
# Risk and health: Review of current research and identification of areas for further research

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2000

# RISK AND HEALTH: REVIEW OF CURRENT RESEARCH AND IDENTIFICATION OF AREAS FOR FURTHER RESEARCH

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**February 2002**

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## EXECUTIVE SUMMARY

The Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) commissioned this review to examine the potential for applying social science perspectives on risk to practical medical and health issues. The specific aims were; to synthesise current research on risk and health; to identify research gaps; to identify themes and issues that would be productive for further research. The review draws on existing knowledge and expertise of the authors; a selective review of the literature on risk and health; and consultations with risk researchers and health-related 'users'.

*Defining risk*
Risk is a key concept in health and health care, but there is potential for misunderstanding and confusion about its meaning and use. In making decisions about risk, a range of different types of knowledge may be relevant, which reflect different sorts of technical expertise and professional skill, and different sorts of practical experience. There is therefore a matter of judgement about how narrowly a given risk issue is viewed, and the corresponding selection of knowledge which is utilised in a decision process. There is a need, through detailed research into every-day clinical and health care practices, to explore how such variations in definitions and knowledge selection are used in practice.

*Lifestyles, health and risk perception*
In modern societies there is a commitment to the enhancement of the well-being of individuals, and to the provision of choice enabling individuals to exert control over their health. Individual's understanding of and responses to risk is influenced not only by expert assessments but a range of personal and social factors. There is scope for exploring these 'other factors' by considering, for example, the relationship between expert assessments, individual perceptions and behaviour, or the relative influence of individuals' own experiences of risk compared to the information they acquire from other sources such as the media, including the Internet.

*Treatments, decision-making and risk communication*
Health care systems are a major source of knowledge about health risks and the main location in which such risks are managed using preventative, diagnostic and treatment technologies. Central to these processes are the relationships between health professionals and patients and their communication about risk. Effective communication depends on the ability of professionals to assess and make available information and patients' willingness to trust professionals and use their assessment to manage their health. However in contemporary society these processes are subject to widespread doubt. These difficulties are currently evident in the low take-up of the MMR vaccine. There is need for research which explores the ways in which trust is developed and information effectively communicated and used.

*Affect, anxiety and risk amplification*
In modern societies while objective indicators of well-being indicate substantial improvements, there is little evidence that individuals' sense of wellbeing has also improved. Negative affective state such as worry and anxiety are evident and that may be linked to distorted perceptions of risk. Certain types of risk, especially low probability/high consequence risks such as train crashes or terrorist attacks, are amplified by the mass media. While the evidence may be open to

dispute, there is clearly scope for further research in this area. Important issues for future research include the ways in which anxiety is created and managed in modern societies.

*Managing Risk in Health Care: Medical Errors and Clinical Governance*
While the prime function of the NHS is to minimise risk and harm, there are concerns that medical errors or mishaps are undermining confidence in the service. Inquiries into health disasters indicate the now-familiar pattern of events that result from organisational failure of foresight, a series of systemic and communication failures contribute to oversight of an 'incubating' hazard leading to disaster. The implementation of clinical governance is designed to restore public confidence by creating a more effective system of risk management in the NHS. Given the limited research into both risk management and clinical governance there is scope for a more sustained examination of the ways in which risk is managed in health care systems.

*Managing risk in society: regulatory systems*
The effective management of risks, especially through regulation, is an important element of governance in contemporary society. Governments are expected to regulate risks which individual citizens cannot manage for themselves either because obtaining necessary information or taking evasive action is not feasible. There is regulation across a range of settings: from individual health behaviours, through clinical practices, to large-scale public health interventions. To be effective and acceptable regulatory systems need to be based upon risk/benefits assessments. Regulation is inextricably embedded in social structures and processes. For example rather than reassuring the public, regulation of a specific hazard may reinforce perceptions of its dangerousness and lead to pressure for more regulation. There are a number of issues that need to be researched in this broader governance context including: the social influences on risk regulation; the impact of different perspectives on risk regulation; and the impact of risk regulation.

*Managing the future: societal change, health and the precautionary principle*
Risk is forward-looking and intimately linked to the future: indeed current concerns about risk can be seen as attempts to map and control possible futures that await us. Major scientific, technological, economic and social developments have changed the nature, pattern and perception of health risks. There are major concerns about the risks and acceptability of new technologies and the government is seeking to address these concerns by increasing public participation in decision and improving the transparency of decision making. There is scope for research on health futures especially on the nature of risk futures, the interaction of technological changes and the role of public acceptability and consultation.

*The Need for Interdisciplinary Research*
A substantial social science-based knowledge about risk and health already exists. However there are a number of impediments that need to be overcome before that knowledge can be more generally applied within various spheres of health-related practice. Much of this knowledge has been developed through, and is embedded in, the study of specific health issues and medical conditions, and while its relevance is made explicit in managing these issues and conditions, its broader applicability may be obscure. Risk, by virtue of bringing together the social and the material in a dynamic way, inevitably poses serious practical questions concerning the implementation of research that crosses boundaries between conventional disciplines. These barriers need to be overcome by programmes of research which focus on cross-cutting health themes, and which includes social, cultural and environmental determinants of health.

## ACKNOWLEDMENTS

This review was funded by an ESRC award for a Health and Risk Consultancy L700310033. As the authors of the review, we have been responsible for its organisation and writing, however we have received considerable help from a number of scholars and health professionals. David Guy of the ESRC and Joan Box of the MRC were involved in commissioning the review, and maintained a close and enthusiastic interest in its development. In response to a consultation exercise, we received over 50 detailed sets of comments on early drafts of our report, all of which were thoughtful and helpful. Over 40 academic and users of risk research contributed to a consultative workshop that we organised, and again their contributions were invaluable.

## INTRODUCTION: DEVELOPING RESEARCH IN RISK AND HEALTH

In recent years there has been rapid growth in social science research into risk and society (Lupton, 1999, Horlick-Jones, 2000). In the UK this growth has been stimulated by research funding, for example the ESRC's Behavioural Aspects of *HIV/AIDS Programme* (1987-92) and *Risk and Human Behaviour Programme* (1994-2000), and will be further stimulated by the current ESRC programme on *Innovative Health Technologies* and formation of an ESRC Network on *Risk and Its Social Context.* Other evidence of significant investment by the ESRC in risk-related research is provided in the form of its continued support for Centre for Social and Economic Research on the Global Environment (CSERGE), and the recent establishment of the Centre for the Analysis of Risk and Regulation (CARR).

With the growth of research funding and activity Risk has become a mature area of study with its own academic associations such as the *Society for Risk Analysis* and its own journals such as *Risk Analysis*. Health did not initially act as a catalyst for the development of this area of study: environmental issues were and remain more prominent (see for example Cottam et al, 2000a and 2000b). However during recent years researchers have begun to address health issues using a risk perspective. Blaxter (1999), for example, noted in her commentary on the ESRC's *Risk and Human Behaviour* programme that virtually all the projects had implications for risk and health. These developments are reflected in increased interest in risk in established academic journals (and see for example a monograph on health and risk edited by Gabe (1995) for the *Sociology of Health and Illness*) as well as the appearance of high quality journals like *Health, Risk and Society* and *Clinical Risk.* These changes have been reflected in the active participation of the UK Department of Health in the Government's Interdepartmental Liaison Group on Risk Assessment (ILGRA), and in recent initiatives like the inter-departmental workshop on risk and public health which took place in London in the summer of 2001 (www.doh.gov.uk/risk/riskpublichealth.htm).

The ESRC and MRC commissioned this review to examine the potential for applying a social science perspective on risk to practical medical and health issues. The aims of the review are:

- to synthesise current topical quality research on risk and health;
- to identify research gaps;
- to identify themes and issues that would be productive for further research.

The review draws on multiple sources of data:

- the existing knowledge and expertise of the authors who have undertaken previous research and reviews in these areas;
- a selective review of the literature on risk and health;
- consultations with risk researchers and users through the circulation of drafts of the review and through a consultative workshop held in London on the 15th December 2001.

We had neither the time nor resources available to undertake a fully systematic review of the evidence. Indeed given the wide scope of the area and the very substantial body of related literature, it is not clear that such a review would have been feasible, nor would it have

necessarily enabled us to achieve all our objectives. Instead we undertook a focussed and selective review. From our existing knowledge we identified key themes and issues and brought together initial evidence. These formed the basis of the first draft of our review which was circulated to risk researchers and users, and to all participants in the consultative workshop. Responses to this consultation plus a selective review of the literature informed the final version of the review.

Following an introductory section in which we examine the contested nature of risk and the importance of social context to an understanding of risk, the main body of the report addresses risk and health, first from the point of view of the experiences of individuals and communities, and then of institutional life. In each area we have identified a number of generic issues. Each issue cuts across a range of health-related contexts, and each is considered according to why it constitutes a source of practical and policy problems, the evidence of current research findings, and those topics which appear to merit further research. In the concluding section we emphasise the importance of interdisciplinary research in this area.

## 1. DEFINING RISK

For the purposes of this review, risk is defined as:

> The probability of an event occurring combined with the magnitude of losses or gains that would be entailed (Douglas, 1990, p. 2).

As Douglas has documented the relative emphasis on the different components of risk has changed over time. In the 17th Century risk was associated with gambling and games of chance whose study created a specialist branch of mathematics, statistics (Douglas, 1990). In modern society interest in risk is more generalised and links to desire to use knowledge gained from the past to predict and manage the future (Giddens, 1991) and to allocate responsibility and blame when this process fails (Douglas, 1986, p. 59). Green (1997) has identified a similar shift in the area of public health albeit over a shorter time period with a shift from accidents as statistical events in the 19th century to minimising harm and 'preventable injury' in the 20th Century. In the 20th Century research has generated new forms of technical expertise in risk, which has been applied across a bewildering range of areas of policy and practice (Lupton, 1999; Rose, 1999; Horlick-Jones, 2000).

It is therefore important to recognise that risk is defined and used in different ways. In the medical and health care literature the dominant approach is in terms of the 'risk of' specified adverse health events assessed in terms of mortality and morbidity. This involves the identification of factors associated with such events within populations, 'risk factors' or personal characteristics that make individuals 'at risk' (see for example the BMA's influential guide, The British Medical Association, 1990). A keyword search of the National Library of Medicine's database PubMed using 'risk' identified 482,260 publications of which nearly half (211,148) were also identified using 'risk factors' as a key word. These publications were mainly concerned with factors that affected the incidence of specific clinical conditions, for example 'Diabetes mellitus a risk for osteoporosis? (Leidig-Bruckner and Ziegler, 2001) or 'Hypoglycemia risk reduction in type 1 diabetes' (Cryer, 2001). However it was possible to identify 'risk in' health care, in which the emphasis is on the social processes which shape and influence health outcomes. These processes include 'risk communication', 'risk perception' and 'risk management'. The keywords 'risk perception' for example identified 347 articles which focussed on the ways in which specific health risks were perceived, as in 'Risk perception and psychological strain in women with a family history of breast cancer' (Neise, Rauchfuss, Paepke et al, 2001) or 'Perception of risk of vaccine adverse events: a historical perspective' (Spier, 2001).

While some commentators have argued that such variations seriously limit the utility of risk as a concept (see for example Dowie, 1999), an alternative approach is to acknowledge such variations and examine the range of meanings that people find in risk issues. These meanings are linked both to the symbolic associations of risk and the variety of perspectives which individuals and groups use in making sense of risk (Walker, Simmons et al, 1998; Petts, Horlick-Jones and Murdock, 2001). While social scientists initially tended to uncritically accept 'common-sense' definitions of risk as anxiety provoking danger (see for example Turner's

comments on Beck's usage, 2001), there is increasing awareness that risk is not only a contested concept, but in practice the experience of risk offers many attractions to individuals: it can provide opportunities for excitement, challenge and personal fulfilment (Cohen and Taylor, 1976, Lupton, 1999). One of the few studies to explore the ways in which risk is conceptualised in health and social care settings (Alaszewski et al, 2000) examined alternative definitions associated with the risk of supporting vulnerable adults in the community. The dominant conception of risk which was shared by professionals, users and carers, emphasised hazard or danger-oriented dimension of risk. However there were other broader definitions which did not command as much support. These included recognition of uncertainty and possible positive outcomes that either had to be balanced against negative outcomes or were themselves a product of empowering individuals to take risks.

As Eldridge (1999) points out, an area of central importance in risk research is to explore which and whose definitions of risk are accepted in different contexts. Jaeger et al (2000) have argued that there is a need to take into account different forms of rationality exhibited by agents in different real-world risk-related contexts. The 1992 Royal Society report utilised the concept of 'social framing' as a framework for exploring the often radically contrasting views of 'expert' and 'lay' groups concerning specific risk issues. Alternative approaches to risk issues can be understood in terms of the 'framing' of (often unarticulated) assumptions, expectations and norms, which are shared by a given social group (see also Wynne, 1982). In this way, the existence of implicit assumptions entailed in the production of specific risk evaluations are taken into account, as is the relevance of wider issues and concerns in which the 'risk object' (Hilgartner, 1992) is embedded.

- *Risk in every-day practice* Harper, O'Hara and colleagues (1997) undertook an ethnographic examination of the use of preoperative risk assessment forms by anaesthetists. They found that the real-world practical use of documents by medical professional can be fundamentally at odds with how the organisation as a whole would like to use them. Their work indicates the need for a greater research emphasis on the empirical detail of risk-related practices across the variety of health contexts. This direction would address both our current gaps in understanding, and respond to calls from within health-related professions for much-needed research into routine aspects of everyday health-related practice, for example in occupational health issues such as Repetitive Strain Injury, stress for both workers and management (Fox, 1998), and low level toxic exposures;
- *Individual and institutional variations in risk definitions* Individual variations could be explored in terms of the influence of care and treatment contexts on definitions of risk. For example are there systematic variations between definitions and practical reasoning utilised by doctors, nurses, professionals allied to medicine, social workers, users, carers and the public within specific care or treatment context? Examination of institutional variations would need to develop ways of characterising risk approaches used and how they vary between different agencies and their component parts, and across different activities within such agencies.

## 2. RISK AND HEALTH: INDIVIDUALS AND COMMUNITIES

Although there has been a substantial growth in the knowledge about the risk factors associated with ill-health, the full benefits of such knowledge can only be gained if it is used by individuals as the basis of their decision-making and behaviour. However as Sir Colin Berry has succinctly pointed out there is little evidence that knowledge about risk is effectively used:

> We consistently overestimate the dangers and undervalue the benefits we obtain by living in a complex society. For various reasons, we do not think rationally about risks – the problem is that this failure has reached a level where perverse judgements are damaging to society: about rail-related risks or MMR for example (Berry, 2002).

Although the research evidence on the difference between expert and lay judgements about risks is open to dispute (Rowe and Wright, 2001), it is evident that risk knowledge as embodied in expert assessments does not provide a very useful guide to the ways in which non-experts perceive and respond to risks and dangers (Slovic, 2000). In this section we will examine three areas in which these tensions are impeding health improvements: risk, individual behaviour and life style choices, decision-making in health care settings, and the relationship between risk and affective states such as anxiety.

### 2.1 Lifestyle, Health and Risk Perception

*Context* While pre-modern causes of morbidity and mortality are primarily seen as environmental, i.e. inadequate food supplies and hygienic technologies, the causes of modern 'epidemics' such cancer and heart disease and infectious diseases such as HIV are associated with individual variables such as genetics and individual behaviours. Improvements in genetic knowledge hold out the prospect of long-term health gains, however changes in 'risky' behaviours would appear to provide the most immediate prospect for health gains. Effective utilisation of risk knowledge can make a major contribution to improving health. Since the 1990s the Department of Health has developed targets for improving the health of the nation. The most recent statement includes targets for saving 300,000 lives by 2010. To achieve this target the government has made a commitment to develop a new relationship with the public over risk (DoH, 1999, para 3.15-20) by providing information on risk so that the public can make informed decisions. One major area of concern is the way in which individual lifestyle factors are shaped by social and community networks and underlying socioeconomic, cultural and environmental issues creating inequalities in health between socio-economic and ethnic groups (see for example DHSS, 1980, Acheson, 1998). As the NHS Plan stated that 'No injustice is greater than the inequalities in health which scar our nation' (DoH, 2000a, p.106) and it identified public health measures to improve health and reduce inequalities.

*Evidence* Since the 1950s epidemiologists have identified a range of risks associated with different patterns of behaviour. Studies have identified the harmful consequences of a range of behaviours including, smoking, alcohol consumption, drug misuse, 'unsafe' sex, and diet (excess as well as underconsumption) resulting in premature deaths from coronary heart disease, cancers and accidents. The public health response has been to reduce risk factors at a population and

individual level. This can clearly be seen in relationship to coronary heart disease which is the most common cause of death in the UK (Peterson, Raynor and Press, 2000) and considered to be largely preventable (Department of Health, 2000c). The population approach aims to reduce the level of risk factors in the population (Sivers, 1996) by reducing smoking and excess alcohol intake and by improving diet and physical fitness (Department of Health, 2000c). The individual approach seeks to reduce individual risk factors through behaviour change and by treating specific risks such hypertension. In practice, many individuals fail to respond to either population or individual approaches (see for example Davison, Frankel and Davey Smith, 1992 and Frankel, Davison and Davey Smith, 1991).

Observed behaviour for many individuals and groups do not conform to prescribed 'safe' practice (Stoebe and Taylor, 1995; Hsieh, Yen et al, 1996; Forster, 2001). Attempts have been made to understand this 'irrationality' in terms of 'denial' (eg Moore and Rosenthal, 1992), individual personality (Zuckerman and Kuhlman, 2000) and distorted perceptions (Viscusi, 1992, Sutton, 1999, Slovic, 2001). In economic terms, smokers, for example, have a 'high discount rate', with their health insurance costs being borne by others in society. Economists and many psychologists would tend to see smokers as actively embracing a short-term pleasure and long-term danger, however much of this work has been rooted in notions of rationality which is both individualistic and instrumental, for example the 'rational actor paradigm' (Jaeger et al, 2000) (see also the 'Transtheoretical Model':Prochaska, Norcross and DiClemente, 1994). Such models have been used to target interventions to change behaviours by influencing individuals' calculations of the benefits of adopting less risky behaviours (Bracht, 1999, pp. 36-37, Lawrence, 1999). However there is little evidence that these approaches have made a major impact, despite the investment in health promotion and public health, targeted in particular at 'at-risk' groups: for example sexual health behaviour (Alder, 1997) or smoking and young adults (Denscombe, 2001, Milam, Sussman and Ritt-Olson, 2000). In contrast, however, there is some evidence that interventions that contextualise otherwise abstract information about health threats can be more effective. Recent systematic reviews of behaviour change in the context of health threats indicate the importance of providing information about the effectiveness of protective actions (Milne, Sheeran and Orbell, 2000; Witte and Allen, 2000). Psychological work on changing behaviour which take account of environmental influences (eg Leventhal, Benyamini et al, 1997; Petrie, Cameron et al, in press) has been regarded as particularly successful. Thus there is the evidence that interventions that address risk issues *within the social context of individuals' lives* have some effect in changing behaviour (see for example Coleman, 2002).

How can one understand the limited success of health promotion campaigns? Some clues can be found in recent work on AIDS and HIV, which, perhaps unsurprisingly, constitute about half of social science-based work on health-related risk perception (as revealed in a BIDS publications database search). Bloor's (1995) important work in this area has been critical of individualistic conceptions of health rationality, based as it is on a recognition of the ways in which individual actions are embedded in situations of interpersonal interaction and expectations. While individuals may be aware of the potential negative consequences of engaging in risky behaviours, other concerns may given priority in some social contexts (see for example Wallman, 2000, 2001 on behaviour and HIV and Graham 1987 on women's smoking). Furthermore, risk-related behaviour forms an important part of an individual's identity, and Green and Sobo (2000) have shown how this interaction is carefully managed by individuals who are HIV positive (see also Blaxter, 1997). Risk-taking may provide individuals with the feeling that they are in control of their own lives and fate (Lupton, 2002). There is, then, evidence that people's relationship with health risks entails more complex forms of rationality

than those implicit in much work on health perception and health promotion. Indeed, a recent study (Edwards, Matthews et al, 1998) of physicians' views of proposals for a standardised 'language of risk' (eg Calman and Royston, 1997) found considerable scepticism about its potential usefulness in communicating with patients. Projects funded through the ESRC Economic Belief and Human Behaviour programme, also identified the limitations of narrow rationality models in predicting and explaining behaviour (Taylor-Gooby, 2000a). Sociological studies of 'risky' behaviour indicate the importance of social context in shaping and sustaining such behaviour, especially the ways in which individuals establish trust (Misztal, 1996).

The nature of lay knowledge about health-related matters has generated a rich literature which offers valuable insights into these matters. The recognition that ordinary people have informed understandings, by virtue of their everyday experiences of health, illness and related matters, has prompted the coining of the term 'popular epidemiology' to capture this notion of 'unofficial expertise' (eg Brown ,1987; Williams and Popay, 1994). Recent research in risk perception suggests that gaining access to such lay knowledge is an important prerequisite for effective risk communication (Walker, Simmons et al, 1998; Horlick-Jones, Sime and Pidgeon, 2002), and that the specific ways in which language is used to communicate risk information affects the ways in which that information is received, interpreted and used (Heath, 1992; Sarangi and Roberts, 1999; Gwyn, 2002).

*Research issues* Given the limited understanding of how individuals and social groups utilise sources of knowledge, and identify and respond to threats to their health, there are a number of areas of research which should prove fruitful including:

- *Risk and behaviour* Individuals' view their own behaviour as reasonable or rational and therefore if the consequences of a particular pattern of behaviour are harmful, effective interventions need to be based on an understanding the reasons that underpin that pattern of behaviour. This type of analysis has proved fruitful in relationship to HIV-related behaviours which have identified the ways in which individual actions are embedded in situations of interpersonal interaction and expectations (Bloor, 1995). Taylor Gooby (2002) has argued that this approach can be extended to other risk area by focussing on the ways in which social context shapes identification and understanding of risks and in which appropriate responses are formulated and justified. In particular he argues that it is important to identify and make explicit the assumptions that underpin the identification or 'framing' of risks and ways in which risks are described or communicated. Such an approach can be applied to a range of different behaviours, for example the preparation and consumption of food, the use of psychoactive substances or 'unsafe' sex.
- *The relationship between direct and mediated experiences of risk* Individuals make use of multiple sources of information, including direct experience from their every-day lives, and information mediated by other sources such as the mass media. While individuals evaluation of these sources plays an important role in shaping their understandings of, and behaviours in relationship to, risk (Petts, Horlick-Jones and Murdock, 2001), how this takes place is not clearly understood and there is scope for more research into role of current media (eg Karpf, 1988; Gwyn, 2002), as well as new forms such the Internet and NHS Direct.
- *At risk groups* There is concern about social exclusion, health inequalities and the social factors which sustain them. In this context there is scope for research which focuses on the variation between resources which different social groups have to identify and manage risks and whether risk accumulates over the life course (Bartley, Blane and Davey Smith, 1998);

- *Evaluations of interventions* While some evidence is accumulating about the effectiveness of interventions designed to manage risk and minimise harm, there is clearly scope for developing more research in this area. Such research could explore combinations or clusters of risky behaviours to examine the ways in which they interact and support each other, for example consumption of alcohol and unsafe sex or dangerous driving and evaluate different intervention strategies.

## 2.2 Treatment, Decision-making and Risk Communication

*Context* Most health resources are allocated to health interventions designed to prevent, diagnose and treat disease. The development of medicine has been characterised by the development of medical knowledge and technologies based on this knowledge. Health care professionals have played a crucial role in the development of this knowledge and applying it within clinical settings. The acceptability of this process depends on the trust which patients and others have in medical practitioners and the scientific knowledge which they use. If it is unacceptable, users will not co-operate either by not using established professionals or by not following treatment regimes. For example in the UK there are concerns that despite evidence that baby's immune systems can safely cope with the MMR vaccine (Boseley, 2002, p. 9) media reports of a link between MMR and autism has reduced take-up rates increasing the likelihood of a measles epidemic (Rawnsley, 2002, Jewell, 2001). The World Health Organization has stressed the importance improving communication about vaccines to enhance public confidence in their safety and efficacy (Dittman, 2001). To develop public confidence and trust in the NHS, the Department of Health is committed to open and shared decision making in the NHS and the provision of information to empower patients and strengthen their choice (DoH, 2000a, pp. 88-95).

*Evidence* There is evidence of a number of interrelated changes which appear to be altering the acceptability of medical knowledge and therefore the basis of the professional/patient relationship. These include changes in access to such knowledge, increased awareness of the uncertainty implicit in such knowledge and the increased distrust of scientific knowledge and the experts who apply it (Studies on the public understanding of science are relevant here, see for example Elston, 1997).

The development of new media such as the internet and facilities such as NHS Direct have created easier access to medical knowledge. This has undermined the position of medical practitioners as the sole source of expertise (here, studies on the media and risk are highly relevant, Miller, Kitzinger et al, 1998; Philo, 1999a). Similarly audits, inquiries and legal actions increase the external scrutiny of professional decision-making. There is awareness of uncertainty in medical knowledge. This was particularly evident in the uncertainties surrounding new health risks such as vCJD and HIV. These in their early stages were 'virtual risks' which created considerable debate between experts. Politicians, policy makers and the public did not have reliable sources of information on which to base their decisions. Similarly the identification of new hazards associated with, for example the use of Terfenadine an antihistamine which was licensed for treating hayfever but was also used for asthma, resulted from an emphasis on the routine, safe and beneficial nature of the drug, to a more questioning that acknowledged the uncertainty of modern medicine (Ward, Bissell and Noyce, 2000).

These uncertainties evident in new knowledge plus the development of new health risks has the potential for undermining the relationship of trust which provides patients with a sense of security. For example the uncertainties and threats associated with conventional medicine and the belief that non-orthodox medicine is 'safer' as it is 'natural' (Cant and Sharma, 1996), and provides more control for patients (Killigrew, 2000) are factors in the growth of non-orthodox medicine (Thomas et al 1991, Goldbeck-Wood, 1996). Trust in medical expertise has also been undermined by medical failures such as the Bristol child heart surgery affair, BSE and inadequacies in screening programmes, and by evidence that there are often unexplainable variations between clinicians in decision-making (Dowie and Elstein, 1988). Responses to disasters such as BSE indicate the need for major institutional reforms based on institutional openness, an opening-up of the use of scientific expertise in policy, and an explicit handling of uncertainty in risk management and risk communication. Together they indicate the need for a fundamental shift in institutional culture and behaviour for both government and business (Horlick-Jones and Pidgeon, 2001).

Studies of doctor/patient interactions indicate that traditional stereotypes paternalistic doctor/passive patient do not reflect the actual range of relationships that exist, and in particular do not reflect moves towards more openness, equality, non-judgementalism in decision-making and tolerance, and understanding of 'non-compliant' behaviours (Hyun, 2000). While rational models of decision making tend to predominate (see for example Dowie and Elstein, 1988) there is increasing awareness of the impact of affective states on decision-making (Maule, Bdzola, Hockey et al, 1998). Other recent work has addressed the importance of the format of risk information used in communication processes (Gigerenzer and Hoffrage, 1995; Gigerenzer, Hoffrage and Ebert, 1998). The theme of shared doctor/patient decision-making has played an important role in recent thinking about medical practice (Coulter, 1999). However the implementation of such interactive approaches to health decision-making has been uneven across different medical settings (Edwards, Barker *et al*, 1998; Elwyn, Edwards *et al*, 2000).

There is a developing body of evidence on risk communication. This explores both the general communication processes (Edwards and Elwyn, 2001, Chess 2001 and Tinker, Zook and Chapel, 2001) and also communication in relationship to specific hazards or health events such as the release of pathogens (Covello, Peters, Wojtecki et al, 2001) or cardiovascular conditions (Dudley, 2001). The evidence is best developed in areas in which there is particular public concern such as food safety (Connolly and Knuth, 1998 and Frewer, Howard, Hedderley et al, 1997), radiation (Lakey, 1998, Golding, Krimsky and Plough, 1992) and vaccination (Dittman, 2001) and/or professional interest in communication such as genetic counselling (Farrell, Certain and Farrell, 2001) and cancer care (Ratzan, 1999, Rothman and Kiviniemi, 1999). However in our examination of one area which is of current concern, MMR, we could find little systematic evaluation of risk communication. One of the few studies of decision making (Bond, Nolan, Pattison et al, 1998) found that mothers were seeking to balance the risks of immunisation and non-immunisation and that one of the main barriers to the decision to immunise were a lack of 'balanced', detailed information and poor communication between health providers and parents.

Recent work based at the Department of Health (Bennett and Calman, 1999) has brought together current research on risk communication to identify good practice. However there is evidence that current practice falls short of best practice (Barry et al, 2000 and Mohanna and Chambers, 2001, pp. 15-26). Even in areas such as genetic screening where there are strong historical sensitivities about communication and choice following abuses linked to the eugenic movement, there are effectively still restrictions of information and choice (Petersen, 1999;

Hallowell, 1999). As Edwards and Prior (1997) note, a key role for general practitioners in making information about health risks relevant to the context of patients' own lives. There is a need for policy development here to be based on more systematic studies of doctor-patient interaction of the kind that have recently been appearing in the literature (Perakyla, 1995; Silverman, 1997; Elwyn, Edwards *et al*, 2000)

*Research* There is considerable scope for examining how risk is constructed within, and shapes, clinical exchanges. These include examining:

- *Communication of risk and maintenance of trust* The recent House of Lords (2000) report on science and society concluded that research into how non-expert individuals and groups receive and make sense of risk information is likely to have considerable policy relevance. Studies of the ways in which more open access to information affects decision making can be developed by examining how different social groups and different groups of patients access and use information and how they evaluate the trustworthiness of different and competing sources of information. In particular there is scope for exploring why some patients are willing to trust alternative medical practitioners when there is little evidence of the efficacy of their practice;
- *Communication risk with different groups* Recent research into health and risk perception indicates the need for purposeful risk communication to take account of the existence of multiple 'publics' (Williams and Poppay, 1994; Walker, Simmons *et al,* 1998; Slovic, 2000). Some groups appear to be more willing to accept expert assessments of risk (for the so-called white male effect see Finucane, Slovic, Mertz, 2000) while others disregard such assessments (for women's tendency to disregard risks of coronary heart disease see Rushton and Clayton, 2002). There is a clear need for more systematic research into the variations in interpretive practices utilised by these publics across socio-economic, gender and ethnic dimensions (House of Lords, 2000; Petts, Horlick-Jones and Murdock, 2001).
- *How risk influences decision making* There is now a substantial literature on clinical encounters which addresses the interactional complexity of relationships between doctors and patients, and how this affects decision-making (Silverman, 1987; Heath, 1992, Elwyn, 2001). There is a need to link these insights with research into risk-specific issues, including the role of professional cultures in insulating decision-making and sustaining paternalism, and the influence of judicial pressures for doctors to balance risks in defensible and logical manner. Such work promises significant advances in the production of guidelines to clinical practice, and the development of decision support methods and technologies (Elwyn, Edwards et al, 2000; Elwyn, 2001).

### 2.3 Affect, Anxiety and Risk Amplification

*Context* Health includes psychological as well as physical wellbeing, and while health risks are predominantly seen in terms of possible physical harm, there is also a link to affective states such as fear, anxiety and worry. In line with long-standing practice, fear can be defined as a negative affective or emotional response to a specific threat, while anxiety or worry relates to the response to generalised or unspecified threats or uncertainties (Freud, 1974). Recognition of the importance of affective states underpin attempts to develop 'safety cultures' in public services which are designed not only to minimise harm but also to ensure public confidence and trust and to provide individual and collective security (Turner and Pidgeon, 1997). Thus the aim of criminal justice system and the health care system are not only to reduce levels of crime or ill-

health but also reduce fear of crime or ill-health. Changes in health care such as the modernisation programme and the Food Standard Agency are justified not only in terms of improving health but also in restoring public confidence and trust (DoH, 1997; MAFF, 1998; Cvetkovich and Lofstedt, 1999; Gray, Laing and Noaks, 2002). For example in 1999 the Minister of State for Public Health stated when announcing the establishment of the Independent Expert Group on Mobile Phones that 'it is very important that we ...work very hard to keep ahead of public anxiety' (cited in Burgess, 2002).

Increases in objective levels of 'safety' do not necessarily lead to increases in perceptions of individual well-being, as demonstrated, for example, in studies of fear of crime, which consistently shown that the least 'at-risk' group, namely elderly females, are the most fearful (Jefferson and Holloway, 1997). Within the social science literature a number of commentators have identified the existence of endemic anxiety as a characteristic of the 'late modern' or 'risk' society in which we find ourselves (Giddens, 1991; Beck, 1992; Bauman, 1993, p. 235; see also Glassner, 1999). Taylor-Gooby, in his overview of the findings of the ESRC programme on Economic Beliefs and Behaviour, refers to 'timid prosperity', in which increased levels of collective safety and welfare are associated with increased levels of anxiety about personal security (Taylor-Gooby, 2000b, pp. 1-6).

*Evidence* In the health care system individuals who are anxious about their health, i.e. whose personal assessment are more pessimistic than those of experts, have been identified as a distinctive category. Balint (1964), in his classic study of primary care identified a group of patients who presented repeatedly with often changing physical symptoms but whose pattern of behaviour and symptoms indicated an anxiety disorder that was undiagnosed and untreated. In the 1970s the term 'worried well' was used to describe (Del Guercio, 1971, Ross, Collen and Soghikian, 1977, Wagner and Curran, 1984) individuals who were seen as inappropriate users of medical services. The emergence of a high profile new disease in the 1980s, AIDS, was associated with the development of AIDS anxiety (Harowski, 1987, Cochran and Mays, 1989). The relationship between the worried well and individuals experiencing extreme anxiety is not clear. Davies (2000) has argued that there should be clear differentiation so those individuals with 'genuine' anxiety disorder avoid the stigma associated with the worried well. However Gillanders, Buss and Gemmel (1992) were unable to identify a clear category of elderly worried well and Bowers (1997) review of mentally ill worried well found that these patients had significant symptoms. Extreme anxiety or emotional distress is recognized as a type of mental disorders and there is consensus amongst clinicians over the symptoms which indicate 'generalized anxiety', 'panic' and 'obsessive-compulsive disorder' (Wilkinson, 2001, pp. 49-50). These types of mental disorder have a major impact on modern populations, for example a OPCS survey identified a prevalance rate of 14% amongst adults between 16 and 64 and lower socio-economic classes have higher rates (Wilkinson, 2001, p. 54).

Wilkinson (2001) has argued that anxiety in contemporary society is closely associated with risk and especially uncertainty. As Furedi (2002) has noted public panics have been commonplace with scares about issues as diverse as childhood immunisation programmes, mobile phones, global warming, foot and mouth disease in livestock, and the risks of long haul flights. Following the terrorist attack on the World Trade Center on the 11$^{th}$ September and subsequent deliberate releases of anthrax, the Chief Medical Officer in the UK has accepted that measures against terrorism should form part of the government's strategy for protecting the public (DoH, 2002). Furedi (2002) has suggested that these attacks have heightened anxiety creating a society terrified of terror.

While health services such as the NHS are intended to protect and reassure individuals, they may unintentionally increase anxiety. Screening for diseases such as cancer is anxiety (Shaw, Abrams and Marteau, 1999) especially for those who have false positive tests (Petticrew, Sowden and Lister-Sharp, 2000). In mammography screening false-positive identification of breast cancer was associated with short term distress (Aro, Pilvikki Absetz and van Elderen et al, 2000) while anxiety has been identified as a major reason for non-attendance (Aro, Konnig and Absetz et al, 2001, Caruso, Efficace, Parrila et al, 2001). Following diagnosis anxiety may be result from uncertainties, for example there are a variety of ways of managing early-stage prostate cancer but due to an absence of randomized controlled trials patients and their families have to manage the anxieties resulting from conflicting and confusing information (Wilt, 2002). The ways in which services are organised and information provided can affect the level of patient anxiety. For example providing information prior to surgery reduces anxiety and facilitates recovery (Johnston & Vogele, 1993). Anxiety can affect health outcomes, for example in chemotherapy higher levels of anxiety prior to treatment have been linked to higher levels of nausea during treatment and lower levels of adaptation to cancer (Blasco, Pallares, Alonso et al, 2000).

Psychometric studies which have examined factors which make individuals more sensitive or anxious about risk. Individuals are likely to be more sensitive to a risk if it is inter alia, involuntary, inescapable, man-made, poorly understood by science or subject to contradictory statements (Calman, Bennett and Coles, 1999). There is recognition that anxiety about possible health problems, in the context of the proximity of possible hazardous industrial facilities, may itself undermine health (Hallman and Wandersman, 1992; Moffat, Phillimore et al, 1995).

Many regard the mass media as playing a major role in the development of anxiety about risk. Furedi (1997), for example, argues that the media emphasises the hazards associated with new technologies, foodstuffs and dangers to children. While experts can measure risk and (attempt to) communicate their measurements to the public, this information is filtered through various media and interpreted by social groups and individuals (Kasperson, Renn, Slovic et al, 1988; Kasperson, 1992; Pidgeon, 1999; Pidgeon, Kasperson and Slovic, 2002). Amplification of specific hazards by the media appears to play an important role in shaping perceptions of risk and associated behaviour (Miller, Kitzinger et al, 1998; Reilly, 1999). Philo, for example, provides evidence that individuals give precedence to media accounts of people with mental illness as dangerous and violent over their own contradictory experiences even when they recognise that the media accounts may be fictional, as in soap operas (Philo,1999b).

The social amplification of risk framework has been used by a number of researchers to provide plausible accounts of risk-related behaviour. Breakwell and her colleagues, for example, have explored the ways in which social amplification has influenced responses to BSE, AIDS and the 1995 'Pill Scare' (Breakwell and Barnett, 2000). However critics have observed that this framework fails to take full account of the diversity of the media and its dynamic role as a symbolic information system, or of the active nature of the accomplishment of associated sense-making by lay audiences (Petts, Horlick-Jones and Murdock, 2001; Horlick-Jones, Sime and Pidgeon, 2002). In addition, other conceptual frameworks which arguably offer important insights are not incorporated into the social amplification framework. Over twenty-five years ago, for example, Cohen (1972) showed how the emergence of 'moral panics' reflect deep-seated tensions within society which find expression through the identification of 'folk devils'. Another important dimension is identified by Glassner's (1999) more recent work on North

American society which recognises that the promotion of some risk issues satisfies specific interests.

*Research* Measures which, in some objective sense, improve safety and health are unlikely to reduce anxiety unless health agencies are able to address the wider range of associated issues and concerns that have meaning for lay audiences. There is scope for research on a number of dimensions of the relationship between objective measurement or expert judgements and lay or subjective assessment of risk. These include research into:

- *The public acceptability of health risks especially within the context of health impact assessment* This area of study could also include studies of individuals' understanding and responses to social and health care changes. This can be done in terms of individuals' perceptions of the utility of acquiring additional protection, for example through private insurance, or their perception of the likely consequences of new technologies such as gene therapy. While there is a growing body of research on individuals' perceptions of health risks, there is less research on the ways in which changes in perception impact on changes in behaviour and how differences in the decision context affects behaviour, for example difference between older people and young adults with children;
- *Societal health decision-making* Accompanying the UK Government's 'modernisation' process is a new emphasis on involving lay publics in decision-making and standard-setting (HMG, 1999). This trend is also present in current academic thinking about risk and health decision-making in democratic societies (Stern and Fineberg, 1996; Rowe and Frewer, 2000). More work is needed into how social science research can be incorporated into the design and evaluation of such processes of public involvement;
- *Anxiety and health care* There is potential for research on the formation and implications about fear and anxiety. There is little understanding of the extent to which screening, diagnosis or treatment generate uncertainty, how this uncertainty influences and is managed by individuals and whether changes in practice can be demonstrated to have an impact on anxiety. Areas which might be particularly fruitful include cancer which appears to be a 'fear factor' in its own right;
- *Impact of medical mishaps and disasters* The continuing occurrence of such failures poses serious questions about how changes in technology, modes of economic behaviour and organisational practices may combine to generate unanticipated vulnerabilities (Turner and Pidgeon, 1997). Freudenberg's (1993) suggestion that the impact of a perceived background 'ticking' of such organisational failures may engender a generalised sense of anxiety and erosion of trust in expertise ('recreancy'), offers an intriguing way of understanding certain aspects of contemporary sensitivities to, and political potency of, risk issues (see also Horlick-Jones, 2001b).

## 3. RISK AND HEALTH: INSTITUTIONS AND SOCIETY

In section 2 we focussed on health risk and the individual. In this section we develop our review by examining the ways in which institutions, such as health care agencies and regulatory bodies influence perceptions and management of risk in society. We examine the role of risk *within* organisations such as health care agencies, the role of regulation and regulatory bodies, and the future of risk in society.

### 3.1 Managing Health Care: Medical Errors and Clinical Governance

*Context* The government expects the NHS to protect patients and is committed to systems which 'minimise the risk to ... patients and improve the quality and safety of patient care (DoH, 2000a, p. 90). However the government acknowledges that its standards are not currently being universally achieved. For example a recent retrospective review of records identified an overall adverse event rate of 11.7% with a third resulting in moderate or greater disability or death (see Vincent, Neale and Woloshynowych, 2001 and linked editorial comment by the President of the Royal College of Physicians, Alberti, 2001). Some work has been undertaken on the socio-legal aspects of health and risk especially in relationship to medical negligence. Fenn and his colleagues have explored the changing pattern of negligence by analysing the database of medical negligence claims of Oxfordshire Health Authority. They identified an increasing propensity to claim (0.46 to 0.86 closed claims per 1000 finished consultant episodes between 1990 and 1998) and increasing costs (£52.3 million in 1990-1 to £84 million in 1998). They estimated that the overall liability was in the order of £1.8 billion rather than the £2.8 billion estimated by the National Audit Office (Fenn, Hermans and Dingwall, 1994; Fenn et al, 2000).

There have been a series of well documented health disasters including, unacceptable paediatric heart surgery failure rates at Bristol Royal Infirmary and the failure to identify the harmful activities of the general practitioner Harold Shipman. As part of the post 1997 'modernisation' strategy the current government is commitment to developing a more effective system of risk management. It has put in place a framework which includes clinical governance, changes in professional regulation, national service frameworks and the National Institute for Clinical Excellence, the Commission for Health Improvement and a new system reporting of near misses (DoH, 2000b). The Department of Health has identified and targeted for improvement four area in which there is a regular pattern of errors: maladministered spinal injections; obstetrics and gynaecology; errors in the use of prescribed drugs; and suicides by hanging from non-collapsible rails on wards (DoH, 2001, p. 45).

In some services concerns about the safety of the public, service providers or patients have become so great that traditional approaches to decision making are being replaced with approaches which give primacy to risk (Heyman, 1998 and Waterson, 1999). Traditionally public services including the health service have allocated resources and planned services to meet need. To acquire the necessary information to do this they have used systems of assessment and surveillance to identify need and developed audit to assess the extent to which service provision meets need. The shift from need to risk is most evident in services that have experienced high profile disasters such as child protection (Munro, 1999) and mental health

services (Department of Health, 1996). In other services risk can be seen as a way of managing the ethical problems associated with rationing resources (see for example Prior (2001) on risk assessment as a mechanism for rationing in clinical genetics and Hughes and Griffiths (1996) for an analysis of the use of risk in decision making in cardiac surgery).

*Evidence* There is a well-developed body of work and evidence on the ways in which organisations manage risk in routine and exceptional conditions and the circumstances in which they fail to do so (Royal Society, 1992; National Audit Office, 2000). As Douglas (1992, pp. 12-13) has pointed out two organisations performing the same function may have quite different ways of managing risk. Max Weber (1947) seminal analysis of bureaucracies identified a rational system in which the systematic accumulation of knowledge is used as the basis for making decisions and managing risk. However subsequent work has criticised traditional bureaucracies as risk averse. For example Burns and Stalker (1961) identified bureaucratic or mechanistic organisation with rigid hierarchical structures which did not provide incentives for risk taking and innovation. They contrasted these with organic organisations based on flexible, task-oriented teams that emphasised the importance of rapid and creative responses to opportunities. Hood and his colleagues (1992) have developed this approach in their review of organisational management of risk. They identified seven areas in which organisations can make choices about how they manage risk. For example they indicated that organisations can use internal incentive systems to manage risk. They can either have systems that emphasise the allocation of individual responsibility and blame or systems that emphasise the importance of learning rather than punishing mistakes. Although it has not proved easy to build up an evidence base to support this analysis, organisations often have inconsistent policies and formal policies do not necessarily determine informal practice (see for example Alaszewski et al, 1998), it has influenced current developments and underpins the creation of a National Patient Safety Agency whose function is to create a process of learning from adverse events and near misses 'to improve patient safety by reducing the risk of harm from error' (DoH, 2001, p. 31).

Given the hazardous nature of many of the activities of the NHS (Crawshaw et al, 2000) and the vulnerabilty of many of individuals who use it service, it is inevitable that there are concerns about failures to manage risk or medical mishaps (Rosenthal et al, 1999). The Phillips Inquiry report identified in the BSE case the now-familiar pattern of events that result from organisational failure of foresight, a series of systemic and communication failures contribute to oversight of an 'incubating' hazard which ultimately leads to disaster (Turner and Pidgeon, 1997). The continued occurrence of high profile 'adverse events' is one of the drivers of the modernisation programme and especially of the development of clinical governance (Bogner, 1994, DoH, 1997; Toft, 2001).

As Flynn (2002) notes the precise definition and meaning of clinical governance is vague and elusive. However it is possible to identify two related themes, participation and knowledge management. The movement from government to governance involves a shift from narrow centralised control to a broader participation involving wider participation in risk management and decision making (for corporate governance see Turnbull, 1999 and NHS, Donaldson, 1998). This broader participation is designed to empower patients by seeking their views, involving them throughout the NHS, providing redress and better information (Halligan and Donaldson, 2001). Corporate governance also involves a shift from knowledge and risk primarily embodied in and managed through professional practice to evidence-based knowledge encoded in guidelines and subject to audit and scrutiny (McColl, and Roland, 2000, for 'embodied' v 'encoded' knowledge see Lam, 2000).

Despite the centrality of risk to current development of clinical governance within the NHS, much of the literature is concerned with exhortations to shift organisational and professional cultures (McNee, 2001, Masterson and Teare, 2001, Bunch, 2001 and Cowan, 2001). As Walshe (2000a) noted in his review of the evidence on clinical governance while 'techniques such as risk management are... [widely used].. we have relatively little research evidence or empirical evidence on which we can base an assessment of how well they work, or of why they do (or do not) work. (p. 3)'. Walshe and his colleagues (Walshe et al, 2000b) undertook a study of the implementation of clinical governance in the West Midlands. Respondents did acknowledge risk management was an important component of the reforms for example in shifting organisational culture from blaming and punishing to learning and restoring public confidence by preventing medical disasters, however risk management did not form a prominent theme within their accounts of the actual changes. Similarly Franks (2001) reviewed 21 of the first annual clinical governance reviews and concluded that they indicated an organisational separation between risk and other elements of clinical governance. This separation may mean that the participative and knowledge management components of clinical governance are separated with knowledge and risk management developing within a traditional risk-averse bureaucratic framework. Such deviations from an integrated approach to risk management have been observed in a number of related fields. In their study of risk management in learning disability services Alaszewski and Alaszewski (2001) identify a tension between empowerment and protection. Similarly, Kemshall (2000) in her review of risk management in the Probation Service noted a the dominance of narrow protective approach in probation practice, prompting her to argue for a broader participative approach.

*Research* Given the changing framework of risk management in health care there is considerable scope for examining the ways in which the changes are shaping the construction and management of risk. Possible areas of research include:

- *Organisational foresight and rationality* including the ways in which organisations gather risk-related information, by engaging in surveillance and 'scanning the horizon', how they decide on what constitutes appropriate knowledge to gather, and the processes entailed in interpretation and making sense of risk issues;
- *Influence of difference organisational contexts* The existence of different patterns of organisational behaviour emphasises the influence of specific organisation contexts on the management of risk and points to the need for detailed investigations of risk-related practices within their specific settings (Harper, O'Hara et al, 1997; Rose, 1999; Horlick-Jones, 2001a);
- *Professional responses to risk governance* It will be important to examine whether health professionals accept or seek to resist the change, how it influences their decision making and practice, the ways in which they communicate risk issues to patients and whether there is evidence of defensive practice;
- *Risk versus need* There are concerns that the move from need to risk involves an implicit rationing of services. There is therefore scope for comparing the systems based on needs versus those in which risk is prioritised in terms of systems of information collection and assessment, decision-making and management systems, methods of evaluating outcomes and the ways in which evidence is used both in practice and in service developments.

### 3.2 Managing Risk in Society: Regulatory Systems

*Context* McKeown (1976), in his study of the improvement of health in the modern period, identified environmental improvements as the major contributory factor. These improvements were associated with the more effective regulation of hazards through public health measures. Changing economic and social conditions brought with them the development of new challenges to health, including by-products to industrial development, and now we are faced with transnational, even global, risks. Modern societies seek not only to manage restricted local hazards, but also widespread hazards, through, for example, the requirement to undertake health impact assessments as part of the planning for major developments, and increasingly, transnational initiatives on global risks such as HIV/AIDS and global warming (see Alaszewski, 2001).

There are a variety of mechanisms which may be utilised for managing hazards. The ESRC Addiction Research Centre reviewed the management of two potentially hazardous substances, alcohol and tobacco, and identified a range of strategies for minimising the harm associated with their use: including increasing price through taxation, restricting advertising, restricting availability especially to vulnerable individuals such as children and regulating production and distribution (Robinson, Maynard and Chester, 1989, Godfrey and Robinson, 1990). Within modern societies mechanisms have been introduced for managing hazards across the spectrum of settings from domestic and workplace environments, to the range of public spaces. Regulation of domestic environments is based on a balance between protection and privacy and generally is used as a last resort to protect the vulnerable, for example children from abuse (Munro, 1999). Even in care environments such as residential homes there is a concern to balance regulation with informality (Holland and Peace, 2002). In Britain the working environment is regulated through a well-established legislative framework. The corresponding regulatory agency, the Health and Safety Executive, is committed to not only preventing harm but also to making all working environments safer and healthier places (HSE, 2001). Regulation of public spaces is fragmented, and tends to focus on specific hazards, particularly those associated with offsite hazards of industrial plant, dangers associated with the built environment like fire, and various modes of transport. The increasing complexity of urban environments, and associated processes like the 'privatisation' of public space (Davis, 1990; Horlick-Jones, 2001b), is significantly shaping the physical and institutional character of health risk for the majority of the population.

*Evidence* Hood and his colleagues groups (Hood et al, 1999; Hood et al, 2001) have developed a conceptual framework for exploring the ways in which risks can and should be regulated. They argue that it is rational for the state to intervene and regulate risks where there are market or legal failures: when it is too expensive or too difficult for individuals to either obtain the necessary information to identify a hazard or take protective action. For example the costs of identifying and protecting against domestic radon are limited compared to cost of identifying and avoiding ambient benzene. They review the regulation of four hazards, radon, ambient benzene, dangerous dogs and pesticides identifying aspects of regulation which either exceed or fall short of expectations. The variations were explained by government response to public opinion or producer or professional pressure. For example higher than expected regulation of pesticides related to public attitudes to pesticides as a 'dread' risk and lower than expected regulation of ambient benzene related to the unpopularity of heavy restrictions on traffic in town centre. On

the other hand higher than anticipated regulation of radon related to professional pressure or capture by the nuclear science community through the National Radiological Protection Board.

Burgess has developed this analysis of regulation with a comparative study (2002) of the responses in five countries to the hazards associated with mobile phones and especially mobile phone masts. Burgess found that while the risks were the same in different countries the regulatory responses were highly varied. In Scandinavian countries despite high levels of mobile phone usage and masts, there was little evidence of concern and regulation. In contrast in Australia and especially Italy there were high levels of concern plus close regulation of masts. Burgess provides evidence that in both countries politicians aligned themselves with pressure groups articulating public concerns through the media. Burgess suggests that rather than assuaging fear regulation actually reinforced it creating a cycle of increased regulation. Turner (2001) in his review of risk and globalisation argues that it is possible to identify cycles of regulation and deregulation in which government desire to provide security leads to increased regulation and as the costs of this regulation become evident pressure builds for deregulation.

These findings point to the different ways in which knowledge can be used to identify and manage risk and to the deeply political character of risk in real-world settings. It also underlines the dangers in seeking to understand risk-related behaviours, whether by individuals, regulatory agencies of governments, entirely in terms of the neutral and disinterested exploitation of knowledge. In the context of occupational health, work by Nelkin and her colleagues (1985) and Bellaby (1999) has clearly shown how vested interests, different conceptual assumptions, professional biases, industrial relations and political ideologies all contribute to shaping the very definition and assessment of risk, as well as its management, in workplace settings. Abrahams (1995) has examined the ways in which risk assessments have been structured within their commercial and regulatory settings and, in particular, the influence of commercial interests on the process alignment of drug regulation in the USA, Japan and EU (Abraham and Reed, 2001) and on the approval of Halcion in the USA (Abraham, 2002).

Systems regulating risk utilise risk-benefit analyses. In the newly created regulatory body, the Food Standards Agency, the components of this system are clearly identified. The Agency is committed to assessing the costs and benefits of its actions on those affected included consumers and to undertaking risk assessments based on the 'best available methodology, drawing on expert scientific advice and making appropriate allowances for the inevitable uncertainties involved' (MAFF, 1998, p. 6). Risk-benefit analyses involves not only assessment of risk but also evaluation of the consequences (Wilson and Crouch, 2001), and there is a substantial body of research which attempts to explore the public acceptability of different levels of risk and its willingness to pay for safety and risk reduction (Covey, 2001). However, as we have seen in sections 2.1 and 2.2, lay perceptions of risk issues do not relate to objective or expert assessments in any simple or direct way and this would appear to present profound difficulties for such willingness-to-pay methods which seek to use objective measures of risk (Wynne, 1992; Horlick-Jones, Sime and Pidgeon, 2002). Recent work, including UK-based research sponsored by the Health and Safety Executive, has attempted to reconcile willingness-to-pay methods with insights produced by social science research into risk perception (Burton, Chilton, Covey et al, 2000). Although progress has been made, it is clear that much more research is needed to resolve conceptual anomalies and generate practical policy tools.

*Research* There is potential for researching the ways in which health risks are identified and regulated both nationally and transnationally.

- *Societal context of risk regulation* The work of Hood and his colleagues (2001) indicates that regulatory processes are influenced and structured by broader social processes and there is scope for exploring both how these influence the 'demand' for regulation and the operation of regulatory systems. Whilst there is evidence that regulatory bodies are beginning to take into account social science research findings in their policy development (HSE, 2001), there is considerable scope for both conceptual and practical work in this area.
- *National regulation* At the national level there is scope for examining the rules for setting priorities and for making decisions about investments, for example in terms of absolute value for risk reduction in an area as judged by professional, public and politicians; compared to the relative value in terms of extent of risk reduction gained by a given investment given current state of the art; compared to trends in risk in the area. It could also involve exploration of different institutional settings for identifying and managing risks and their relative benefits;
- *Impact of different perspectives on risk regulation* Given the range of perspectives on the management of hazards (see for example Daykin and Doyal, 1999), there is a need to gain a better understanding of the nature of such discrepancies in order to identify policy options that are able to address public concerns, and to ensure that resources are allocated to ensure that given risks receive appropriate prioritisation in comparison with other threats to public health. Regulation of risk in the workplace would be a fruitful area for such work.
- *Regulation and risk transfer* There is little research on behavioural responses to regulation. For example Adams (1995) postulated the existence of a risk thermostat which serves to undermine the aims of regulation, for example if interventions such as seat belt legislation makes drivers feel safer so that they compensate by driving more dangerously the net effect of the intervention is not to reduce the overall level of harm but to redistribute it from drivers to pedestrians and cyclists, effectively the risk is transferred between individuals. Similarly differential national regulatory regimes may transfer risks. If one regime permits activities, for example the release of GMOs, which is prohibited in another then the activity and associated risks may be transferred. Thus comparison of regulatory regime could examine whether there is a transfer hazardous activities to less rigorous regulatory environments.
- *Transnational regulation* At international level there is scope for researching the ways in which different types of health risks are regulated, for example those associated with different forms of population movements, with mobility of practitioners, the movements of health hazards and those associated with licit and illicit trade in materials used in medical care, for example drugs or body parts.

### 3.3 Managing the Future: Societal Change, Health and the Precautionary Principle

*Context* While there are debates over concepts such as globalisation there can be no doubt that the major scientific, technological, economic and social changes of the 20th Century have changed both the nature, pattern and perception of health risks. In advanced industrial societies demographic and social changes such as ageing populations, increases in single person households and concentration of economic activity, wealth and population in metropolitan areas have all changed the distribution of risk. The technological changes have affected the nature of work with increased stress and inequalities, transport with increased individual mobility and changing exposure to health risks and the ways in which illness and health can be managed. The importance of providing the public and service users with information was acknowledged in the government's response to the BSE Inquiry report (HMG, 2001) and underpins the current

programme of modernisation of public services (HMG, 1999, Horlick-Jones, 2001a). A number of policy options are captured in the recent Parliamentary Office of Science and Technology report *Open Channels: Developing Public Dialogue in Science and Technology*. Stakeholder involvement now plays an important role in policy-makers' thinking about risk-related decision-making in a diverse range of areas from hazardous waste management to the examination of treatment options in general practice as in the development of patient-centred medicine (Stewart et al, 1995).

*Evidence* Beck's (1992) and Giddens' (1990) conceptualisation of these social and technological changes as a significant development that underpins a new social formation, 'Risk Society' has been highly influential and has begun to stimulate empirical research. Beck argues that the development of modern technologies have created hazards which in many cases can only be identified by experts using appropriate technologies. The nature and distribution of these hazards is a major political and social concern in advanced industrial societies. As Webster (2002), Director of the ESRC/MRC programme on Innovative Health Technologies, notes such technologies have play a central role in this process in the health field by destabilising traditional notions of medical authority and trust and creating new dilemmas over the meaning of health and illness. They are reshaping major areas of human experience, for example facilitating individual construction and manipulation of body (Featherstone, 2000), and creating major ethical and commercial impacts (Glasner and Rothman, 1999, Petersen and Bunton, 2001). There are major concerns about the risks and acceptability of these technologies (Siegrist, 2000) and the government is seeking to address these concerns by increasing public participation and improving the transparency of decision making (HMG,1999).

The global impact of technological and economic change and the changing pattern of and responses to risk was initially conceptualised in terms of environmental changes. Beck's initial analysis (1992) of modernity focussed on globalisation, risk and the environment. While this area remains important (O'Riordan and Timmerman, 2001), there is increased awareness of the impact of changes on health and health care. For example the development of new infectious diseases (30 previously unknown since 1970s including HIV/AIDS, DoH, 2002), the spread of diseases normally associated with tropical areas such as Malaria to temperate areas as a result of tourism or migration (Prothero, 2001; DoH, 2002) or the development of strains of microrganisms immune to normal drug therapies such as MRSA (Andersen, Lindemann and Bergh, 2002, Campillo, Dupeyron and Richardet, 2001). The development of biotechnology such as the genetically modified organisms has major implications for ethics (Almond, 2000) and the environment and health (Achyra, 1999, De Waele, 1997). These developments have drawn attention to the role of science and expertise in predicting and managing future change and potential risks.

One response to the inherent uncertainties of prediction has been the 'precautionary approach' in which the onus is placed on innovators to demonstrate that proposed will not have harmful effects (Kreibel, Tickner and Epstein, 2001) and involves a negotiated consensus over risks and benefits (Calman and Smith, 2001). There are concerns that a systematic use of the precautionary principle would undermine scientific research and innovation (Holm and Harris, 1999). Burgess (2002) argues that in the case of mobile phones and mobile phone masts the application of the precautionary principle increased the very concerns it was designed to assuage. Despite these concerns there is evidence of the use of the precautionary principle. For example there has interest in using this approach to manage the release of potentially harmful agents such as genetically modified organisms into the environment. For example in Germany the Federal Environmental Agency accepts that the precautionary principle should be applied in cases where

the extent or probability of damage are uncertain (Steinhauser, 2001). There is evidence that interest in this approach is spreading to health and health care (Calman and Smith, 2001). A medline search identified 72 citation of which 45 related to health and explicitly argue for the extension of the precautionary principle. This is most evident in public health, Goldstein (2001) and Kreibel and Tickner (2001). Interest in the precautionary principle has been manifested in a range of health issues including food production (McMichael, 2001), xenotransplantation (Michie, 2001 and Julvez and Vannier, 2000), endocrine disruption agents (Vandelac, 2000), genetics (Rosa, 2000), drugs (Joly, 2000), blood transfusion (Sicard, 2000), breast cancer (Davis, Axelrod, Bailey, 1998) and children (Tickner and Hoppin, 2000).

*Research* While there is work on the impact of social and technological changes on risk and health, it is currently relatively piecemeal and there is scope for developing research in a number of ways:

- *Mapping risk futures* the impact of research on the human genome has stimulated a body of research on the social and ethical issues and the management of the new knowledge. However these studies tend not to be placed within a wider framework, a mapping of 'risk futures', the changes in knowledge, hygienic technologies and the interaction between social, economic changes that will all shape the future pattern and management of health risks. Such a mapping exercise would identify trends and facilitate the development of proactive policy and debate;
- *The social context of changes in medical technology* Attempts to understand and manage the rapidly-changing circumstances that we face will need to take into account the ways in which both the production of medical knowledge, and the implementation of clinical and other health-related practice, are both accomplished within specific contexts (Atkinson, 1995; Hughes and Griffiths, 1996; Prior, 2001). This is another (ostensibly technical) area where social science knowledge and methods can provide invaluable insights into the real-world nature of professionals' practical reasoning and skilled practice. Similarly, technological innovation in the health area, rather than providing changes that can be understood purely in terms of their technical characteristics, have the capacity to both shape, and be shaped by, the working context into which they are introduced (Faulkner and Kent, 2001);
- *Public acceptability and consultation* The Government following the failures associated with BSE (HMG, 2001) accepts the need to explicitly involve the public in policy making about risk issues and the development of technologies increases the scope for intervention that have social and ethical implications and raise issues of public acceptability. Mechanisms for effective public participation need to be developed and evaluated taking into account 'deliberative processes' (Renn, Webler and Wiedermann, 1995; Petts, 2001);
- *Responding to non-clinical medical emergencies* There are difficulties in managing such emergencies associated with, for example the accidental or deliberate release of pathogens such as anthrax, in terms of evaluating associated risks and hazards, predicting the resource demands of response, and crisis management (Murray, 2002; Farrow, Wheeler et al, 2000). There is scope to utilising social scientific knowledge in preparing for and managing such situations (Rosenthal, Charles and 'T Hart, 1989; Horlick-Jones, Amendola and Casale, 1995; Turner and Pidgeon, 1997).

## CONCLUDING COMMENTS: THE NEED FOR INTERDISCIPLINARY RESEARCH

It is clear from our review of current research that substantial social science-based knowledge about risk and health already exists. However there are a number of impediments that need to be overcome before that knowledge can be more generally applied within various spheres of health-related practice. Much of this knowledge has been developed through, and is embedded in, the study of specific health issues and medical conditions, and while its relevance is made explicit in managing these issues and conditions, its broader applicability may be obscure. This perhaps is evident, for example, in the study of HIV/AIDS. As we noted, within recent social science-based work on health-related risk perception over half the references cited in BIDS relate to HIV/AIDS, and this research has important implications in other health fields, yet it is very difficult to discern a significant number of examples of such knowledge transfer. An additional impediment may be that the 'risk' implications may not be evident in a specific body of health-related knowledge. In our discussion of risk and affective states, for example, we referred to the literature on worried well, affective disorders and the anxiety associated with cancer screening and treatment. Within those fields of study, these phenomena may not necessarily be conceptually linked to risk, or articulated in terms of the language of risk.

Risk, by virtue of it bringing together the social and the material in a dynamic way, inevitably poses serious practical questions concerning the implementation of research that crosses boundaries between conventional disciplines (Freudenberg, 1988; Horlick-Jones, 2000). Tait and Lyall (2001) in their review of ESRC funded interdisciplinary research did not identify any practices within ESRC inhibiting interdisciplinary research though they felt that there was a lack of clear guidance. They did identify barriers in the universities and the Research Assessment Exercise. The discipline-oriented structure of academic social science, although important with respect to maintaining academic excellence does present difficulties when seeking to address hybrid areas like risk. As Shove (1998) has noted, not only does the academic system value what she terms 'disciplinary purity', but takes measures to guard it. Indeed, exaggerated and confrontational positions are sometimes adopted as part of what Gieryn (1983) has termed 'boundary work', as scientific professionals seek to enhance the status of their activities by portraying their work and that of 'non-scientists' as separated by a categorical demarcation.

Health issues, similarly, might be expected to have generated much cross-disciplinary research activity (Dowie and Elstein, 1988; Rosenfield, 1992). Where it has occurred, such interdisciplinarity has tended to bring together 'hard' science disciplines (Wilson, 1990; Vandenberg, 1995; Anderson, 1999; Gershon, 2000) or teams of professionals with different technical specialisations (Hinojosa, Bedell et al, 2001). A search of medical and health-related journals on the *ScienceDirect* database revealed only around 300 references to interdisciplinary research, and these were dominated by work which brought together 'hard' disciplines. There are examples of health-related work which reports on integration between clinical science with social science (eg Mayer, J., 1989; Meyer, R., 2001), however, as Rosenfield (1992) observes, such collaborations have been limited by 'powerful centifugal forces'. Blaxter (1999) notes that the recent ESRC Risk & Human Behaviour Programme, although established in part to promote cross-disciplinary work, in practice produced only a few examples of 'truly' interdisciplinary research.

Within industry, some researchers have argued that fundamental changes are taking place in the way knowledge is produced (Gibbons, Limoges et al, 1994; Nowotny, Scott and Gibbons, 2001), being rooted in a 'transdisciplinary' focus on application rather than scholarly reflection. Analagous changes involving academic and public-sector researchers may be observed in connection with, for example, genomics research (Anderson, 1999; Gershon, 2000). However these changes seem to largely reflect 'hard science interdisciplinarity' rather than 'hard/soft integration'.

The conventional notion of knowledge 'dissemination' suggests a linear process from production to exploitation. Newby (1994) has noted that in practice the application of new knowledge comes about as part of a complex interactive process. When social science has been successfully applied, what mechanisms have been responsible? A recent study argues that 'influence' is a better description that 'exploitation' in most cases (Rayman-Bacchus, Williams and Bechhofer, 1998). Another mechanism is provided by the what one might call 'knowledge brokering'. A range of quite disparate organisations serve this function with respect to social science risk knowledge: for example the Royal Society (1992), the Royal Geographic Society and the Royal Society of Medicine.

New forms of relationship with 'users' would entail a level of engagement in problem situations characteristic of so-called 'action research'. Such problem-oriented research tends to be associated with good working relationships between practitioners and fewer difficulties with cross-disciplinarity. As Eden and Huxham (1996) observe, such engagement provides understanding that is 'grounded in both data and action' (see also Reason and Bradbury, 2000).

The challenge of 'hard/soft interdisciplinarity' has recently been taken up by the UK research councils, as, for example, in the form of the recent transdisciplinary research seminars competition, the water industry workshop, and the ESRC/MRC collaboration which sponsored this review. One possible related model for institutional change is provided by the formation of the Canadian Institutes for Health Research (CIHR) which brings together government agencies responsible for medical research, and health research and development (Bisby, 2001). This change has resulted in a programme of research focused on a number of cross-cutting health themes, and which includes social, cultural and environmental determinants of health. It seems clear that these disciplinary and research management considerations need to play a central role in formulating future priorities for research council-supported work in the area of health and risk.

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