacceptable social conditions (shyness, unwanted childlessness, inadequate feelings of lust, or ageing) lays them bare for exploitation by 'engines of medicalisation' about which Peter Conrad (2005) and others (Healy, 2006; Moynihan, Heath, & Henry, 2002; Phillips, 2006; Wolinsky, 2005) have written.

This Special Issue has papers that speak to these on-going sociological concerns: classification, illness narratives, lay epidemiology, sociology of science and technology, social movements and medicalisation are all touched upon. A variety of methodologies too are deployed. But what transcends all the papers is the focus on diagnosis in terms of categorisation, process or consequence with most papers illuminating all three of these dimensions of diagnosis. Before we examine the papers themselves in terms of what they add to these on-going debates, let us reflect on what a diagnosis is, within the context of health and medical care.

### What is diagnosis?

At its most basic, a medical diagnosis is both a category and a process (Blaxter, 1978). A medical diagnosis is perhaps most

readily recognized as the official label that classifies disease or a medically-related problem. Clinical practitioners are able to draw upon a range of nosologies, taxonomies and other authoritative classification systems for diagnostic guidance. The *International Statistical Classification of Disease, Injuries and Causes of Death* (ICD) the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), *Read Codes*, *Systemized Nomenclature of Medicine* (SNOMED) and dozens of other classification systems, with varying purposes, are amongst the array of resources available to clinicians, statisticians and hospitals and states (Jutel, 2011a). However, each classification system has its own history, and serves its own purposes. The ICD grew out of a political context in the early 20th century wherein European countries were extending their empires and their citizenry, traversing boundaries in ever quicker and more invasive ways, bringing, among other things, viruses and epidemics to new locations. It sought to track and compare disease patterns between populations (Bowker, 1996). The DSM, on the other hand, initially published in the early 1950s as a slim volume of psychopathology was, by its third revision in 1980 and henceforth, to become a tool by which psychiatry could assert its authority at time when many other professions were encroaching upon its domain (Mayes & Horwitz, 2005). These classificatory infrastructures did far more than simply develop simple taxonomies.

The diagnosis finds expression outside of the classificatory infrastructure when an individual decides he or she is ill and presents this supposition to someone with diagnostic authority. Usually a doctor (but also a nurse practitioner, physiotherapist or others) examines the patient, assesses the evidence, and diagnoses their ailment. The diagnosis may (or may not) take into account a lay version of events; may (or may not) rely upon clinical judgment, or alternatively laboratory findings; and may (or may not) align with the patient's own diagnosis of her symptoms.

Analytically separate, the category and process of diagnosis are of course inextricably interlinked and mutually constitutive. What is poignant here is the degree to which the diagnosis does 'work.' As soon as it is defined (category), or implemented (process), it categorises health realities in tangible ways, determining who has access to what resources, under whose jurisdiction the management of the condition will fall, and what the individual's experience now means in terms of identity and prognosis. As classification theorists Bowker and Star (1999) point out, the diagnostic category, once formalized by its inclusion in a classificatory scheme (say ICD or DSM), cements a particular view of illness that will invariably privilege certain voices, and silence others. It is the expert consensus panel that tends to have the last word in the establishment of diagnostic categories. Robert Aronowitz has underlined that the evidence viewed by such panels to arrive upon their definitions of disease cannot be easily separated from knowledge of who will benefit (or alternatively, suffer) from a disease being named in one way, as opposed to another (Aronowitz, 2001). And of course these are not static, but change over time not least as they are applied and implemented in a variety of contexts.

We are using Blaxter's (1978) diagnosis-as-category and diagnosis-as-process as the starting point for introducing the content of this Special Issue. However, we have added classificatory decisions of our own and have a third rubric—'consequences of diagnosis'—to describe the important papers which follow this introduction.

### Diagnosis as category

While medical classification of the 18th century rested on symptom-based taxonomies, wherein there was a correspondence between the symptom and the disease; and the medical classification of the 19th century determined that diseases were based on

observable pathological lesions; 20th century classifications became increasingly fuzzy. Blaxter's (1978) paper took the case of alcoholism to demonstrate this problematic. It was an example of the vogue to reinsert the person in to the patient's body. A 'liberalising of the disease concept,' that 'represents a very fundamental switch of emphasis: an acknowledgement of the multi-causal nature of disease, an attempt to see illness as related to a host of environmental, constitutional, occupational, behavioural and psychological factors' (p.10). Her case study shows that disease labels such as alcoholism can be difficult to assign in practice.

The patient-as-person whose actions were more difficult to tame than biological processes made doctors reluctant to apply the diagnosis of alcoholism. Once a person was diagnosed as an alcoholic, the doctor's potential contribution became less clear. Blaxter demonstrated how the absence of a suitable medical prescription for a particular diagnosis led to doctors' resistance to use this diagnostic category. Nevertheless, as Blaxter drafted her paper, a growing array of social taxonomies designed to capture both disease *and* behaviour were being developed for use in primary medical care and for statistical records of morbidity throughout the world. The diagnosis as category was becoming broader, encompassing more than the pathological lesion.

David Armstrong's paper in this issue has some degree of overlap with Blaxter's thesis. He addresses the fundamental matter of classification structure through his analysis of diagnosis and nosology in primary care (Armstrong, 2011). Like Blaxter, he documents how various classification schemas deployed by national governments, and more particularly the World Health Organisation, aimed to capture the patients' symptoms, and psycho-social background. Crucially, for his argument, they were intended to capture the reasons patients give for seeking medical help. Thus what we see is not a 'patient as interlocutor for the pathology but the patient as reflective being'. Unlike the patient in the symptom-based classification paradigm who functioned as a vehicle through which the doctor could access the patient's problem, the contemporary patient is a reflective person with whom the medical practitioner must engage. Armstrong demonstrates how medical nosologies, through their application in the process of diagnosis, attempt to promote and maintain a certain medical reality. His review of modern disease classification systems underlines how diseases and diagnoses are made apparent through these systems which also construct the different identities that these systems crystallize.

The formation of medical identities is a point of departure for Charlotte Salter and her colleagues. In their paper, 'Risk, significance and biomedicalisation of a new population: older women's experience of osteoporosis screening' they discuss how clinical risk assessments determine the probability of fracture when combined with dual energy X-ray (DXA) scanning to measure bone mineral density thus predicting and treating an individual patient's absolute risk of fracture and possible osteoporosis (Salter et al., 2011). The focus of their piece is on the consequences for patients, but there is an important point here that relates to diagnosis-as-category. The example serves as illustration of the ways in which contemporary classificatory tensions exist between the clinical categorisations and a changing wider societal context. Citing the work of Novas and Rose (2000), Salter et al highlight how this pre-disease identification gives rise to a new category of patient whose at risk status comprises a novel source of social identity. The well person is diagnosed as the person 'at risk of illness', not only through behavioural or social characteristics but increasingly through the identification of biological makers. This highlights the blurry frontier between risk factors for a disease and the disease itself. Consequently, there is a temporal and spatial fracturing of the diagnostic category (and the diagnostic process) that

contributes to the collapsing of the undiagnosed and diagnosed dualism. Diagnostic labels now go beyond disease itself to include risk factors for disease. In this case, the categories may be overshadowed by diagnostic predictors. At the same time this gives rise to a new source of the social identity, namely a pre-disease (risk of disease) status.

Genomic technologies offer further opportunities to blur the distinction between risk and disease as has been discussed elsewhere (Finkler, Skrzynia, & Evans, 2003), and, it should be said, between category and process. As Patrice Bourret and his colleagues in this volume bring to our attention, genomic information brings a prognostic and predictive dimension to the picture of breast cancer (Bourret et al., 2011). Molecular diagnosis becomes a different form of diagnosis: one which takes diagnosis out of the doctor's hands and into the laboratory, where a cellular configuration replaces the clinical judgement as confirmatory. The locus of the clinical diagnostic process can be realigned by post-genomic technologies. Bourret et al focus on more than the laboratory-clinical interface, but on the wider laboratory-clinical-commercial triad present in cancer genomics. Gene-expressing profiling tests are a point at which commercial, clinical, regulatory, and patient interests collide. Bourret and his colleagues' paper on post-genomic medicine provides an insight into the shifting nature of diagnosis within the landscape of molecular technologies. The doctor's judgement, one might speculate, is being superseded by the 'truth' of the laboratory finding. Certainly, it has been shown elsewhere that working in consumerist environments doctors are nervous about making decisions rooted in judgement and experience. They feel bound to check out their diagnoses with confirmatory tests (Nettleton, Burrows, & Watt, 2008). However, when test results and clinical observations are not compatible, the diagnostician does not simply disregard her or his own assessment but undertakes repair work, at which point we begin to see the interface between diagnosis as a category and a process which we turn to in more detail below.

Disease risk is also critical to contemporary pharmaceutical marketing and has come to form an important component in the social framing of diagnostic categories. Recruiting the public to scrutinise their minds and bodies is of course a particular powerful marketing technique (Moynihan et al., 2002), one that has long been deployed by pharmaceutical companies and is evidenced in direct to consumer advertising. Mary Ebeling's paper in this Issue, taking the example of premenstrual dysphoric disorder (PMDD), reviews these practices through an examination of a number of symptom check lists placed on websites (Ebeling, 2011). These are a tidy means to encourage self-diagnosis and disease awareness, and of course a good example of the commodification of illness and disease and the co-construction of the medical consumer. Responsibility is individualised under the guise of empowerment. Her paper also serves as an example of the way medical knowledge has dispersed and is no longer contained within the traditional domains of institutionalised medicine but has escaped and is escaped throughout the virtual landscapes (Nettleton, 2004).

Pharmaceutical and biotechnology industries are primary movers of contemporary medicalisation. This thesis is explored by Kristin Barker in her paper on fibromyalgia, a pain disorder that is, as she notes, 'a paradigmatic contested illness' (Barker, 2011). In 2007, the USA the Food Drug Administration (FDA) approved the branded name Lyrica as a drug therapy for fibromyalgia and in so doing, not only '[gave] credibility to the notion that fibromyalgia is a discrete biological thing' but also 'what type of biological thing fibromyalgia is'. It is treated as and so confirmed as a neurochemical aberration. Perhaps most powerfully, its basis can be located within the body as the photographic image reproduced in her paper of overactive nerves reveals. The legacy of the

pathological lesion still holds great sway. Her analysis reveals not only lay and professional disputes over the diagnosis, but how the pharmaceutical industry serves to concretise and authenticate the existence of fibromyalgia via what she refers to as 'pharmaceutical determinism.' What is striking about her analysis is the way which the manoeuvres of pharmaceutical companies are mediated by various forms of media and information and communication technologies through advertising campaigns and the forging of alliances between the interests of advocacy groups or commercial enterprises. The salience of gender with women being encouraged to reassess everyday symptoms of life as possible symptoms of fibromyalgia adds to the interest of this reflection.

The social power of diagnostic classification is enacted by the process of diagnosis. We could describe the process of diagnosis as a kind of actualisation; once assigned to individuals, the diagnosis-as-category starts its classificatory work, and exerts its social functions. Given the important consequences that having a diagnosis can confer, the process by which the diagnosis is awarded to the individual warrants scrutiny. Whosoever holds the power to control this process is ascendant wrote Friedson in 1972. Even in our contemporary era, where a greater emphasis is placed on the lay person to play a more active role, the diagnostician in the medical setting remains a key arbiter and thereby still holds significant jurisdictional authority. While the category and process are frequently indistinguishable in practice, their separation offers useful analytic purchase and it is to the work and activity of diagnosis that we now turn.

### Diagnosis as process

The activity of diagnosis is the result of negotiation, multiple investigations, and trial and error. As we have noted above, diagnostic tests may be out of kilter with the observation of clinicians, just as those observations may fail to align with the experience of the individual, or the views of a second clinician. Reading and interpreting the patient's body is a complex business. How practitioners reconcile seemingly incompatible findings is demonstrated elegantly by John Gardner and his colleagues as they follow the clinical pathway of the cardiology patient whose diagnosis is enacted through various clinical and diagnostic settings (Gardner et al., 2011). The intellectual point of departure of their paper is Mol's (2002) STS inspired study of atherosclerosis; they provide an excellent résumé of her book *The Body Multiple*. The diagnostic process reported by Gardner et al. involves multiple players in three locations: a consultation in primary care, an ECG and a consultation with the specialist in the hospital clinic. During the first consultation, the doctor suspects heart disease, and yet during the second consultation results of the ECG indicate the all clear and all seems well with the patient's heart. During the third consultation, the consultant explains away the test results and advises the patient that the ECG is not necessarily a comprehensive arbiter and the patient's clinical profile now suggests he could be at risk from heart disease. And so we see here the power of the 'at risk' discourse that encourages the self-aware, self-managing, self-monitoring patient even in the absence of a technological truth. This paper also highlights the fragile and continuous nature of the diagnostic process. These authors do not so much see disease as socially constructed but enacted through the various clinical and diagnostic practices. The importance of this distinction is that while the former implies the creation of a stable category, the latter alludes to the frailty of assemblages which in turn are contingent to the context, it the clinic, the laboratory, the home and so on.

The diagnostic instrument may become an extension of the diagnostician, as the diagnostic process shifts between the doctor and his or her tools: from the simple to the very complex. Working

within a pragmatist paradigm, Cornelius Shubert's paper treats diagnosing as a 'practical accomplishment' (Schubert, 2011). From this perspective, the technical hardware is not treated as distinct from the practitioner but rather as a form of mediation between the bodies of the patient and the doctor. He illustrates his arguments through the use of two examples. First, he challenges the conventional view that the invention of the stethoscope led to the silencing of the patient in medical work, arguing instead that its use fused 'the bodies of the physician and the patient into a new diagnostic ensemble.' New medical skills in the form of 'a trained ear' that could make sense of what was heard through the stethoscope meant that doctors' and patients' bodies interacted in close physical and intimate ways. His second, contemporary example is modes of ventilation chosen by anaesthetists during operations. He describes how the tactile experience of the rubber, re-inflating ventilation bag by the experienced anaesthetist, informs and shapes their assessment of the patient, dragging them away from the digital read-outs of monitoring systems. Technical mediation is replaced by the kinaesthetics of the soft rubber bag in the physician's hands.

Shubert's paper, like Gardner's, is important, because they both show that diagnostic instruments do not exist independently of practitioners who use them. On the contrary they are embodied, embedded and transformed through their application. Diagnostic instruments alter the relations between doctor and patient as both are drawn into the diagnostic process. Although the tools are used to scrutinise the inner reaches of the patient's body, they do not simply exist as neutral objective arbiters of signs and symptoms. With each new instrument, writes Shubert, a new configuration of contact, kinaesthesia and knowledge takes place, affecting the form diagnostic process will take (see also Maseide, 2011).

Furthermore, knowledge of medicine's object becomes classified within medical sub-disciplines. Michael Halpin explores the intricacies of specialisations in the example of Huntington's Disease, an enigmatic condition which is frequently diagnosed in its early stages as a psychiatric, rather than a neurological disorder (Halpin, 2011). He highlights the tensions and ambiguities which can be present in a diagnosis drawing our attention to the ways in which diagnoses establish jurisdictional boundaries: Who owns the brain? The psychiatrist or the neurologist? Indeed, sociology of diagnosis speaks to the negotiated order of professional boundaries and organisational responses of formal care provision. The diagnostic category does not always fit neatly into professional domains, a problem which is especially pertinent as health care becomes increasingly fragmented and specialised. Doctors who become experts in their own field can soon become ignorant when dealing with areas beyond their specialism and can present difficulties when managing the care of patients with comorbidities.

Learning to diagnose is of course central to becoming a doctor as Atkinson (1995) demonstrated in his classic ethnography of medical students that revealed how doctor are coached into constructing and reconstructing medical realities. Building on this work, Gethin Rees explores training in forensic diagnosis (Rees, 2011). Here medical training is subordinated to juridical factors as is evident in the examination of cases of alleged rape. In this setting, diagnosticians must demonstrate, not so much what they believe to be medically correct, rather what they believe they can validate to a standard that will withstand the examination of a court of law. Diagnosis may be initially medical, but ultimately, it only counts when it survives the court challenge, thus providing an important demonstration of the way in which institutions other than medicine (in this case the law) can act to shape diagnosis.

Turning to medical training in hospital settings Nancy Davenport's article on medical residents' use of narrative templates

reveals how story telling is at the heart of the diagnostic process in this context (Davenport, 2011). Determining what narrative template will complete the patient story is how they extirpate the nugget of the clinical case. They ‘build the story of this patient-with-disease on the backs of the stories they already know’ to arrive at the diagnostic decision. However, their story telling is contingent, and often facile, capturing the most obvious, but not necessarily the most cogent, narrative.

We finally turn to the matter of consequence as we finish our description of papers in this Special Issue. In this section, we have placed the articles which describe the impact of the diagnosis, once awarded, on individual and on groups.

## Consequence

The final set of papers in this Special Issue considers how diagnosis—as well as the way in which it is organised, structured and delivered—results in consequences for those to whom the diagnosis applies. These papers focus on the consequences for patients and carers. They also reveal the contrasting implications of the absence and conversely, presence, of contested diagnoses. There are paradoxes inherent in medical diagnosis. A diagnosis can vindicate and blame, can legitimise or stigmatise, can facilitate access to resources just as it can restrict opportunities. A diagnosis can be welcomed or eschewed.

Catherine Trundle presents an ethnography of nuclear test veterans from the south Pacific ocean (Trundle, 2011). Exposed to high dose radiation in a non-combat setting, many of these veterans seek to establish political culpability for their current illnesses. The pursuit of a biomedical explanation for their ailments is inseparable from the acknowledgement of liability by the armed services. Without a diagnosis, state recognition and ultimately compensation are impossible. Diagnosis however, is politically charged, because it implies culpability. In the fraught debates over whether their ailments are the result of their exposure to overwhelming amounts of radiation, test veterans are denied the reality of suffering as they, and their families, experience it.

By contrast, other diagnoses can be (albeit ambivalently) welcomed. Iina Singh’s study reports the accounts of children with a diagnosis of Attention Deficit Hyperactive Disorder (ADHD) (Singh, 2011). She demonstrates how children negotiate this label, consciously inhabiting it, exploiting it, but also fearing it (what does the future hold?). There is a delicate interplay, she writes between self-control, stigma and agency, but perhaps as well, legitimization and de-victimization (ADHD adoption/exploitation). The disorder resides not in the child or in the environment, but somewhere in the nexus of the two.

How we talk about diagnosis in relation to ourselves or amongst those close to us provides an insight into values, structures and contexts. Once labelled with a particular diagnosis, the individual may develop an identity, or alternatively be identified in differing ways. Numerous discourses are available in Western industrialised countries to speak about the cancer, and in an autobiographical piece Carla Willig describes how these framed her own experience of a cancer diagnosis (Willig, 2011). A strong moral tone infuses these discourses which focus on ‘thinking positively,’ and examining patient lifestyle for self-initiated carcinogenic behaviours such as sunbathing, smoking, and poor diet. They cast the patient as an active agent in the cancer drama with similar responsibility for the outcome. As we discussed earlier in this piece, diagnosis and identity become mutually constitutive but are, as we see here, contingent upon, and given shape by the cultural context.

Rebecca Olsen also explores the reaction to a diagnosis, in this case, carers’ responses to their spouses’ diagnosis of cancer

(Olsen, 2011). She offers a novel conceptual tool. Olsen develops a Durkheimian inspired concept that she calls ‘temporal anomie’, a notion designed to capture the salience of the disruption of time that is experienced when people are diagnosed with cancer. Hitherto, the literatures on the communication of cancer diagnoses have tended to be dominated by notions of hope, coping and denial. In taking a more sociological, rather than a psycho-social approach, and drawing on the sociology of emotions, Olsen demonstrates how carers reassess views of the future by focussing on the present and/or reassessing future expectations. What is striking from the data is the way in which the diagnosis is embedded in the context of the patients’ and carers’ everyday lives.

These findings are congruent with Karen Schaepe’s thesis, which is also based on a study of patients and their family’s accounts of disclosure of cancer diagnosis (Schaepe, 2011). The way they experience the news was found to be related to the nature and quality of their encounters within the health care system prior to disclosure. Confusion, poor quality interactions, misinformation and so on could mean that even in the presence of good news, the disclosure itself could be distressing. It is not individual health workers, the treatments or tests that are distressing but the way in which the medical care is orchestrated that can create difficulties. We are reminded here of Mildred Blaxter’s (2009) autobiographical piece (cited above) in which she concludes that it “is the system within which these hospital doctors worked which created alienation” (p. 776). In terms of the communication itself an important finding was the way in which certain types of phrases seem to endure or stand out from within the disclosure of the diagnosis. Schaepe calls these ‘prognostic phrases,’ and include non-technical terms freighted with hope, such as: ‘very treatable’ or ‘a good kind of cancer’. What is notable is that the disclosure of the diagnosis does not take place at a discrete moment, but rather is part of a series of interactions and encounters with a variety of health care personnel. The diagnosis of cancer is mediated not only by the quality of this one-off social interaction but also by the quality of the preceding pathways through the health care system and subsequent care.

Jurisdiction over a diagnosis can also trouble lay-professional divides in classification structures as is evident in the work of Lindsey Prior and his team, who explore lay accounts of the differentiation between colds and influenza (Prior and Evans, 2011). Their exploration of older people’s descriptions of the difference between influenza and the common cold shows how their views contribute to lay epidemiology and surveillance: albeit not necessarily in line with public health initiatives. While there is a degree of congruence between lay and professionals’ listing of the symptoms, the former tend to emphasise the behavioural correlates of the conditions. The study participants emphasised the way which flu affects the whole body and leaves a person bed-ridden whereas a cold does not. Lay talk about causation places significant weight on adverse effects, resistance and on lifestyle-as-prevention in a way that counters immunisation campaigns, and demonstrates the continuing importance, for this cohort at least, of beliefs that circulate amongst family and friends. Lay epidemiology explains causation in ways that it behoves public health to consider. We see again how diagnostic categories are context bound and malleable; there is no simple category that becomes a given and simply adhered to even though professionals and lay people ‘share a similar overarching medical landscape’ as Olafsdottir and Pescosolido (this volume) would put it. Like other studies of lay views on illness causation and symptoms Prior and Evans rely on qualitative interviews, however the data are analysed using novel text-mining methods that calculate the likelihood of co-occurring concepts thereby giving more than impressionistic interpretation of views.

Sigrun Olafsdottir and Bernice Pescosolido also focussed on lay understandings of disease, and rather unusually for this topic, relied on quantitative survey methods to investigate how lay people from eight different countries recognised and labelled mental illness (Olafsdottir & Pescosolido, 2011). Study participants were asked to respond to a vignette written to capture the symptoms of schizophrenia. Cross-nationally, it would appear that people are able to identify the case as mental illness, but less likely to label it as schizophrenia. Indeed an advantage of their large data set is that it permits insight into cross-national differences that beg further analysis. It also reminds how very little we know about cross-national variations in the interpretation and construction of diagnostic categories. Such comparative work between countries and cultures should be an important strand of a sociology of diagnosis as it progresses. Comparisons too with complementary and alternative practices merit attention.

### Towards a sociology of diagnosis: issues and agendas

What this collection of articles presents is, we hope, a valuable insight about the social framing and consequences of diagnosis within Western medicine. But it is far from the last word. The assembly of these papers punctuates additional layers and complexities of this topic. If we see diagnosis as medicine's classification tool, and if the power of classification is, as David Armstrong writes in this volume to both define and limit analytic possibilities then we can hardly group the contents unself-consciously. How we present things as similar to one another, or conversely different, depends on the mental representations that we, as editors, have made of the subject (see Zerubavel, 1991). Our power to classify the subject constructs the categories as natural, rather than as the privileged vision of the individuals who happen to have, in this instance, editorial control. However, Thomas Arnold, in 1839, reflected that "We are not to suppose that there are only a certain number of divisions in any subject, and that unless we follow these, we shall divide it wrongly and unsuccessfully: on the contrary every subject is as it were all joints, it will divide wherever we choose to strike it, and therefore according to our particular object at different times we shall see fit to divide it very differently" (p. 4–5). We chose to divide the contents of this issue around a model about which one of us (AJ) has previously written: the social framing of diagnostic categories, the process of diagnosis, and the consequences of diagnosis (Jutel, 2011b). We have been able to coax the papers in this Special Issue into these fields, bolstering our model, and by so doing undoubtedly repudiating others.

Diagnosis as category as process and the consequences of both can form the object of sociological scrutiny. Working with diagnosis as an object, we might examine impact and consequences of a diagnosis for patients, practitioners and societies. This might involve examining how the designation can have consequences for a person's life, how it is communicated in the clinic, how disease categories can come to carry a symbolic significance and so on. But we might also usefully deploy diagnosis as an analytic tool which can prize open some of the central problematics of the experience of illness and the practice of health care. Diagnosis serves thus as an analytic device that can explore the way classifications and labels are constructed, framed and enacted. They can be deconstructed to reveal their social content (readers who haven't already should take a look at Keith Wailoo's (1997) fascinating history of blood disorders to see social shifts in diagnoses across time and place. What would, he asks, a 19th century scientist make of the human immunodeficiency virus? Certainly something very different from how scientists see it today).

Perhaps suitably, we return to comment on Phil Brown's work to draw our editorial to a close (Brown et al., 2011). With his colleagues Mercedes Lyson and Tania Jenkins, he brings the conversation full circle. In 1995, Brown named the sociology of diagnosis. Today, in the commentary in this Special Issue, he along with his colleagues, proposes an integrated perspective of diagnosis which connects illness, diagnosis-as-category and diagnosis-as-process to numerous social, economic and political factors. This approach de-constructs the diagnostic category to connect illness and disease with a range of extra-medical factors influencing health and illness.

What Brown and colleagues suggest is that no medical diagnosis can be delivered "baggage free" (Brown et al., 2011) In the case of obesity amongst a group native Americans (from the Mowhawk Nation Akwesasne Reservation), the example they explore in their contribution, the disease (if it is indeed one), emerges from a context of post-colonisation and globalisation in which commercial and colonising factors present the social group with more physical affronts than their waistlines or endocrine systems can handle. Suppression of native habitats, cultural practices and eating patterns; exposure to toxic wastes; Big Food and Big Farm lobbies all converge to produce increased disease frequencies amongst Indigenous peoples (similar observations could be made in the Pacific Islands). Even without refuting the materiality of adiposity or hyperglycaemia, we can see the limitation of conceiving of these diseases in the simple pathophysiological terms. Like "excited delirium" (the death in custody of an agitated inmate or patient held under restraint), it is an example of how a social locus of causation may be shifted onto pathophysiology (Paquette, 2003), obliterating as it does, any external culpability.

The sociologist should see diagnosis as a kind of focal point where numerous interests, anxieties, values, knowledges, practices and other factors merge and converge. It is also a point from which emerges an increasingly widening set of social consequences. These go well beyond the individual stigma, entitlement or identity which comes from being diagnosed. It also imposes collective labelling: the obese Pacific Islander or diabetic Native American becomes a global liability, an undeserving citizen (or nation). The cultural group is tarred by global indignation as they are ranked and coded by fatness (World Health Organisation, 2009). And, its influence is felt not only by the diagnosee, but by the diagnostician as well, a consideration that hitherto has received little attention. Indeed, this issue is one of a number of matters that we think should drive the sociology of diagnosis (there are of course many more).

Whilst this Special Issue has discussed the consequences of diagnosis on the patient, it has not discussed the social consequences of diagnosing on the diagnostician. There is an important conversation to have about how diagnoses, and indeed specific diagnostic categories, impact those who apply the labels. The health professional experiences a different set of vulnerabilities to the lay person, but nonetheless is exposed to increasing pressure to diagnose in particular ways by administrative, commercial, professional, economic and patient forces.

How does the study of one diagnosis complement, contradict or modify studies of other diagnoses? Identifying how similar (or contrasting) forces are at play in a range of diagnoses provides a more detailed canvas against which to understand disease and its impact. The importance of this perspective is easily revealed by the detailed historical and political work undertaken around contested and psychiatric diagnoses. The same analytic tools can be used to explore tangible, physical disorders (Wailoo's (1997) work on haematological diseases, or Aronowitz (1991) on Lyme disease, for example) and to elucidate social processes of classification. Stepping back to see a diagnosis in the plurality of diagnoses enables the identification of whose interests are served, and alternatively,

whose are disappointed, when a given diagnosis is agreed upon: an important agenda item for the sociology of diagnosis.

Similarly, clarifying what social forces converge into and emerge out of any diagnostic label should be a high priority for the field. This includes exploring what institutions, other than medical are involved in disease causation and disease labelling. This is part of what Brown et al admonish us to do in the pages of this issue, and is demonstrated by many more papers herein. However, there is more to be done. We have not explored the role of insurance, candidates for high public office, educational institutions or state administration in the creation, maintenance or denial of particular diagnoses.

It is worthwhile to consider how diagnosis creates and/or challenge territorial boundaries: between professions, within medicine, and between lay and professional. Earlier in this paper we asked: 'what is a diagnosis?' And, our answer focussed on Western medicine's diagnoses, their construction, enactment and impact. Clearly the codification of official diagnoses is an important strand of research for sociologists. However, it is also clear that diagnosis does not operate within a circumscribed boundary as any consideration of lay, unofficial, alternative and non-biomedical classifications of disease and illness would attest. The contemplation of diagnosis in non-Western medicine settings as well as in complementary and alternative therapies is an essential direction for scholars of diagnosis. The topic of lay epidemiology has been considered in more than one paper in this collection, but is particularly salient in minority, marginalised and indigenous cultures, where divergent disease explanations often undermine health outcomes for the lay person.

We can pursue a sociology of diagnosis at the macro, mezzo and micro level. For example, diagnosis is implicated in the play of global politics, economic and commercial agendas when resources and multinational corporations work with stakeholders in health care to concretise diseases and conditions. Organisationally diagnoses are shaped by and provide a means for casting light on the interplay between medical care providers and professional territories. In terms of social interactions, the application of diagnoses by the practitioner in the clinic reveals much about the nature of professional patient relations and how the wider societal contexts permeate the diagnostic process.

There are many more threads like these which should interest the sociologist of diagnosis, and which we expect will become the focus of the field. What ultimately should drive a sociology of diagnosis is the goal of defining how diagnosis fits into the wider structures of society and how these wider structures implicate diagnostic categories, processes and consequences. Diagnosis can provide a means for understanding forms of knowledge, social structures, relationships and actions. It is central to medical and health knowledge and as such provides a not only a category and process but a neat analytic tool that serves as a prism that reflects and casts light on a multiplicity of issues in health, illness and medicine.

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Annemarie Jutel\*

Victoria University of Wellington, New Zealand

Sarah Nettleton

University of York, United Kingdom

\* Corresponding author. Tel.: +64 21 513 305.  
E-mail address: [annemarie.jutel@vuw.ac.nz](mailto:annemarie.jutel@vuw.ac.nz)

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