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Original Citation

Heyman, Bob, Alaszewski, Andy and Brown, Patrick (2012) Values and health risks: An editorial. *Health, Risk & Society*, 14 (5). pp. 399-408. ISSN 1369-8575

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VALUES AND HEALTH RISKS: AN EDITORIAL

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Short title: Values and health risks

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ABSTRACT

This special issue is the second in a four-part series *Health Care Through the 'Lens of Risk'* which focus on risk categorisation, valuing, expecting and time-framing respectively, and published or to be published in 2012-2013. The present editorial introduces the issue of risk valuing in relation to an interview-based article and four substantial research papers. It will be argued that the notion of 'adverse event' projects negative value onto events themselves, directing attention away from the observer's active judgemental role. The location of value judgements in the perspectives of social actors allows their potential variability to be more clearly recognised. This issue will be explored in the editorial which introduces papers concerned with hard drug consumption, self-hurting, the community rehabilitation of forensic mental health service users who have committed serious offences against other persons, the treatment of anal cancer and the perspectives of young pregnant women. The common theme linking these papers is the positive valuing of risk-taking officially designated as unacceptable.

Keywords: risk, health risks, values, the 'lens of risk', risk analysis

VALUES AND HEALTH RISKS: AN EDITORIAL

This editorial introduces the second of a series of four special issues, *Health Care Through the 'Lens of Risk'*, which will be published in *Health, Risk & Society* over the next year. The series will focus on health risk-thinking, with its starting point the Royal Society *Risk* report (1992, p. 2) definition of risk as *the probability (3) that a particular adverse (2) event (1) occurs during a stated period of time (4a), or results from a particular challenge (4b)* (our numbering in brackets). The report framed this definition as the grounding for quantitative risk assessment, portrayed as '*a powerful tool for investigation and reduction of risk*'. The ambition of measuring risks, viewed as if they were material entities possessing the objective properties of adversity, probability and temporal extension, would not be put forward with so much confidence today, 20 years after the report was published. The integral role of the observer in the construction of risks, as argued for in a later section of the Report itself (Pidgeon *et al.*, 2002), is now widely recognised. Nevertheless, the Royal Society definition offers a good starting point for an interpretive deconstruction in which events are reframed as categories, adversity as negative value, probabilities as uncertain expectations and time periods as time frames (Heyman, Shaw, Alaszewski and Titterton, 2010). The present special issue, concerned with valuing, follows the first (Volume 14, number 2, 2012) which focussed on health risk categorisation.

Although each of the four special issues in the present series will foreground one of the four elements folded into the Royal Society and other definitions, their interconnectedness ensures that one cannot be adequately conceptualised without consideration of the others. In relation to valuing, a contingency will only become a recognised risk if it involves outcomes which matter to the members of a particular social group. The chance of losing ball-point pens has received little research attention, except perhaps among their producers, despite its annoyingly high probability! Conversely, an outcome cannot be valued in the general terms of risk analysis unless a diversity of unique events have been homogenised into a single differentiated category such as child-abuse, terrorism or depression. Hence, risk construction and (negative) valuingⁱ must occur conjointly, since only what is categorised can be valued as an abstract entity, while the trivial will not be marked out as worthy of consideration as risky. Social groups who think in terms of risk attempt to organise themselves around contested and shifting selections of possibly occurring unwanted events which are plucked from the infinity of contingency, i.e. from the boundless set of what **might** come to pass.

Continuing with the theme of interrelationships between the four identified elements of the risk compound, even when probability calculations draw on experience, as when rates of health outcomes are observedⁱⁱ, the results will depend upon value-driven, often implicit choices about what to look forⁱⁱⁱ, and about how to group the unlimited variability of nature into categories. In relation to the latter, probabilities calculated through induction from observed frequencies can only be applied to categories which specify what should and should not count as a case. In consequence, one way to protect a valued activity from the charge of irresponsible risk-taking is to differentiate safe and dangerous sub-categories. This socio-cognitive manoeuvre will be documented in the present special issue in relation to illicit drug consumption (Caiata-Zufferey, 2012) and self-hurting (Barton-Breck and Heyman,

2012). Similarly, choices about time-framing and time-discounting can be used to change the value of an outcome, for instance if the effectiveness of an intervention is only considered over a short period so that relapses occur beyond the observer-set temporal horizon. The UK smoking cessation programme which measured 'successful' quitting over a four week time period (The NHS Information Centre, 2008) provides a good example, as does attempts by the nuclear industry to set a 500 year temporal horizon for considering the health cost of radioactive waste (Atherton and French, 1999).

Valuing is the most ethereal of the four risk elements folded into the Royal Society definition quoted above. Categorisation and time-framing can sometimes be anchored to qualitative shifts such as the presence of a carcinoma or death, and probabilities can be grounded in induction from observed frequencies. However, values can **only** be located in perceivers, without whom events would merely happen. Some of the dauntingly complex issues which lurk concealed in the apparently '*surprisingly simple*' process of everyday and formal cost-benefit analysis (Wolff, 2007) will be briefly outlined below in relation to the contributions of the included original papers. The editorial writers aim not to argue against utilitarian rationality, a quixotic and self-defeating endeavour since collective and individual healthcare decisions must be made somehow, but to counterpoint the apparent simplicity of this form of rationality against the many complexities which it glosses over.

ADVERSE EVENTS VERSUS VALUING HEALTH RISKS

In keeping with the predominantly objectivist proclivities of its senior authors, the Royal Society *Risk* report (1992, p. 3) defined '*an adverse event*' as '*an occurrence that produces harm*' as a result of '*damage*', in turn rendered as '*the loss of inherent quality suffered by an entity (physical and biological)*'. Common biology combined with shared culture (but complicated by multiculturalism and value pluralities) ensure that social actors will often agree at least about what is and isn't adverse, even if they differ as to the degree of adversity to be attached to a particular 'event' category. Nevertheless, as already argued, value arises in the observer, not in what happens. As Rescher (1983, p. 27, quoted author's emphasis) put it, people '**ascribe values to negativities**'. Shakespeare's Hamlet made a similar point when he asserted that '*There is nothing either good or bad, but thinking makes it so*' (Hamlet, Act II, Scene ii). In consequence, the same outcome category may be valued differently (Rosa, 2003). Both Rescher, writing about risk philosophy, and Shakespeare, speaking through his imagined character, felt that they were challenging common thinking which **projects** the observer's values onto events, so that their perceived adversity is experienced as an inherent external property. As long as social actors share the same values, such epistemological distortions will matter little. However, they can result in conflict derived from the mystification of value divergences, as when parents who positively value the birth of a child with disabilities encounter health professionals who consider such births to be a self-evidently adverse events (Oulton and Heyman, 2009). Projection of values onto events serves the function of reducing value divergences, thereby facilitating the alignment of social groups, and shoring up prevailing social power structures, however temporarily^{iv}.

Recognising that valuing is an action gives rise to a whole set of issues which may be obscured by its projection onto events, starting with the question of what a person does when they value. At the minimum, valuing might be reduced to demonstrating a preference. In this sense, tropisms, simple electronic devices wired up to move towards light sources, might be said to 'value' light. This behavioural definition gives rise to the possibility that individuals or social groups do not understand their own values, as when employment practices (Bell and Blanchflower, 2010, p. 4) and matched guise experiments (e.g. Purkiss *et al.*, 2006) reveal the collective negative value, in many developed societies, of non-standard race or ethnicity. Although demonstrated in what social actors actually do, most people, including the present authors, would reject this 'value' as repugnant if asked. As argued by Slovic (2012) in this special issue with respect to smoking, affect can shape behaviour outside conscious awareness, a 'valuing' process which stands in contrast to deliberative rational decision-making.

The minimalist behavioural approach to valuing gives rise to at least two fundamental problems, briefly considered below: that of encompassing moral considerations; and that of taking into account multiple qualitatively distinctive consequences.

The interplay of preferencing with moralising

Calculation of expected value entails identifying a set of consequences for a possible action, multiplying the positive or negative value of each by its probability, and then summing these products. In the health domain such actions can take a huge variety of forms, e.g. health promotion, implementing a medical intervention, discharging a residential patient or removing a child from their family. (Some of the many issues associated with utility calculation will be briefly outlined in the next section.) It might be supposed that preferencing can be cleanly separated from moralising, as argued by Nord (1999, p. 18).

Broadly speaking, the utility of a health state is the same as the "goodness" of it to the individuals who are in it. By goodness I thus mean the well-being or quality of life associated with the state. (Note that goodness in an ethical sense is not implied).

The above description excludes a key ingredient of valuing, its penetration by moral judgement (Erikson and Doyle, 2003), which greatly complicates quantification. Any number of thought experiments can be devised to illustrate that excluding moral considerations leads to culturally absurd conclusions. For instance, since women live longer than men, *ceteris paribus*, a given medical intervention will generate more quality-adjusted life years (QALYs) if focused on them rather than on men. Since this case has not been made, it can be concluded that the hard calculation of net utilitarian benefit is being softened by the tacit application of implicit ethical principles. Nord (1999) tried to include distributive justice in his expected value equations. But once this consideration has been recognised, the question of trade-offs between fairness and utility has to be addressed. For example, in relation to randomised controlled trials the 'myth of equipoise' (Fries and Krishnan, 2004) requires expected value equivalence between patients entered into the different arms of a study to be maintained. However, the long-term collective interest in

weeding out ineffective treatments leads to even the terminally ill being given placebos rather than medicines which offer their only hope of survival. The operation of mathematically sophisticated expected value equations requires the application of potentially contentious presuppositions, some involving delicate but unspoken moral judgements. Human valuing cannot be reduced to mere personal preferencing, as could be done for tropisms, without creating intuitive absurdities which arise from violations of tacit encultured moral considerations.

The problem of multiple consequences

The most important and difficult value issue for risk assessment and management derives from the inevitability of human actions having multiple incommensurable consequences. The notion of the '*adverse event*' draws attention towards an apparent singularity, and away from the widening chains of causality which spread out from any health-relevant action. Risk factor-outcome linkages such as smoking-lung cancer, cannabis-psychosis, obesity-diabetes themselves reflect tacit cultural work which foregrounds a single collectively selected consequence (Heyman, 2010, pp. 45-46). But blessings are almost invariably mixed, and most clouds have a silver lining. Even an overwhelmingly beneficial intervention such as immunisation must be weighed against a very small possible risk of brain damage. Conversely, the generally lethal habit of smoking can confer some emotional benefits and contribute to stress management (Graham, 1987), can be used for weight control, and has been linked to reduced risks of Alzheimer's disease (Lee, 1994) and endometrial carcinoma in postmenopausal women (Weiss, 1985)^v. In general, official healthcare narratives tend to downplay such ambivalences, particularly when costs and benefits can be viewed as finely balanced, as in the cases of breast cancer screening, moderate alcohol consumption and sun exposure^{vi}.

The iron law of unintended consequences ('Sod's Law' in the UK) almost guarantees that any major collective and/or individual healthcare intervention will have unanticipated unwanted effects. For instance, widespread use of pharmaceutical products has conferred huge health benefits, but also released a potentially significant cocktail of risky chemicals into rivers and drinking water (Houtmana, 2010). Similarly, antibiotics have saved millions of lives, but their widespread and often inappropriate use in response to social, cultural and economic pressures (Jin *et al.*, 2011) is creating super-resistant strains of bacteria, which, in some cases of tuberculosis, have become untreatable (Shelko, Van Wart and Francis, 2009). Research into the epigenetic effects of famine on pregnant women and their unborn children suggests that the latter are at greater risk of obesity and diabetes, and that this effect is transmitted over more than one generation (Godfrey *et al.*, 2007). Hence, even specifying the consequence list is problematic. Peterson (2007, p. 74) argued that '*there might be more than one way to construct a list of attributes for a given decision problem*'. He also suggested that writers who recommend quantification of expected value across sets of qualitatively different consequences may be '*not aware of the problem*'. Consequence lists tend to be produced on metaphorical backs of envelopes, and are inevitably encultured via the operation of affect, taste, habitus and intuition (Brown, 2012).

Given that a consequence list has somehow been constructed, a daunting set of issues confronts anyone attempting to validly assess expected value (Heyman *et al.*,

2010, pp. 66-76). On account of their incommensurability, consequences can only be summed through conversion to a common value currency. But any fuzziness in the conversion terms will allow an indefinite number of summative values for a decision to be generated. Peterson (2007, p. 81) concluded from consideration of just this one issue, that *'our present theories of rationality are not sufficiently well-developed'*. Decision-makers may simply not be able to guesstimate how they might feel about an unexperienced risked future health-related state such as being blind, requiring a permanent colostomy bag or caring for a child who has a severe disability. But healthcare decisions grounded in such value anticipations are frequently irreversible. The value which an individual places on a health outcome may change through experience which is itself dynamically affected by the consequences of risk management decisions. Living with a stoma provides a particularly clear example of both value fuzziness and dynamics which are difficult to anticipate at the time when choices must be committed to. Patients may, on average, overestimate the adversity of subsequently living with a permanent stoma (Bossema *et al.*, 2007), and some of the early problems appear to be experienced as less adverse after a year of usage (Grumann *et al.*, 2001). This analysis represents social actors as passive experiencers of value, but individuals may attempt to actively **mitigate** risks, as illustrated by Barton-Breck and Heyman (2012) in this volume, a possibility which renders static cost-benefit analyses more or less useless.

Calculations of net expected utility are 'directionless' in terms of **who** gains and loses, but this issue is critical to the politics of risk decision-making, for example between those who will profit from pollution and those who will have to live with it. And the values of health outcomes may be dialectically affected by their probabilities and temporal characteristics. For instance, the multiplicative computation built into cost-benefit analysis relies on the dubious assumption that members of the public will equate a low probability/high adversity outcome with a high probability/low adversity one if their measured utilities are similar (Renn, 2008). Health economists may discount time at the long-run true financial interest rate (Viscusi, 1992), but the judgements of people confronting serious health problems can be much more complex. For example, patients with lung cancer have been found to prefer to avoid surgery which would increase their overall five year survival chances at the price of an immediate increased risk of death resulting from the operation (McNeil, Weichselbaum and Pauker, 1978). This finding, perhaps generalisable to other conditions, suggests that patients faced with a high risk of death may discount time at a particularly high average rate.

As decisions must somehow be made, the calculation of expected value on the basis of available evidence may offer the best practical guide to collective and individual risk management decision-making. Where the *ceteris paribus* assumption can reasonably be made, e.g. in relation to two cancer treatments with different financial costs and efficacies but similar side-effects, such calculations can be undertaken with reasonable confidence. However, Sod's Law guarantees that this simple template is rarely adequate. In the more usual and more complex cases, a becoming modesty, sometimes lacking in those who spawn 'metrics', is required. In such cases, 'encoded' best practice (Alaszewski, 2010) grounded in expert evidence and opinion must be viewed with a degree of caution.

THE PAPERS IN THIS SPECIAL ISSUE

The present special issue offers an editorial on smoking and values, an interview-based article considering the views of Joost van Loon and Ortwin Renn (Brown and Heyman 2012) on the social science of risk-thinking, and four original research papers concerned with the ways in which individuals make value judgements when confronting health risks.

Slovic (2012) in his editorial draws upon an extensive body of research to challenge calculative models of young people's decision-making about whether to take up smoking. He argues that many simply do not consider long-term risks, and are swayed by the iconography of shiny packaging and glamorous associations. Although the much derided 'nanny state' has proved remarkably successful in reducing the prevalence of this lethal habit in many developed societies, tobacco companies have found new markets in vulnerable poorer countries, and certain forms of tobacco advertising are currently allowed in the USA, as Slovic points out.

The interviews with Ortwin Renn and Joost van Loon (Brown and Heyman, 2012) touch upon a range of salient themes pertaining to debates about values, amongst other aspects of risk. In focusing on the perceiving subject, certain social scientific approaches to risk have mapped out a range of value formats from a highly constructionist position. Though coming from somewhat different disciplinary backgrounds, both theorists seek to affirm a more realist ontology while recognising the important role of socially-embedded subjects. Van Loon, for example, develops the possibility of distinguishing between real and phantom risks from the starting point of conceptualising risks as virtualities.

The four original research papers offer explorations of value issues in specific health risk domains. Caiata-Zuffrey's (2012) analysis of drug-taking illustrates the interrelationship between risk categorisation and valuing. She interviewed ex-drug addicts who considered that they could safely use cocaine or heroin recreationally. In the paper, she analyses the socio-cognitive steps which respondents took to differentiate their actions from dangerous drug-abuse. Whether or not such distinctions are accepted in official circles, the risk management decision-making of those who think like her research participants cannot be understood outside this framework. A similar differentiation of recreational and dangerous drug use has been noted in North-East England (Crawshaw and Bunton, 2009).

Barton-Breck and Heyman (2012) consider the perspectives of individuals who have self-hurt as a way of coping with mental distress and who have never engaged with healthcare systems for this reason (as is the case with the majority of those who self-hurt). The research shows that some individuals normalise self-hurting as equivalent to taking aspirin or a stiff drink, homogenising it with socially acceptable means for dealing with stress; and that most attempt to mitigate perceived risks of exposure, escalation and injury. However, some research participants experienced unanticipated longer term negative consequences. Emergent difficulties included: decline in the efficacy of self-hurting linked to a strengthening propensity towards escalation; existential isolation resulting from long-term concealment; and exhaustion from living with underlying emotional problems which self-hurting had allowed respondents to postpone dealing with. This paper thus documents some of the

issues outlined above: the role of 'thinking' in judgements about the value of apparent negativities such as severe physical pain; the importance of risk mitigation which allows decision-makers to attempt to actively change expected value; and the temporal dynamics that make the future value of an action trajectories difficult or impossible to anticipate at the time when individuals become more or less committed to it.

Coffey (2012) discusses the findings of a study in which he compared the perspectives of discharged forensic mental health service users and professionals charged with their care in the community. This issue has received little investigative attention as most research has been concerned with in-patient care or risk management in decision-making about discharging patients who have a history of offending. His research well illustrates the issues arising from multiple consequences, differences in value direction and value dynamics. Staff prioritised the risk of discharged patients reoffending. They implemented intensive monitoring processes in order to reduce the chance of members of the public being harmed. The subjects of monitoring were concerned primarily with the risk of their community integration being impeded by this very public prophylactic process. One perhaps Panglossian service provider argued that patients could benefit therapeutically by rising to the challenge of becoming locally accepted despite being overtly marked out as risky.

Finally, Heyman *et al.* (2012) offer a single case study of a woman who received successful treatment for anal cancer. The paper explores the ways in which one individual can put together multiple risk and value considerations in their own personal way. The authors attempt to explain from their informant's perspective why she metaphorically 'risked exploding' by 'absconding' to have sex with her boyfriend with stitches still in place immediately after undergoing major surgery. The paper shows how an action which seems irresponsibly and irrationally dangerous from a medical perspective can be understood in relation to the complex range of risked consequences over and above survival which trouble a particular person.

CONCLUSION

This special issue is concerned with the role of valuing in the perception and management of health risks. Adversity is always ascribed to, and never an intrinsic attribute of, events which are themselves constituted by culturally mediated categorisation processes. If it is accepted that values are always located in the 'thinking' of social actors, it follows that the view of adversity as a property of events themselves must be underpinned by unreflective projection. Value externalisation is embedded in everyday reasoning which tends to be carried over into healthcare practice. This tacit socio-cognitive manoeuvre directs attention away from the possibilities of different value positions being adopted. It thereby helps to align organised social action, but only at the price of suppressing alternative views and inviting resistance.

The papers presented in this special issue all challenge prevailing value schema in different ways. From the perspectives of social actors themselves, 'hard' drugs may be taken softly; self-hurting may be prescribed for mental health problems; the community integration of serious offenders against the person can be facilitated by

the curtailment of external monitoring; and personal relationship issues can appear as important as bodily health. Better understandings of such contrarian perspectives can facilitate improved communication with representatives of standard views. But doing so requires their subversive implications to be reflected on.

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ENDNOTES

ⁱ Its negativity has often been challenged, but in late modern societies designation as a risk requires at least one adverse contingency to be identified. The idea of positive risk-taking (Titterton, 2005) invites consideration of the counterbalancing benefits, but does not remove the core precautionary strand in risk-thinking. Invoking 'risk' requires prophylaxis to be at least considered. Linguistic choice of the term 'danger', in contrast, encodes the observer's belief that a risk **ought not** to be taken (Heyman *et al.*, 2010, pp. 25-27).

ⁱⁱ Inductive probability estimation can only be attempted for high frequency events such as population mortality. Large data sets can usually be established for health risks. This approach cannot be applied to low frequency events such as nuclear accidents, although the rate of disasters is beginning to look suspiciously high.

ⁱⁱⁱ Notoriously, US General Tommy Franks claimed in 2002 that "*We don't do body counts.*" (The Guardian Newspaper, 22nd October, 2010). This comment on civilian deaths during the second Iraq war has stuck in the public imagination, and offers a poster-child for value-driven risk selection.

^{iv} According to the historian Josephus Flavius, the Israelites of the first century AD were less than impressed by the Roman gift of games involving gladiatorial combat and human sacrifice (Eisen, 1998, p. 494). It may appear obvious to neutral observers that members of one society view as an abomination activities which those with a different world-view consider to represent the height of civilisation. But such radical value divergences are not always so apparent to those who are immersed in a particular cultural conflict.

^v As discussed in this special issue (Slovic, 2012), tobacco companies attempt to **attach** positive value to smoking through shiny packaging and its representation as cool and sophisticated. In the UK at least, despite impressive advances in the public health fight against smoking, mass media vehicles such as BBC drama continue to portray the deliberate inhalation of tobacco smoke as a glamorous life-style choice.

^{vi} The first author was amused to read a recent UK newspaper article enjoining him to take the opportunity afforded by a rare break in the rain-clouds to absorb some mid-day sun. For many decades, he had been covering up, using high factor sun blocks and staying in the shade. Unfortunately for those who seek to promote simple health promotion messages, it is currently believed that sun exposure may both increase the risk of skin cancer and reduce the risk of multiple sclerosis.