Risk, uncertainty and knowledge: The case of health care

Abstract
While the development of modern medicine is associated with both increase in scientific knowledge and improved outcomes in health care it is also associated with increased uncertainty as expert and lay knowledge bases have diverged and separated. The development of a principal-agent relationship in the late 19th and early 20th century in which medical practitioners used their specialist knowledge to make decisions for and on behalf of their patients provided one way of managing this uncertainty. However the development of a less deferential and more consumerist culture associated with medical scandals in which trust has been betrayed have led to increased regulation of medical practice, especially the development of national standards based on encoded knowledge. Even if governments can overcome the practical problems of using such systems to structure decision-making, because these systems fail to address the personal and emotional components of trust they are likely to create a ‘trust deficit’, a system that may work better but is trusted less.

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Knowledge in late modern society
Modern science has created a sophisticated body of knowledge of the causes and most effective ways of treating diseases. For example research programmes such as the human genome programme have deciphered the human genetic code facilitating the identification of genetic errors associated with breast and cervical cancer (Human Genome Project Information, n.d.), and the development of disease specific research networks (Department of Health, 2006a) means that new treatment regimes can be rapidly tested enhancing treatment outcomes. Such developments have had clear measurable benefits. In 1970 approximately 50 per cent of women diagnosed with breast cancer survived 5 years currently 80 per cent survive (Lyall, 2006, p. 1).

However such objective population-wide improvement in health and wellbeing is not reflected in individual subjective assessments of health and security. Indeed as Wilkinson (2001) has noted anxiety appears to have increased in contemporary societies creating the paradox of anxious or timid prosperity (Taylor-Gooby, 2000).

Anxiety and uncertainty are especially associated with illness and disease whether this is the threat of pandemic disease such as SARS or the more personal experience of chronic illness. For example Locker notes in many chronic conditions uncertainty often starts ‘when the individual first notices
that something is wrong and may continue throughout the entire course of the illness’ (Locker, 2003, p. 87).

Science is seen as a source of knowledge which can reduce uncertainty but paradoxically it may contribute to increased uncertainty in a number of ways. While science and the professions that applied science to practical issues such as medicine commanded considerable public support in the early 20th century, events of the late 20th century have tended to undermine this authority. For example Moran (2003) notes the ways in which in the UK the BSE Disaster and subsequent Inquiry exposed the limitations of scientific knowledge and ‘was part of a larger crisis of confidence in the food safety regime that produced periodic ‘food scares’ (2003, p. 149). As the Inquiry into BSE examined the ways in which the government handled a particular hazard which was ‘a known hazard to cattle and an unknown hazard to humans’ (BSE Inquiry, 2000, p.1). The Inquiry noted that The Ministry of Agriculture, Food and Fisheries relied heavily on experts, seeking and following ‘the advice of independent scientific experts’. While the Inquiry did not feel that the government sought to mislead the public, its misplaced attempts to reassure the public backfired undermining public confidence:

The Government did not lie to the public about BSE. It believed that the risks posed by BSE to humans were remote. The Government was preoccupied with preventing an alarmist over-reaction to BSE because it believed that the risk was remote. It is now clear that this campaign of reassurance was a mistake. When on 20 March 1996 the Government announced that BSE had probably been transmitted to humans, the public felt that they had been betrayed. Confidence in government pronouncements about risk was a further casualty of BSE (The BSE Inquiry, 2000, p. 1).

While disasters such as BSE can emphasise the limitations of current knowledge and undermine confidence, there are other more fundamental problems in applying and using knowledge in contemporary societies. In premodern society knowledge systems, especially those used to explain and manage threats to collective and individuals wellbeing such as illness, tend to incorporate religious and supernatural system. Such systems provide both provide an explanation of past events, i.e. why a particular individual died, and also provide a means of predicting the future and avoiding hazards. For example Evans-Pritchard (1976) in his classic study of a traditional society in Southern Sudan demonstrated the ways in which the Azande could explain all misfortune, often combining empirical evidence, e.g. termites eating through the wood support of granary or the skill of a particular potter, with religious ideas such as witchcraft or sorcery to explain why a particular individuals was sitting under a granary when it collapsed or a particular batch of pots misfired. They used the same knowledge to predict the future.

Such systems explain everything (and therefore to modern minds nothing) and have no space for uncertainty. In contrast the modern scientific
theories and knowledge that have come to replace such belief systems are essentially limited. For Beck this uncertainty underpins contemporary concerns with risk:

Risk society begins where tradition ends, when, in all spheres of life, we can no longer take traditional certainties for granted. The less we rely on traditional securities, the more risks we have to negotiate. The more risks, the more decisions and choices we have to make (1998, p. 10).

While science has considerable enhanced knowledge of the natural world, it does not necessarily provide the type of information which individuals can use to manage their lives. For example epidemiology which is based on a mapping of the incident of diseases in defined circumstances, e.g. time and space (see C.1) provides information on the factors associated with the development of disease. For example since publication of the first findings in 1950 that smoking was linked to lung cancer (Doll and Hill, 1950 and Wynder and Graham, 1950), the consensus is that about half of regular cigarette smokers will be killed by the habit (Peto, 1994). However an individual smoker can’t know for sure which group they are in. This uncertainty does, of course, open up a gap which the individual can exploit to disregard information that would suggest an undesired change in behaviour whether this is stopping smoking (Sutton, 1999) or changing diet to reduce the risk or heart disease (Ruston and Clayton, 2002).

The growth and increasing fragmentation of scientific knowledge into specialist disciplines creates an additional area of uncertainty. As experts become increasingly knowledgeable and specialised so the gap between their knowledge and that of non-experts increases. Thus while consultations between Azande experts and their clients are based on the assumption that they share the same knowledge and beliefs, equivalent consultations in contemporary society are based on the premise that the parties do not share the same knowledge. A crucial part of the interaction is ‘communicating’ or translating between different bodies of knowledge. Morgan (2003) suggests that experts such as doctors can either seek to impose their knowledge by focussing ‘on objective descriptions of symptoms… within a reductionist biomedical model’ or seek to translate and adjust to ‘patients’ own illness framework’ (p. 55). Nettleton (1995) also notes the ways in which scientific knowledge is challenged by other forms of knowledge such as that derived from personal experience and the ways in which this undermines experts own confidence in such knowledge (p. 33).

Thus the growth of knowledge undoubtedly creates social benefits in modern society, for example a healthier population living longer, but such knowledge does not reduce uncertainty, indeed for a variety of reasons, it actually increases it. In the next section we consider ways in which such uncertainty may be managed.

Response to uncertainty and risk in contemporary society
Individual responses

There are in contemporary societies a variety of ways of responding to the uncertainties of scientific knowledge. One response to uncertainty is to accept the world as essentially unknowable and therefore uncontrollable and therefore to be relatively passive, dealing with problems of an immediate or daily basis and avoiding longer term planning. Wallman (2001) in a study of migrant sex workers in Europe identifies the range of dangers these face. Sex workers tend to respond to these dangers in an ad hoc and pragmatic ways as the source of the threat is beyond understanding and control. From the point of view of the sex workers these threats are ‘virtual risks’ or ‘dangers whose magnitude...scientists do not know or cannot agree about’ (p. 78). Only when sex workers accept that there is relevant knowledge and expertise do such dangers become manageable risk which can be anticipated and planned for (pp. 78-82).

Passivity is a response to overwhelming uncertainty but does not necessarily imply inaction, rather it implies responding to events and concentrating on the present rather than seeking to predict and control events and the future. In his study of mental health service users, Ryan (2000) identified three distinct approaches to risk management: no risk strategy, passive and proactive. The difference between no risk strategy and passive strategy was one of degree. Both were characterised by an emphasis on the present and an apparent acceptance that dangers and therefore the future were essentially uncontrollable. In the no strategy approach there was an apparent failure to acknowledge the dangers whereas in the passive approach the dangers were addressed as they arose and were recognised and dealt with by adopting the line of least resistance. In our study of stroke survivors we (Alaszewski, Alaszewski and Potter, 2006) found that immediately following their stroke survivors were faced not only with the uncertainties of everyday life and how and in what ways they would recover but also the unquantifiable possibility that they would have another stroke thus they could avoided the uncontrollable future by living and acting day-by day and dealing with dangers on as they arose. This response is very much a personal choice and decision which may conflict with dominant cultural values.

While the passive strategy is a response to uncertainty and threat, Douglas notes that such a response may represent a cultural choice, i.e. a deliberate decision to reject scientific knowledge. In her analysis of a study in Brittany of the ways in which individuals threatened by HIV treated expert advice and knowledge she noted that:

The most baffling thing about the pattern is that a large number of the community at risk are impervious to information; either they know unshakeably that they are immune, or recognizing that death is normal they draw the conclusion that to live trying to avoid it is abhorrent (Douglas, 1992, p. 111).

There are alternative responses to the uncertainties inherent within scientific knowledge. Individuals can look to other types of knowledge.
Such knowledge can be highly personal and individual. Thus individuals can develop their own personal theories about nature and causes of dangers from practical experience and use such personal knowledge to predict and understand. One form of this knowledge is simple heuristics (Hutchinson and Gigerenzer, 2005), i.e. the common-sense which individuals use to guide their judgement in complex uncertain conditions. For example a commonly used heuristic is the more expensive something is, bottle of wine, drug, or treatment, the better it is and this ‘knowledge’ will shape predictions and decisions (Johnson, 1993). In the study of health and illness the term ‘popular epidemiology’ has been used to refer to knowledge which individuals develop through their everyday experiences of health, illness and related matters (Brown ,1987; Williams and Poppay, 1994). Wall and his colleagues (2004) used this approach to examine the ways in which people make judgements about regulatory agencies. They found that participants in their study used simple heuristics such as ‘safety vs. profit’, combined with inferences about the name of an agency to judge whether they felt the agency was likely to act in the public interest:

Participants do not deploy a formal logic in assessing whether or not they trust risk regulators. Rather, people use what information is necessary to ‘get on’ in the world, something that we may term ‘practical knowledge’. Nor do people necessarily search for consistency in information: rather they negotiate and accept ambiguity. In the context of everyday life people frequently deploy heuristics to make sense of the world around them. Indeed, the data seem to suggest that stated trust/distrust in institutions is a negotiated combination of weakly formulated sentiments – with distinctive affective components - alongside direct or mediated knowledge. People will reason by analogy and use such lay heuristics in the absence of firm (or publicly validated) knowledge (Wall et al, 2004, p. 146).

Such use of simple heuristics and reasoning by analogy can be seen as the use of embrained or tacit knowledge (Lam, 2000) which individuals build up through experience and trial and error. It can be expressed as ‘common sense’ (Schutz, 1971, p. 6) or intuition (Benner, 1984) and forms the basis of ‘practical reasoning’.

Collective responses

While lay knowledge may for the basis of individual and personal judgements, it can also form the basis of social movements that challenge scientific knowledge. Brown (1995) has analysed the ways in which popular epidemiology has developed and been used by the toxic waste movement in the USA to challenge the expert-based systems used by government and corporations to justify systems of managing toxic waste. The toxic waste movement tends to be a localised response to specific hazards and evidence of harm focussing on the unfair distribution of harm. For example in Woburn, Massachusetts local citizens identified a cancer cluster stimulating a scientific study and then took legal action against the companies they felt had caused the harm (Brown, 1995, pp. 93). While the
activist are willing to use scientific methods to develop knowledge they use it to challenge accepted knowledge and to redefine the waste management problem emphasising the precautionary principle:

Minority activists have made much of empirical research, but not usually epidemiological studies. Instead, they have focussed on demonstrating the geographical distribution of environmental hazards on the basis of race and class (Brown, 1995, p. 107).

Alternative medicine can be seen as a social movement which focuses directly on the limitations and uncertainty of medical science. As Cant and Sharma (1999) point out in their overview use of alternative medicine is extensive, at least one fifth of the population use some form over a year. While individuals use alternative medicine for a variety of reasons it provides an alternative form of knowledge which is grounded in social networks. Cant and Sharma argue that the limitations of scientific knowledge underpin the survival and growth of alternative practitioners:

Where the expansion of scientific knowledge promised progress and predictability… instead there have been unforeseen and unwelcome consequences associated with the expansion of knowledge…(1999, p. 25).

Killigrew (2002) in a study of traditional Chinese medicine in the UK notes the ways in which it operates as a social movement. Most individuals are casual users and mix Chinese medicine with other forms of treatment. Some individual ‘recognise’ the benefits and become regular users and develop relationship with practitioners. Some of these regular users then train and themselves become practitioners and the knowledge and practice of Chinese medicine becomes an important part of their life. They are fully integrated in the movement.

Social movements tend to generate embedded knowledge (Lam, 2000), i.e. knowledge which is shared between the members of the movement and forms part of and is evident in common practices. It is embedded in custom and practice.

Official responses

Individual and groups can seek alternative sources of knowledge to overcome the limitations of scientific knowledge, however there is an officially sanctioned alternative, the use of an agency relationship. One way in which an individual can manage risk and uncertainty is to rely on agents with appropriate knowledge, who make decisions on behalf of their behalf given ‘the potentially high costs associated with the actual process of decision-making and those associated with making the wrong decision (i.e. anxiety costs)’ (McGuire, Henderson and Mooney, 1988, p. 186). This is the ‘officially’ sanctioned approach in state health care systems, such as the UK’s NHS, and insurance systems in Europe and the USA with expert
professionals acting as agents for their patients. However such an approach can only work effectively when there is trust, i.e. the individual believes that the agent will act in good faith. As Boon and Holmes note trust can be defined as the as “confident expectations about another’s motives with respect to oneself in situations entailing risk” (Boon and Holmes, 1991, p. 194) and therefore trust is an important resource and mechanism for dealing with ignorance and uncertainty (Giddens, 1991, p. 244).

The UK NHS which was established in 1948 centred on the doctor patient relationship. The aim was to give doctors the resources and autonomy to identify and meet all patient need for physical and mental health care. Thus the government entrusted the profession with the provision of ‘comprehensive medical care and treatment’ (Webster, 1988, p. 112) and accorded the profession its ‘traditional freedom and dignity’ and expected the population to trust their doctors. While the doctor/patient relationship and the agency structure which underpins it remains central to the delivery of health, it has been modified and developed. The expectations that patients will have complete and unqualified trust has been modified initially by the development of informed consent and more recently by clinical governance so that trust has become problematised and current government effort is directed at maintaining or restoring trust and it is to these developments we turn in the next section.

Trust, informed consent and clinical governance

The development of informed consent is a relatively recent phenomenon in medicine. In the early 19th century there was an ethical debate within health care in which Percival in a text on medical ethics first published in 1803 (Leake, 1927) argued that it would be ‘gross and unfeeling wrong to reveal the truth’ to a patient if such truth was harmful. His friend the Rev Thomas Gisborne dissented arguing in 1794 that: ‘The physician… is invariably bound never to represent uncertainty or danger as less than he actually believes it to be’. In some areas of medical care, there was a consensus that fully revealing the diagnosis and prognosis would harm the patient either by undermining their confidence or by exposing them to stigma. For example Holland (2002) notes that before the 1970s most patients with cancer were not informed of their diagnosis (p. 206). In the 1970s there was a ‘paradigm shift’ (ACOG, 2004, p. 9) from a ‘protective’ approach to one in which the patient has the right to enough information to make an informed decision and give informed consent to treatment. The doctor must effectively communicate all medically relevant knowledge including the risks and uncertainties. The American College of Obstetricians and Gynecologists state that the patient should be:

given adequate information about her diagnosis, prognosis, and alternative treatment choices, including the option of no treatment (2004, p. 10).
The development of informed consent involves a major shift in medical practice and medical role. The doctor can no longer make decisions on behalf of the patient, i.e. act as agent, but becomes an adviser or counsellor who provides knowledge about both the benefits and risks of treatment so that the patient can make an informed choice. Thus the doctor has a duty to effectively communicate information on risks.

This change in medical practice and medical roles was the product of a combination of factors including the increased involvement of the law in medical cases, a decline in deference and the rise of consumerism in post-industrial democracies medical scandals. Dissatisfied patients have always had recourse to the law. For example in 18th Century England a patient sued two doctors who had rebroken and reset his fractured leg without his consent (Slater v Baker and Stapleton, K.B. 1767, cited in Jester, 1998, p. 1). In the 20th century informed consent became the basis of legal judgements. In the USA, Justice Cardozo presided over a case in which a woman had consented to an abdominal examination but not an operation under anaesthetic and during the operation the doctor had found and removed a tumour. In a landmark decision the Judge found in the patient’s favour ruling ‘that an individual had the right of bodily self-determination’ (Schoendorff v Society of New York Hospital, N.Y. 1914, cited in Jester, 1998, p. 1).

The decline in deference post-industrial societies appears to be a long-term trend which sociologists and social historians have noted in a variety of areas. For example Goldthorpe and his colleagues (1968) in their study of manual workers in Luton in the 1960s noted the ways in which traditional acceptance and support of institutions such as trade unions and political parties had replaced both more instrumental attitudes.

In the domain of healthcare, Blaxter (1982) studied the attitudes of three generations of working class women in a town in Scotland to health and health care. She found that women born after the formation of the NHS were less deferential, they were less willing to tolerate the symptoms of illness and had higher expectations of health care.

With the decline of deference users of the health care are increasingly seen as ‘active’ consumers rather than ‘passive’ patients. In the UK the development of the consumer movement in the 1970s provided a stimulus for this shift. The consumer association and its publication Which? initially focussed on providing the public with information on commercial services and goods but expanded to include public services, especially health which now forms one of the 10 key topic areas on its campaign website (Which? 2006). The government endorsed this approach with the publication in 1991 of the Patient’s Charter that outline patients rights and the standards of service which they could expect to receive.

Although the government formally abolished the Charter in 2001, the consumerist impulse underpinning the Patient’s Charter found expression in a number of new policy initiatives, especially patient choice and the expert patient programme. From the start of 2006 the Department of
Health has directed that all patients should have the choice of four or more providers when they are referred for a plan admission. Central to the new system is the provision of information about hospitals which ‘gives people the opportunity to directly share their experiences and generate user ratings of the services they have received’ (Department of Health, 2006b, p. 8).

The Expert Patient programme is a lay led self-management programme in which patients with chronic illness are taught to be effective users and consumers of health care. They are trained in five core self-management skills: problem solving; decision making, resource utilisation; developing effective partnerships with healthcare providers; and taking action (Department of Health, Chief Medical Officer, 2006). The use of expert in the title of the programme indicates that is designed to restructure the relationship between users and providers of health care.

Medical scandals have often been decisive in changing perceptions of the nature of medicine, especially of medical research and knowledge. In 1946, 23 Nazi doctors and administrator were brought before the Nuremberg War Tribunal for undertaking medical experiments which lead to extreme suffering and death of inmates in concentration and prisoner of war camps. The basic principles used by the tribunal to judge these cases were codified in the 1947 Nuremberg code based on the principle of informed voluntary consent and the minimisation of risk and harm to participants (Lifton, 1987).

Medical scandals in the UK, particularly at Royal Liverpool Children’s Hospital and the Bristol Royal Infirmary, have also contributed to changing conceptions of doctor/patient relationship and have provided a pretext for government to increase the regulation of medical practice. In 1999 the government established a public inquiry into treatment of dead children’s bodies at Alder Hey Hospital. The Inquiry found a ‘long-standing widespread practice of organ retention without consent’ (The Royal Liverpool Children’s Inquiry, 2001, p. 444). The Inquiry felt that these practices were unacceptable and reflected an outdated approach to medical ethics and practice that should be consigned ‘to the annals of history’ (p. 445):

Their [the medical profession] approach has been paternalistic in the belief that parents or relatives would not wish to know about the retention of organs and the use to which they were put... In the current climate of frankness and openness it should no longer be possible for organs to be retained without the knowledge or consent of the parents (The Royal Liverpool Children’s Inquiry, 2001, p. 4).

The policy response focused mainly on the regulation of medical and other health research with the development of research ethics and governance framework.

The Bristol Royal Infirmary Inquiry (2001) examined the services provided the paediatric cardiac surgical team at Bristol Royal Infirmary between 1984 and 1995. The Inquiry found that the service was so poor that it
exposed children under the age of one to an unacceptable level of risk or ‘beyond those ordinarily to be expected in the time and context’ (p. 131) and that estimated that between 1991 and 1995 30 and 35 children died who would not if the quality of services at Bristol had been comparable to that of other regional centres (p. 4). As at Alder Hey there was a problem of informed consent, at Bristol parents were not aware of the risks to which their children were being exposed.

The Inquiry found that a club culture had developed at the hospital in which a core group of managers disregarded information and withheld held it not only from parents but also from other professionals, managers and the public:

**Openness:** Bristol was awash with data. There was enough information from the late 1980s onwards to cause questions about mortality rates to be raised both in Bristol and elsewhere had the mindset to do so existed. Little, if any, of this information was available to the parents or to the public. Such information as was given to parents was often partial, confusing and unclear. For the future, there must be openness about clinical performance. Patients should be able to gain access to information about the relative performance of a hospital, or a particular service or consultant unit (The Bristol Royal Infirmary Inquiry, 2001, Synopsis, para 18).

The Inquiry drew on and stimulated contemporary government thinking linking enhanced medical regulation and clinical governance, i.e. enhanced accountability for medical decision-making. These changes are designed to enhance public confidence in health care through a process of quality assurance which linked openness to self and external regulation:

Clinical governance will be the process by which each part of the NHS quality-assures its clinical decisions… Professional self-regulation provides clinicians with the opportunity to help set standards. People need to be confident that the regulatory bodies will exercise rigorous self-regulation over the standard and conduct of health professionals and will act promptly and openly when things go wrong (NHS Executive, 1999, pp. 2-3, emphasis added)

This new approach to regulation is based on a critique of the ways in which knowledge is used in the NHS. For example the Bristol Inquiry identified a ‘club culture’ (2001, Synopsis, para 8) in the hospital that insulated internal practices from external scrutiny based on national standards. Thus the new system of regulation is designed to replace local knowledge based either on group custom and practice or personal intuition with evidence-based or scientifically grounded practice. Thus in the ‘New’ NHS national systems for encoding knowledge in guidelines and national frameworks provide the basis for the regulation and scrutiny of the delivery of health care.

While the NHS and related research programmes are designed to provide the basic knowledge or evidence, a variety of Institutions, which are supported by the Department of health, such as the Cochrane
Collaboration and National Institute for Health and Clinical Excellence (NICE) summarise and codify this evidence. The Cochrane Collaboration (2006) sees itself as ‘a reliable source of evidence in health care’ while NICE emphasises its role as:

an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health… [including] guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS (NICE, 2006).

This codified knowledge provides the framework of clinical decision-making. Doctors are expected to use it and managers are expected to check that it is being used. The main source of evidence for compliance with national standards is the outcome of clinical practice. The 1997 White Paper sees outcome measurement as the basis of the relationship between the NHS and its users asserting that the NHS ‘will place greater emphasis on the outcomes of treatment and care. It will focus on things that really matter (DoH, 1997, p. 66). These outcome measures will be used to identify potentially dangerous practitioners should be rapidly identified from the evidence of the outcome of their practice and action taken when necessary to minimise harm.

In the final section of this chapter we will consider whether this approach is likely to succeed.

The limits of knowledge machine

While the government in the UK may increase its control over the production and use of knowledge, this may not increase public and patient confidence. Not only may the shift may be seen as one of rhetoric rather than reality but there are also some fundamental flaws in the strategy. Encoded knowledge by itself is not an adequate or sufficient basis for clinical decision-making and the policy conflates confidence or trust in the NHS, a relatively abstract concept, with trust in the doctors and nurses delivering the service, which is based on concrete face-to-face relationships and experiences. In seeking to restore confidence the policy makers have modelled patients as rational actors and this has totally neglected he affective or emotional components of confidence and trust.

New relations between the NHS and patients: Rhetoric or reality?

There has been a major shift in the rhetoric of treatment in health care from paternalistic compliance with or adherence to treatment to a partnership based on agreement or concordance over treatment (Marinker et al, 1997). Concordance is based on communication and exchange of knowledge between expert and patient with the expert providing knowledge on prognosis and the risk and benefits of treatment and the patient being provided with an opportunity to articulate their beliefs about and priorities for treatment. Concordance emphasises the importance of patient knowledge and belief:
Patients have their own beliefs about their medicines and medicines in general. They have their own priorities and their own rational discourses in relation to health and care, and risk and benefit (Marinker and Shaw, 2003, p. 348).

When expert knowledge and patient belief are irreconcilable, then precedence should not be given to the expert’s knowledge as in the paternalistic compliance approach but to the patient’s view (Marinker and Shaw, 2003, p. 348-9).

This approach to knowledge has been widely endorsed. For example the World Health Organization sees concordance as a key step in supporting patients with tuberculosis through the process of treatment (Maher et al, 2003). In the United Kingdom the Department of Health endorsed the principle in 2002 and established the Medicines Partnership was established by to promote ‘the concept of concordance - or shared decision-making - as an approach to help patients to get the most from their medicines’ (Medicines Partnership, 2006).

The issue of concordance exposes the tension in health policy between building an efficient health service based on the codification and application of best available knowledge or evidence and developing a patient centred health service which gives precedence to patient’s beliefs and desires (Marinker and Shaw, 2003, p. 349). In practice precedence is given to codified knowledge or evidence.

Maher and his colleagues in discussing concordance in TB treatment, give the example of the Bangledesh Rural Advancement Committee that achieves a high cure rate of 85 per cent (Maher et al, 2003, p. 823). There appears to be a power imbalance restricting choice and a clear structure of compliance. Patients can only access the full service if they sign a written agreement and are then bound by the terms of that agreement.

The difference between the rhetoric of choice and the reality is evident in areas in which government has evidence of risky and harmful behaviour that it wants to change to improve public health. Lee (2007) has undertaken a study of child rearing practices particularly focussing on the experience of mothers who have bottle fed their babies. Lee found that official information provided on baby feeding emphasised the benefits of breast feeding and the risks of bottle feeding. For example in the USA the scientific adviser to the Department of Health and Human Sciences equated the risk of bottle feeding with those of smoking in pregnancy (Lee, 2007, p. xx). Within British hospital the provision of information on bottle feeding has been restricted, e.g. group demonstration of bottle feeding are no longer sanctioned, and mothers who chose to bottle feed are informed of the risks. In Lee’s study there was no evidence of concordance between health professionals and bottle feeding mothers some of whom felt such pressure to comply that they concealed the fact that they were bottle
A similar bias is evident in the treatment of coronary heart disease. As Crinson and his colleagues (2007) note government policy as expressed in the National Service Framework (Department of Health, 2000a) identifies two interacting causes of coronary heart disease, broader socio-economic factors such as social and economic deprivation and individual risk factors identified such as raised blood pressure and cholesterol levels. The government has chosen to concentrate on the individual risk factors issuing guidelines for general practitioners to identify and treat high risk patients using drugs to reduce blood pressure and cholesterol levels. These are now backed up with financial incentives for GPs. Effectively this is a system designed to ensure [high-risk individual’s] compliance with recommended drug therapies by appealing to their essential “rationality” (Crinson et al, 2007, p. xx).

Thus where there is a conflict between evidence-based practice and a patient-centred choice base system, there is a tendency for policy makers to favour the evidence-based approach. They have after all invested heavily in developing the evidence base and believe it should deliver better, more effective and safer health care. However pressuring patients into compliance especially when there is a rhetoric of patient choice is likely to undermine patient confidence in the system.

The limits of encoded knowledge

While the current emphasis on the develop of a health care system creating and using encoded knowledge may create a tension with aspirations to develop a patient-centred system, there is a crucial problem. While encoding knowledge may be designed to structure and control professional decision-making, it is not clear it can achieve this. In particular it appears that encoded knowledge needs to be interpreted and appropriately applied, i.e. it requires other forms of knowledge.

While there are few areas of health care in which there has been such a complete shift to encoded knowledge, in many areas of practice there is increased use of computer-based systems designed to ‘support’ clinical decision-making. Such systems provide a new context and set of resources but they do not remove judgement or negotiation from decision-making. Prior and his colleagues (2002) examined the ways in which clinicians used Cyrillic, a computer-based programme, to estimate patients’ risk of cancer. Cyrillic made risk ‘visible’ by using inputted data on relatives to draw a family tree of cancer and providing a numerical estimate of personal risk (p. 248). It was found that clinicians had to make ‘sense’ of results and images and this involved craftwork especially in the laboratory. Such craftwork meant that there was ‘always a large chunk of “tacit knowledge” embedded in professional decision making’ (p. 256).

Even where there is a major shift to the use of encoded knowledge, research has found that such knowledge is not adequate or sufficient as a basis for
decision making. NHS Direct is a telephone advice service in which nurses use knowledge encoded within computerised decision support software or algorithm to advice callers about self-care and use of other services. In an observational study Ruston and her colleagues found that following an initial conversation with a caller nurses often made a judgement on the best course of action, they then checked this against that prescribed by the algorithm, overriding the algorithm if there was disagreement (Ruston, 2004, pp. 18-19).

The limits of rationality

The development of a health care system based on the application of encoded knowledge is designed not only to improve outcomes and reduce dangerous practice but also to increase public and patient confidence in the NHS creating a ‘high-trust’ organisation (DoH, 2000b, para 6.1). As Taylor-Gooby notes current reforms in the health care focus on the development of a system which makes effective use of knowledge and make available knowledge which patient-consumers can use to base their decisions, e.g. for choose and book:

The reforms address some of the problems of information asymmetry identified in healthcare markets (Barr 1998 282-4) through the widespread publication of league table results, star-ratings and Commission reports

Leaving aside the practical problems involved in developing this system, i.e. whether it really works in terms of providing patient choice and controlling professional decision making, there is serious flaw in the logic. It emphasises the instrumental rationality of patients and the public and their acceptance and response to information on the overall performance of the system and neglects the more personal and emotional ways in which individuals judge and respond to their interaction with health professionals. As Calnan and Rowe note trust can involve using and processing knowledge to reach a judgement but it can also be more intuitive and be based on feelings or emotions:

Trust has been characterised as a multi-layered concept primarily consisting of a cognitive element (grounded on rational and instrumental judgments) and an affective dimension (grounded on relationships and affective bonds generated through interaction, empathy and identification with others) (2005, 1).

The emotional component of health care is likely to be quite high. Not only does health care involve intimate personal interventions that have a major impact on personal identity and sense of self (Alaszewski et al, 2006) but individuals often have to make ‘fateful’ life and death decisions in stressful and uncertain situations (Barbalet, 2005).

As Taylor-Gooby notes the current health reforms in the UK tend to neglect the personal and emotional aspects of care, especially the extent to which patients feel that they and their values are respected:
The current direction of reform leaves affect and emotion out of consideration. There is no sentiment in business, or in a business plan, however good a business plan it happens to be. The appeal is entirely to reason, both in the way the reforms work (through shifting incentives to change the way those involved behave) and in the understanding of people’s perceptions of and responses to public sector institutions which is implicit in them (Taylor-Gooby, ???).

As Taylor-Gooby notes, the effect of concentrating on cognitive rationality is a system that works efficiently caring for and curing patients but which fails to meet the personal and emotional needs of patients and therefore does not inspire confidence and trust.

Conclusion
This editorial traces the move from traditional society, where empirical and other sources of knowledge including social values and beliefs are integrated into a single explanatory system, towards a modern society where an enhanced explanatory potential of natural science is accompanied by increased lay-awareness of the limits of this knowledge and corresponding uncertainty. The agency relationship represents one potential means of reducing the complexity inherent in this uncertainty, though this relationship is highly dependent on trust in the professional. The fallibility of the expert, epitomised in various medical scandals, has lead to an increasingly rationalised healthcare system in the UK where the systemisation and monitoring of medical practice is applied in an attempt to assure the quality of medical care, and thus furnish trust in the NHS, through enhanced auditing and accountability of clinical decision making.

This shift towards a ‘machine bureaucracy’ (Flynn, 2002) misconstrues the nature of medicine. Schön (1983) emphasises the artistry required in the successful practice of medicine as opposed to a more technical/rational model. In particular he highlights the recurrent presence of abnormal situations where usual protocol is not sufficient and creative reflection is necessary. Not only does the move to encoded knowledge fail to consider that it is these atypical scenarios, where protocol is inadequate, which are also potentially the riskiest; but in their more everyday application, ‘routines tend to become increasingly dysfunctional over time: not only do they fail to adjust to new circumstances but ‘shortcuts’ gradually intrude, some of which only help professionals to cope with pressure at the expense of helping their clients’ (Eraut, 1994:112). The rationalisation of healthcare is thus limited in that good practice is reduced to “a matter of convention, efficiency and ‘internal coherence’” (Marcuse, 1989:121) and the importance of the patient is lost under the ‘meta-regulation’ (Power, 2003:198) of the system.

Whereas the Azande can combine empirical and metaphysical understandings due to the latter’s universal acceptance, the instrumental rationality of clinical governance typifies the way modern science, in having to siphon off norms and emotions due to their lack of generalisable validity
Habermas, 1974: 264; 1987), is blind to the human, emotional and communicative dimensions of healthcare which are crucial to positive patient experience and trust.

Risk is being applied in this context as a value-neutral concept, its acceptance achieved by the politicisation of fear (Furedi, 2005:132), yet its effect, paradoxically, is the depoliticisation of everything else (Pieterman, 2005). The ‘heuristics of fear’ (Jonas, 1984) have emerged to fill the ideological vacuum left after the demise of left-right political discourse (Giddens, 1994) and political attention has thus shifted towards security and risk. Risk-aversion, as an apparent universalised moral basis for policy (Furedi, 2005:137), obstructs political debate in that proposals based on this premise are seemingly indisputable. Yet the failure of policies to recognise the affective dimensions of uncertainty is likely to create a ‘trust deficit’, a system that may work better but is trusted less.

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