

## Post-Print

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Health, Risk & Society* following peer review. The definitive publisher-authenticated version [Hooker, C., Carter, S. (2009), and Davey, H. 'Writing the risk of cancer: cancer risk in policy documents.' *Health, Risk and Society* 11, 6, 541 - 560] is available online at <http://www.tandfonline.com/doi/full/10.1080/13698570903329458>

## Writing the risk of cancer: Cancer risk in public policy

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### Acknowledgements

The authors thank colleagues at VELiM for their thoughtful comments, and the reviewers who provided detailed and constructive criticism. The work leading to this paper was funded by Australian National Health and Medical Research Council Grant number 457387.

### Abstract

In this paper we examine how cancer risk is written in cancer policy documents from the English speaking OECD nations. We offer an audit of the multiple ways in which cancer risk is conceptualized and presented in health policy and professional contexts with the long term aim of comparing this with lay conceptualizations. Our study sampled cancer policy documents produced by six nations, the World Health Organisation and the International Union for Cancer Control since 2000 and analysed them iteratively through questions and codes. Whilst the documents contained a comprehensive range of concepts and locations for cancer risk, our analysis found two predominant representations: firstly, well established metaphors that depict cancer as uniformly dreadful and life threatening; and secondly, through a concentration on five behavioural risk factors (tobacco smoking, drinking alcohol, inadequate nutrition, sun exposure and physical inactivity) and one bodily state (overweight). We discuss the implications of this dual focus and of other tensions within ideas about cancer risk that we identified for risk communication.

We begin this paper in the same place that most policy documents on the subject do: by reminding the reader of how dreadful cancer can be and therefore how important cancer is. Depending where one lives in the world, a cancer diagnosis will happen to somewhere between one in three and one in seven people (World Health Organization, 2002), and result in considerable anxiety, physical suffering and not infrequently, death. Cancer has considerable potency in our social imagination, signifying something to be particularly dreaded (Sontag, 1990). For governments, cancer represents high health care costs as well as loss of productivity. Consequently, scientists, public health scholars and professionals and health policymakers have

devoted considerable attention to the question of how best to deal with cancer – how to prevent its occurrence where possible, and how to respond to it when present.

We share these concerns, but are approaching them from a somewhat different angle. All cancer policy documents agree that cancer prevention and control rests in large measure on the public, on individual actions and choices. But the processes by which people take actions or make choices are complex, potentially arising from within themselves, their relationships, and their social context and environment (Carter, Hooker & Davey, 2009). To that end we have begun a large qualitative project exploring lay conceptions of cancer risk. To interpret and make use of the results of this project, we wanted to develop a better understanding of how cancer risk is conceptualised and represented by the health policy and health professional community. We reasoned that if we know what ideas about risk appear in cancer prevention activities and educational efforts in public health, we will be in a better position to assess the degree to which they fit, influence and/or diverge from public ideas about cancer risk. In the long run we can then use the results of our study to make suggestions about strategies or interventions targeting cancer risk.

In this paper we therefore examine how cancer risk is written in cancer policy documents from the English speaking OECD nations. We offer an audit of the multiple ways in which cancer risk is conceptualized and presented. To professional readers, especially those who may have some involvement in cancer control, our account may often seem like a statement of the obvious, since it records the informational content and conceptual outlook of our peers. But our study, inspired by recent social studies of risk, also aims at some reflection on how risk is conceived and written in cancer policy, at least in these countries.

Risk is an increasingly central issue in health and public policy. As epidemiological research into the causes and progress of illness has become increasingly complex, public health policy has shifted toward identifying and managing risks rather than simply managing individual people or places (Petersen & Lupton, 1996). At the same time, a variety of social and psychological studies have indicated that public understandings of – and responses to – risks can be quite divergent from those of experts, influenced for example by social or individual values, cognitive biases and social structures (Pidgeon, Kasperson, & Slovic, 2003; Slovic, 2000). In fact experts themselves are also influenced by all these factors and their conceptions of risk are not simply the straightforward statements of fact experts often believe them to be (Slovic, 2000). And the more technically specific public health conceptions of risk are, the more they will pose a challenge for public communication and public acceptance.

Moreover, critical social studies of risk have indicated that risks are not only empirically observable and measurable hazards but that they are also always at some level social constructions, that is, a product of the ways we make sense of the physical and social worlds around us (Lupton, 1999; for a discussion of how this works empirically, see (Pidgeon et al., 2003)). Risk constructions are influenced by, among other things, our current knowledge, what we choose to research, the way different hazards are depicted and by ‘mental maps’ of hazards, which include imagery and associations (Morgan, Fischhoff, Bostrom, & Atman, 2001). Studies have demonstrated that risk may also serve as a ‘forensic’ device to enable the distribution of blame and responsibility (Douglas & Wildavsky, 1983). Our study of cancer policy documents was informed by these critical studies of risk. In our examination we sought not merely to

identify what sorts of things were regarded as risks, but how the documents wrote risk in terms of values, outcomes and social positioning.

This study is not an assessment of the quality or content of the policy documents. We are not advancing an opinion as to what are real or not real risks for cancer nor about the most appropriate policy solutions. We are, however, interested, in how conceptions of risk are linked to some solutions rather than others, and what the implications of these associations might be.

## Methods

We sampled the major cancer policy and planning documents of the English speaking OECD countries, plus two international bodies (the WHO and the UICC), regarding these documents as sufficiently expressive of the conceptions of cancer risk held by health professionals and health policy analysts in these nations to serve as our primary data. We used the Internet and the databases Medline and ISI Web of Knowledge to identify policy, strategy or planning documents relevant to cancer control from the United Kingdom (UK), the United States of America (USA), Canada, Ireland, New Zealand and Australia, as well as the WHO and the UICC. Similar to Anderiesz, Elwood and Hill (Anderiesz, Elwood, & Hill, 2006) we included only documents which: 1) addressed cancer as whole; 2) presented plans, policies, strategies or positions on cancer risk or prevention; and 3) were published in 2000 or later. Documents focused solely on clinical service improvement to people who were unwell were excluded. The final sample and search strings are listed in Tables 1 and 2 respectively.

**Table 1: Search strategies**

Database/ website	Search string/ strategy
Google	<i>cancer (risk OR prevention OR control) (policy OR strategy OR plan)</i> search repeated six times, each time limited to the domain of one country of interest (the United Kingdom, the United States of America, Canada, Ireland, New Zealand and Australia respectively)
WHO website	Searched by hand using the inclusion criteria
UICC website	Searched by hand using the inclusion criteria
Medline	<i>(exp neoplasms) AND (exp primary prevention OR exp health promotion) AND (public policy OR exp Health Facility Planning/ or exp Health Planning/ or exp Community Health Planning/ or exp Social Planning/)</i> limited to English language reviews
Web of Knowledge	<i>Tl=cancer prevent* OR Tl=cancer control OR Tl=cancer polic* OR Tl=cancer strateg* OR Tl=cancer plan*</i> limited to the years 2000-2007 and to reviews in English.

**Table 2: Final sample of documents**

Australia	<p>The Cancer Council Australia. National Cancer Prevention Policy 2004-06. NSW: The Cancer Council Australia, 2004.</p> <p>National Health Priority Action Council (NHPAC). National Service Improvement Framework for Cancer. Canberra: Australian Government Department of Health and Ageing 2006.</p>
Canada	<p>Prevention working group. A Cancer Prevention System for Canada: preliminary recommendations for leading an integrated approach to primary prevention in cancer control. Ottawa: Canadian strategy for cancer control, 2002.</p> <p>Schabas R, Boscaino A. Report of the National Symposium on Cancer Prevention. Ottawa: Canadian Strategy for Cancer Control, 2003.</p> <p>Health Canada. Progress Report on Cancer Control in Canada. Ottawa: Health Canada, 2004.</p> <p>Primary prevention action group. PP-AG Special Issue Bulletin. Ottawa: Canadian strategy on cancer control, 2005.</p> <p>Establishing the Strategic Framework for the Canadian Strategy for Cancer Control. Ottawa: Canadian strategy for cancer control, 2005.</p>
Ireland	<p>National Cancer Forum. A Strategy for Cancer Control in Ireland. Ireland: Department of Health and Children 2006.</p>
New Zealand	<p>Minister of Health. The New Zealand Cancer Control Strategy. Wellington: Ministry of Health and the New Zealand Cancer Control Trust, 2003.</p> <p>New Zealand Cancer Society. Three Year Strategic Plan for National Health Promotion, 2005-2008. New Zealand Cancer Society, 2004.</p> <p>Cancer Control Taskforce. The New Zealand Cancer Control Strategy: Action Plan 2005–2010. Wellington: Ministry of Health, 2005.</p>
UICC	<p>UICC Global Cancer Control. Introducing UICC Global Cancer Control. Geneva: UICC, 2005.</p> <p>UICC Global Cancer Control. National Cancer Control Planning Resources for Non-Governmental Organizations. Geneva UICC, 2006.</p> <p>Conference delegates. World Cancer Declaration. Washington, DC, USA: UICC World Cancer Congress, 2006.</p>
UK	<p>Department of Health. The NHS Cancer Plan: a plan for investment, a plan for reform. London: Department of Health, 2000.</p> <p>Cancer Research UK. The Cancer Challenge: Cancer Research UK's Agenda for Change. London: Cancer Research UK, 2004.</p> <p>Department of Health. The NHS Cancer Plan and the New NHS: providing a patient-centred service. London: Department of Health, 2004.</p>
USA	<p>Division of Cancer Prevention and Control. Guidance for Comprehensive Cancer Control Planning Volume 1: Guidelines. Atlanta, GA: Centers for Disease Control and Prevention, 2002.</p> <p>Division of Cancer Prevention and Control. Guidance For Comprehensive Cancer Control Planning Volume 2: Toolkit. Atlanta, GA: Centers for Disease Control and Prevention, 2002.</p>

National Cancer Institute. Cancer Trends Progress Report: 2005 update. Bethesda, MD: NIH, DHHS

Holly L. Howe XW, Lynn A. G. Ries, Vilma Cokkinides, Faruque Ahmed, Ahmedin Jemal, Barry Miller, Melanie Williams, Elizabeth Ward, Phyllis A. Wingo, Amelie Ramirez, Brenda K. Edwards,. Annual Report to the Nation on the Status of Cancer, 1975-2003, featuring cancer among U.S. Hispanic/Latino populations. *Cancer* 2006;107(8):1711-1742.

Division of Cancer Prevention and Control. 2006/2007 Division of Cancer Prevention and Control Fact Sheet. Atlanta, GA: Centers for Disease Control and Prevention, 2007.

American Cancer Society. Advocacy and Public Policy: American Cancer Society, 2007.

American Cancer Society. Community Programs and Services: American Cancer Society, 2007.

Centers for Disease Control and Prevention. Preventing and Controlling Cancer, The Nation's Second Leading Cause of Death 2007. Atlanta, GA: U.S. Department of Health and Human Services Centers for Disease Control and Prevention Coordinating Center for Health Promotion, 2007.

Division of Cancer Prevention and Control. National Comprehensive Cancer Control Program Factsheet. Atlanta, GA: Centers for Disease Prevention and Control, 2007.

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WHO

World Health Organization. National Cancer Control Programmes: policies and managerial guidelines, 2nd edition. Geneva: World Health Organization, 2002.

Fifty-eighth World Health Assembly A58/16. Provisional agenda item 13.12: Cancer Prevention and Control Report by the Secretariat. Geneva: World Health Organization, 2005.

Fifty-eighth World Health Assembly. WHA58.22 Cancer Prevention and Control. Geneva: World Health Organization, 2005.

World Health Organization. Cancer Control, Knowledge into Action. WHO guide for effective programmes: planning. Geneva: World Health Organization, 2006.

World Health Organization. Cancer Prevention: World Health Organization, 2007.

World Health Organization. WHO Cancer Control Strategy: World Health Organization, 2007.

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The sample was not expected to be representative. It was a purposive sample, a common sampling strategy in qualitative research (Bryman & Burgess, 1999). In this instance, the purposive sample was designed to provide us with a broad range of recent policies or strategies which had more or less the same end (to prevent or manage cancer risk in a population) and arose from countries similarly well resourced. The limitation to English-language policies was to ensure the quality of analysis and interpretation, as we could not afford to purchase translation of policy documents which often stretched to hundreds of pages. The inclusion of trans-national organisations was intended to ensure that we included the work of peak international bodies which we considered likely to be a driver for policy-making in the OECD nations we sampled. It turned out that the documents in this sample were significantly similar to one another, both in

terms of their data content and their suggested approaches, orientations and solutions, suggesting that the health policy communities in these nations did indeed share some common conceptions of cancer risk. We are conscious that the limits of our sampling strategy also limit the generalisability of our results. It would be fascinating to institute comparisons with the risk concepts, policies and health promotion strategies in the less affluent nations, and those with quite different histories of health organisation (e.g. Scandinavia or Japan), that were excluded for feasibility reasons from our study.

Our analysis was emergent, iterative and rigorous. We adopted the questioning approach formulated by Foucauldian discourse analysis (Shaw & Greenhalgh, 2008), but ensured that the analytic questions we posed arose not only from concerns about power, positioning, etc, but equally from the internal concerns of the documents themselves, identified through a process of close coding and comparison. The documents were read by each author separately and closely coded for themes relevant to concepts of risk. After comparing the initial codes and identifying emerging patterns, we jointly arrived at a list of analytic questions to ask of each document. These questions were oriented around the language and concepts used to represent risk, the location of the risk and the stakeholders affected by the risk. The final list of questions is given in Table 3.

**Table 3. Analysis worksheet structure and questions.**

**General**

- What is the stated purpose and target audience for this document?

**Analysing cancer/risk**

- Do we need to sustain or improve our health, or fight or avoid disease?
- Does cancer/risk live purely in the domain of health, or is it contextualised in whole-of-life or whole-of-government or whole-of-society?
- Is cancer a disease or a risk? Is the focus on cancer/s or causes of cancer/s or the risk of cancer/s or risk factors? Where is risk risk, and where is risk cause? Are we dealing with determinants or risks?
- Where the focus is on risk, what is the risk/threat of, or what kind of risk is being discussed? Risk of death? Harm? Suffering? Diagnosis? Lost years of life? Incidence? Survival?
- Is cancer/risk considered to be a unitary disease or a set of different diseases? If some site specific cancers are singled out for attention, why might that be so?
- Is cancer/risk one of many chronic diseases, or is it a unique disease?
- How is cancer/risk quantified?
- Is cancer/risk frightening? Is it an epidemic? Is it urgent? Is it a challenge? Does it need to be fought? Or are there positive opportunities and solutions?
- To what degree is cancer/risk positive as well as negative (e.g. Are benefits as well as hazards emphasised? Is loss of pleasure as well as avoidance of health impacts acknowledged?)
- How black and white is the cancer/risk? Does it exist in degrees?

**Where is cancer/risk located in this document?**

- Who is 'at risk'?
- Where is cancer/risk located? In individuals? Societies? Cells? Behaviour? Environment?
- Genes? Screening facilities? Treatment capacities?
- Are there people in the documents? Is there any sense of the people who whom these policies are targeted, or is the level of focus more abstract than that?
- To what degree is cancer/risk a product of social structures/determinants?

### **What is the relationship between cancer, risk and intervention in this document?**

- Is cancer/risk certain or uncertain? To what degree are we confident about the science? How is uncertainty managed? What is the role of knowledge in the management of cancer/risk?
- Is the relationship between risk and cancer simple or complex? e.g. Are people being killed or experiencing an elevated risk? Are they balancing risks and benefits of several diseases?
- Are the risk factors acting on one another to make it more complicated?
- What actions constitute a proper response to cancer/risk? (e.g. protection, avoidance,
- positive actions, structural interventions, information giving/knowledge building, creation of a 'system')
- Are there unproblematic solutions, or are solutions problematic, complex or difficult? Are there solutions?
- Where are the solutions targeted? (At the cancer? The risk? The behaviour that creates the risk for the cancer?) What will the outcome be? (e.g. Money freed up for other things?)
- Decreased suffering? Healthier populations? Saved lives? The eradication of cancer?)
- Whose job is it to do something about cancer/risk?

We divided the policy papers between the authors and worked through them again asking the list of questions that we had developed, regularly comparing and discussing our answers. As we worked we collected direct quotations from the documents that encapsulated each point of analysis. A third round of analysis was then entered upon, in which answers were compared across documents and higher-order themes were developed and elaborated, often involving a return to the documents for rechecking and extending our concepts.

We note that in keeping with our larger aim of supporting improved health communication with lay publics by identifying how and where their risk constructions differ from those in the expert and policy communities, we focused our analysis on the prevention sections of policy documents. We did not closely analyse the sections on cancer treatment and end-of-life care, although these were often substantial components of the policy documents, in large part because people with positive diagnoses were represented as a specific population with needs that policy should meet, rather than with risks that policy should minimise. However, our analysis did include questions on risk and treatment, and we do note that the policy documents did at times identify health systems and health services (or barriers to accessing and using these) as risks in relation to cancer.

### **Results**

Our presentation here, in three sections, mimics the common structure of many (but not all) of these documents. They typically began with introductory statements about the character and lethal capacities of cancer, then devoted the most substantive section to the presentation of information about cancer prevention, diagnosis and management. Policy recommendations tended to follow.

#### **1. Representations of cancer**

'Cancer. The word still conjures up deep fears of a silent killer that creeps up on us without warning. Cancer, evoking such desperation that it has become a metaphor for grief and pain, a scourge straining our intellectual and emotional resources' (World Health Organization, 2002).

### Cancer/risk as metaphor

As exemplified in the quote above, the risk that these documents chiefly addressed was 'cancer' itself. Cancer – rather than, for example, behaviors, exposures or genes – was often the risk at issue, and documents spoke of factors that increased people's risk 'of cancer' (Department of Health, 2004), which explicitly did not differentiate between (inter alia) the risks of being diagnosed with (a) cancer from those of dying from cancer(s) . This presentation was so pervasive that we formulated it as 'cancer/risk'.

'Cancer' itself still retained much of the metaphor and imaginative potency first identified by Susan Sontag – firstly, by being equated with, or denoting, suffering and death. That is, in the simplest and clearest terms, in these documents the risk of cancer was the risk of death and suffering. Throughout the documents, cancer and cancer/risk were depicted in the language of fear, death, and pain. Those particularly designated for policy intervention included 'individuals [who have] an increased chance of premature death' (The Cancer Council Australia, 2004) and social groups with a 'worse survival rate'. Documents frequently opened with strong statements about the lives lost and/or the suffering caused by cancer and spoke in negative, antagonistic, even militaristic terms about 'beating', 'fighting' or 'avoiding' cancer (Department of Health, 2004; The Cancer Council Australia, 2004).

'We want a future free from the fear of cancer', (Cancer Research UK, 2004).

'Cancer is one of the biggest killers in this country' (Department of Health, 2000)

Since the sample as a whole clearly perpetuated the dominant negative metaphors Sontag identified around cancer more than fifteen years ago, it is significant that in some documents cancer/risk was also presented as part of wider *positive* policy activity: sustaining or improving health. The UK Department of Health, for example, framed cancer control in terms of 'achieving a healthier population' (Department of Health, 2004). However, although cancer policy was sometimes situated as part of a chronic disease policy programme, this did not necessarily generate positive frames for cancer/risk (e.g. (The Cancer Council Australia, 2004)). While cancer/risk was occasionally reframed in terms of gaining and sustaining health, (National Cancer Forum, 2006) in general risk was represented without a corollary of benefit, except in terms of reductions of illness and death.

### Counting cancer/risk

'Quantification rhetoric' (Potter, Wetherell, & Chitty, 1991) employed in the documents, and especially evident in the highly rhetorical introductory sections, significantly strengthened this representation of cancer/risk as literally *dreadful* by stamping it with scientific authority. Quantification was offered in terms that increased the salience and dread of cancer (Slovic, 2000), and could thus be expected to increase the reader's perception of the importance of cancer/risk. Quantifications were similar across the sample, and included the following:

- i. the number of people diagnosed and/or killed by cancer each year, expressed as a fraction (e.g. 1 in 4 (Department of Health, 2000)) a mortality rate (eg 240 per 100000(Centers for Disease Control and Prevention, 2007)) or a number of new cases or deaths per day; (e.g. (Department of Health, 2000));
- ii. the position of cancer as a killer, nominating it as the leading cause of death, second leading cause of death and so forth (e.g. (Centers for Disease Control and Prevention, 2007));



- iii. predicted increases as the population ages (e.g. ‘an extra 100000 cases diagnosed each year by 2025, if current trends continue’(Cancer Research UK, 2004)); and
- iv. numbers of hospital admissions (e.g. (Cancer Control Taskforce, 2005)).

Quantification rhetoric was also used in positive terms to encourage risk prevention and risk avoidance by specifying probable quantities of lives saved. The most vivid example of this came from the most recent Canadian policy documents, which offered extensive mathematical modelling drawn from financial risk modelling systems to develop policy recommendations for cancer control. This document abounded in quantification rhetoric that aimed to persuade policymakers of the importance of taking action: ‘Depending on what is done in cancer control in the near future, over the next 30 years Canada could either prevent 1.2 million new cancer cases or see an increase of 775 000 new cancer cases over current projections; and Canada could either prevent 42300 cancer deaths, or see an increase of 415 000 cancer deaths over current projections.’(Canadian Strategy for Cancer Control, 2005 ).

#### Other risk representations

In addition to the language and enumeration of mortality and pain, or potential for prevention, in many documents cancer risk was represented in the more abstract terms common to health planning. In these cases the documents discussed the ‘cancer burden’, an umbrella term that included mortality and suffering but also explicitly represented cancer risk in other dimensions, above all economic impacts and logistical impact on health service resources (Centers for Disease Control and Prevention, 2007; UICC Global Cancer Control, 2006; World Health Organization, 2002). In these documents the risk was not only of death, but of a drain on communal economic resources. Quantification rhetoric was employed to emphasise this risk particularly, eg (Centers for Disease Control and Prevention, 2007; Canadian Strategy for Cancer Control, 2005). These economic costs were the only public risks acknowledged: non-economic risks to, for example, community structures, social geography or health services were ignored. Risks to an individual in their position as a *private* citizen – such as, of grief, social disruption, interruption to employment and so forth – were sometimes mentioned in passing, but were never foregrounded.

#### The function of cancer/risk representations

We saw the primary representation of cancer/risk - as denoting pain and death - as being in large measure strategic and in concord with the aims and conventions of health policy writing. It was rhetoric deliberately employed, usually in a document’s introduction, to claim a high priority on the health policy agenda. This convention is employed frequently across many interests in public health. In some cases these representations also served to explain, account for, and justify the work of the institution that produced the document. The moral and emotional impact of the many introductory statements adducing the mortality and morbidity attributable to cancer served to construct the policy recommendations contained in the document as the compelling and sole solutions. Financial incentives provided a complementary political and pragmatic argument for policy development.

This dominant negative representation of cancer/risk in terms of death and suffering was not merely *persuasive* in tenor. It was also *substantive*: policy endeavour and success was conceptualized and was to be measured against the two goals of reducing death and suffering.

While the primary goal was always to reduce mortality, in some documents attention to suffering was considered a key component of cancer policy. Cancer policy documents perhaps stand out for their specific attention to suffering, rather than simply illness and death as a major concern and risk. The quality and nature of suffering was not elaborated upon, but discussions of the importance of providing appropriate palliative measures for cancer patients and, more rarely, support for friends and family, were included.

The alternative frame of cancer risk reduction as a *positive* opportunity also had substantive implications for policy, which tended to be more focused on prevention and integrated planning strategies (more on this in section III below). In this positive frame cancer policy was nested within loftier ambitions: for example, the Centres for Disease Control (CDC) argued that their cancer policy was a means of 'ensuring that all people... will achieve their optimal lifespan with the best possible quality of health' (Centers for Disease Control and Prevention, 2007), while the Cancer Research UK wrote of the National Health Service changing from being a 'sickness service' to a 'health service' (Cancer Research UK, 2004). (See also Cancer Control Taskforce, 2005; Carter, 2009).

While the language and framing of the policy documents established policy intervention around cancer as morally necessary, they provided no specific detail as to how and where such interventions should occur. Instead, one of the stated goals of most of the documents was to present a summary of information about cancer in order to justify their particular policy recommendations and to allow for future discussion about policy options. Our analysis explored the question of where this information located cancer/risk.

## **2. Information: 'Risk factors'**

'Note that the term 'cancer risk' has a broader meaning than the exposure to cancer risk factors such as smoking. The term covers a wider spectrum of the potential impact of cancer risk from the risk of developing cancer, to the risk of misdiagnosis, to the risk of mistreatment, to the risk of being inadequately supported or cared for in the late stages of terminal illness. The ultimate cancer risk is death. The term also includes the broader effects of cancer including the economic and social impacts of cancer.' Canadian Strategy for Cancer Control, 2005)

'GLOSSARY: Risk factor – an exposure or genetic characteristic that is associated with a health-related condition' Canadian Strategy for Cancer Control, 2005)

The locations for cancer/risk that were mentioned in the sample were manifold. They ran the gamut from genes to environment, from the individual to society, and from prevention to treatment and care. Yet we found that the informational content of the documents effectively generated competing ideas about the risks of cancer. There were significant tensions within the documents, between bio-statistical precision and an undifferentiated sense of danger, between cancer as a unitary phenomenon or as a set of highly differentiated diseases, and between broad-based risk and specific risky behaviours.

### Technical precision versus global danger

Concepts of, and information about, risk were sometimes technical and highly specific, appearing to have been written by experts from epidemiology, statistics and biomedicine. For example, at certain times the documents carefully discriminated between 'risk' and 'cause' on the basis of epidemiology, with 'risk' being calculated from a population health perspective and therefore distinguished from cause in any individual. Distinctions were made between the risks of cancer *incidence*, cancer *mortality* (as an expression of population), and lost years of life. Similarly, where documents offered analyses of or made recommendations about health services, risks of incidence were often clearly separated from risks of mortality, since these were seen to be dependent on inter alia different logistical factors, for example the extent and quality of screening services (Centers for Disease Control and Prevention, 2007). 'Causes' were sorted into categories from 'immediate' (alteration in cell function) to 'genetic' and were differentiated from 'determinants', a broader category that encompassed human behaviour, including very centrally access to health services for screening, diagnosis and treatment (World Health Organization, 2002). To an educated audience, therefore, 'risk' shifted the focus from the causative agent to the (susceptible or otherwise) individual: gene action causes cancer, possessing a gene puts an individual 'at risk' (World Health Organization, 2002). Cancer itself caused death (Health Canada, 2004).

However this technically precise language frequently sat side by side with language that made little or no distinction between 'risk', 'cause', 'influence' and 'determinant' nor showed any basis for contextualising or comparing the *degree* of risk. The presentation of risk often elided its complexity and brought it close to being synonymous with 'cause'. Often 'risk' and 'cause' were used interchangeably. Take, for example, the following, wherein both 'carcinogens' and one's 'personal habits' are effectively designated causes of cancer:

'The disease arises principally as a consequence of exposure of individuals to carcinogenic (cancer-causing) agents in what they inhale, eat, and drink and are exposed to in their work or environment. Personal habits, such as tobacco use and dietary patterns, play the major roles in the etiology of cancer' (World Health Organization, 2002)

As we discuss below, the slippage between risk and cause helped establish the policy view taken in these documents, which was that the appropriate domain for action to minimise cancer risk is largely that of individual behaviour. Treating risks – especially small ones – rhetorically as causes establishes both a moral requirement for action at both policy and personal levels, and helps to establish and maintain policy momentum, for example, in health promotion activities. It also tends to preclude the kinds of cost-benefit policy discussions that are appropriate to risk and that occur in depth in, for example, discussions of screening (eg, how many people do we need, at what level of risk, with what sorts of consequences, to justify the economic and social impacts of any given policy intervention? And what sorts of achievements must the intervention make in order to be judged worthwhile?) This slippage also has significant implications for how lay people might understand and react to cancer risk / cancer prevention messages, which we discuss in section three.

### Cancer as unitary, cancer as fragmentary

There was also a tension between cancer as both a single entity and a multiplicity of entities: 'cancer is a generic term used to describe a group of over a hundred diseases...' (National Cancer

Forum, 2006) (200 in a Canadian document! (Canadian Strategy for Cancer Control, 2005). The risks pertaining to different, site-specific cancers (lung, breast, colon etc) were often carefully distinguished in great detail, yet at the same time, these documents were selected for their orientation around controlling 'cancer', generic and unspecified, and cancer was frequently treated as a unitary phenomenon whose precise manifestation was not important. Of course, many cancers share the same risk factors - tobacco smoking, for example; but this was not presented as a rationale for relating the risks of generic to specific cancer in the documents. Different levels of risk were effectively produced by this movement between site-specific and generic cancer: the narrow and precise risks of a *particular* cancer, versus the risks of 'getting cancer' in general. This movement tended to obscure variation in the *degrees* of risk, allowing smaller, perhaps more contested risks to be rhetorically presented in the same manner as more overarching risks. This has implications for both health communication, since the distinction between generic and specific risks might be confusing for lay audiences, and for policy design and management, since the goals, evaluation criteria, political viability, and so on, of cancer policy will differ as policy focus shifts between specific cancers and cancer in general.

#### Behavioural risk factors and the management of complexity

Although several documents in the sample offered detailed technical discussions of available evidence about how cancer is generated at various physiological locations (eg, changes in cell function and behaviour), ultimately concepts of cancer/risk, and planned policy intervention, concentrated on six behavioural 'risk factors', largely excluding other kinds of risk from the policy discussion. Regardless of the amount and type of technical detail synthesized in each document, 'risk factors' were overwhelmingly the dominant expression of cancer risk across the sample. While technically any kind of thing associated with cancer incidence could be described as a 'risk factor' (Health Canada, 2004), in practice the term denoted 5 individual behaviours - tobacco smoking, drinking alcohol, poor diet, inadequate physical activity and exposure to the sun or to UV radiation - and one risky state, overweight or obesity. (As overweight was regarded in these papers as something an individual could intervene in, we will refer to '6 behavioural risk factors' throughout.) Several of the documents were explicitly structured around these risk factors, discussing each in a separate section and listing site specific cancers caused by or linked to the risk factor in question.

These risk factors were presented and discussed in a highly authoritative, scientific manner. The tone of these sections, in contrast to the highly rhetorical introductory sections, was unemotional and formal. Their authority, like the authority of most modern medicine, arose from epidemiological evidence, and this evidence played a central role. Professionally-oriented documents devoted substantial space to a detailed summary of published research in relation to the six factors. Technical biomedical explanations of the six risk factors were given, sometimes in some detail, and quantification featured heavily. There was, however, some variation on what the percentage of cancer incidence and/or mortality could be avoided by eliminating risky behaviours, both individually and across all six (eg from 50% in a Canadian document (Prevention working group, 2002) to 30% in those of the WHO (World Health Organization, 2002)).

The tone of neutral, scientific authority combined with the lists of site-specific cancers related to each factor had the rhetorical effect of heightening the importance of each factor and underscored the moral requirement and urgency of taking policy action in relation to that

factor. At times the vast tracts of risk constructed were overwhelming – even potentially paralyzing – as little was done to prioritise, order or interrelate the six risk factors and their myriad sequelae. Related to this, although these documents claimed authority, the actual information presented within them concerning the six behavioural risk factors was quite variable.

We read this variation chiefly as a means of managing uncertainty about cancer/risk. Although the evidence for each risk factor could be mathematically complex, in the documents the relationship between risk and cancer was represented as simple. Indeed, mathematics was considered to simplify representations of risk (see especially Canadian Strategy for Cancer Control, 2005). This simplicity was framed as intrinsically necessary for action, via statements such as ‘we cannot let the complexity of the issues relating to physical activity deter us from taking immediate action’ (Canadian Strategy for Cancer Control, 2005). Similarly, while risk factors were described as being ‘linked’ or ‘associated with’ cancers, or cancers were described as being ‘attributable’ to them, in most cases, the degree and quality of the link or association was not discussed. The exceptions were tobacco smoking and sun exposure, which were described in terms of ‘causing’ cancer and ‘killing’ (World Health Organization, 2007). Sections concerned with diet and obesity frequently emphasized the seriousness of the behavioural risk in an especially strong and authoritative tone, yet presented evidence that was by their own admission weak or inconclusive (eg (The Cancer Council Australia, 2004)). There was very little sense of risk factors, or risk factors and other factors, *interacting* to produce a more complicated risk picture. A rare exception was the Canadian strategy for cancer control’s preliminary recommendations document (Prevention working group, 2002).

Thus, while we could implicitly see uncertainty reflected across the documents, the language of risk functioned effectively to *remove* uncertainty as far as policy recommendations for appropriate behaviour change were concerned. This was particularly interesting to us in relation to the discussions of diet and its association with cancers. Documents varied considerably in their representation of dietary issues. Some documents heavily emphasized the importance of diet, while others discussed it only in passing or in association with weight and exercise. Some documents – mostly from the USA – concentrated on the specific risks of eating meat, barbeque and animal fats and the importance of vitamins, to the point where a policy recommendation to subsidize multivitamin supplements for all citizens was advocated as a policy approach (Colditz et al., 2002). Other documents either did not commit themselves to more than a general statement about the importance of eating fresh fruit and vegetables or explicitly stated that information has fluctuated in the area and that more research is needed.

Where cancer/risk was not

Our sample was as interesting for what it did *not* focus on as for what it did. In addition to behavioural risk factors, cancer/risk was acknowledged to exist at the genetic level. Some documents discussed specific cancers, above all, breast cancer, as an expression of genetic risk and therefore identified individuals with family histories of cancer as requiring particular attention and monitoring. Outside these specific cases, however, the documents largely dismissed genes as accounting for cancer risk. Indeed, most explicitly framed genetics as *not* significant in explaining cancer risk:

‘Personal habits, such as tobacco use and dietary patterns, rather than inherited genetic factors, play the major roles in the etiology of cancer’ (World Health Organization, 2002).

Risk was similarly *not* located in the actions of the body, mind or self of an individual, for example, in cells changing their character, in the capacities of the body, or as a result of emotional strain (none of which were mentioned, even in passing).

As with genetics, environmental exposures to specific cancer causing agents were identified as a real subset of cancer risk, but one affecting a very small minority of people. Particular infections, especially hepatitis B and human papilloma virus, were sometimes identified as a subset of cancer risk, as were exposures to aniline dyes, benzene and asbestos (World Health Organization, 2002). No broader environmental explanations of cancer risk, such as urban or industrial pollution, smog, or environmental accumulations of specific substances, were raised as possible issues. Given the persistence of environment-cancer links in the public domain, it is interesting that these latter issues were not raised at all, even to be dismissed.

The dominant concentration on behavioural risk factors largely excluded social issues for the location of cancer/risk in these documents. However, most of the documents identified particular subpopulations as experiencing a higher level of risk of both cancer incidence and cancer mortality. No document suggested criteria for determining which social groups required policy attention and which did not, beyond such general claims regarding higher risk or mortality. While several of the documents identified those in low socio-economic categories as being of ‘higher risk’, documents from different countries often identified a population of particular relevance to that nation: African Americans and Latino Americans in the USA, indigenous Australians in Australia. WHO documents particularly emphasized the degree of cancer/risk in impoverished nations in general, to counter impressions that cancer is majoritively a disease of affluence (World Health Organization, 2002). Documents in the UK, Canada and New Zealand represented social determinants of health issues (such as poverty, gender and ethnic identity) as crucial both in conceptualizing the risks of cancer and in framing policy recommendations for cancer control. However, in most cases, risks related to social inequalities were reducible to or reframed through the dominant discourse of ‘risk factors’. The differences between policy elaborated through the translation of cancer/risk to indigenous concepts of health in Maori New Zealand, and policy oriented around the correction of individual behavioural risk factors, was striking. This has been discussed in greater detail elsewhere (Carter, 2009).

Cancer risk was located not only in patients or potential patients, but also in the machinery and contexts of health service delivery itself. Cancer/risk was explicitly located by the documents along a spectrum from prevention to detection to treatment and care. This leads us to the final pattern observed in the documents, in which risk inhered in multiple locations and could best be represented and reduced through appropriate governance and management.

### **3. Policy: Management and planning**

‘Lack of a comprehensive, systematic approach, weaknesses in organization and priority setting, and inefficient use of resources are obstacles to effective programs’ (World Health Organization, 2002).

‘A multisectoral ‘preventive dose’ of policy and program activity is necessary to achieve a meaningful impact on the prevalence of risk factors for cancer and other chronic diseases’ (Health Canada, 2004).

#### Locating cancer/risk in systems

In many documents, an important focus of concern was the provision and management and resources for detection, treatment and care. In this context cancer/risk was located in inadequacies or other difficulties within the health services themselves. Screening was particularly identified as a locus of risk and talked over extensively within the sample in terms of coverage, uptake, and outcomes (Health Canada, 2004; National Cancer Forum, 2006). At times effective diagnosis (assuming – as was occasionally pointed out – that it was followed by equally effective treatment) seemed to emerge as a primary mechanism of reducing cancer/risk. Yet it was also consistently represented as socially and institutionally risky in itself. For example, social inequality was often mentioned primarily in terms of differentials in access to and take up of screening services (Health Canada, 2004). The often lengthy sections on screening conveyed particularly careful and complex discussions of risk because – alone among the risk factors covered by the sample – they also included discussions of the risks produced by screening itself (such as false positives or negatives, and hence costs and confidence in health services). No strong arguments were made for the expansion of screening services as a primary risk reduction mechanism; on the contrary, discussions were generally cautious about the viability of screening, which was seen as dependent on costs, reliability, and public and medical acceptance.

When the documents focused on policy management and planning, cancer/risk was often framed as arising from the complex interaction of multiple stakeholders, mostly government stakeholders drawn from different subsections of the health and medical community (heart health initiatives, diabetes initiative, physical activity initiative etc (Canadian Strategy for Cancer Control, 2005)). A series of second-order, organizational cancer risks were also discussed: the risks of duplicating institutional effort, gaps in service provision, inefficient service provision resulting from inadequate managerial communication, or increasingly unaffordable treatment or access to treatment services resulting from existing policies, such as regulatory pressure on clinical trial management (Cancer Research UK, 2004). Risk was generated by the prioritization of some services over others. It inhered in the ability of the health care system to support cancer control in general. The sustainability of entire health systems were represented as being ‘at risk’ as a result of responding to cancer (Canadian Strategy for Cancer Control, 2005). In this text, therefore, the risk of cancer was constructed, not as a biomedical phenomenon, but as a problem of government. It resided in flaws of government and management:

‘From a national perspective, the much-needed cancer control continuum architecture for cancer control management remains largely an abstraction. As a result, effective decision making on national health priorities is compromised and there is a lack of comprehensive cancer risk management across Canada.’ (Canadian Strategy for Cancer Control, 2005).

In response to these risks, policy solutions were located in the instruments and mechanisms of health governance via the processes and frames of ‘comprehensive cancer control’.

### Addressing cancer/risk through 'comprehensive cancer control'

Our sample demonstrated what several of the more recent policy documents advocated: a shift towards developing 'comprehensive cancer control' plans. These plans were coordinated, multi-stakeholder responses that addressed many issues along a cancer control continuum. 'Comprehensive cancer control' was contrasted with the perceived goals of earlier cancer policy, namely treatment and care:

'Given its growing threat, a much broader definition of 'cancer control' is required. True cancer control aspires not only to treat and hopefully cure the disease, but to prevent it, and to increase the survival rates and quality of life among those who develop it' (Canadian Strategy for Cancer Control, 2005).

Comprehensive cancer control aimed at controlling cancer/risk through governmental processes of collaboration, integration and coordination. Because it called for the pooling of community resources to confront cancer, the development of partnerships between government, health and community players to take action for cancer and the involvement of all stakeholders in generating policy plans and actions, comprehensive cancer control extended the domain for managing cancer/risk back throughout the community. This attributed responsibility for cancer risk to appropriate government management through funding (above all) and the development of adequate managerial strategies. A key concern around responsibility was its assignation among competing government-based health organizations, as opposed to its distribution among the public, industry or other non-government stakeholders. Appropriate governance included supporting community-based capacity building (Prevention working group, 2002).

Just as evidence was key to discussions of behavioural risk, so too information – evidence and data – was considered to be a central means of governing risk in the comprehensive cancer control schema. Most documents advocated keeping the public informed about the six behavioural risk factors. Informing the public was especially identified as a key strategy in areas where risks were sufficiently uncertain – above all, diet and alcohol consumption. But the corollary of this was the enormous demand by government for cancer information. Comprehensive cancer control planning made data collection and hence, evidence-based decision making, the cornerstone of success. Cancer/risk management, like infectious disease control globally, was located in adequate surveillance systems, and appropriate technical (statistical and mathematical) management. One document imported risk management approaches from the financial sector: 'Effective and efficient cancer management and control requires a greater quantitative understanding of how cancer progresses as a population level than what is currently available through existing surveillance systems' (Canadian Strategy for Cancer Control, 2005). Risk factor surveillance was constructed as a need beyond disease surveillance (Canadian Strategy for Cancer Control, 2005). This technocratic approach to cancer/risk management integrated the management of governmental and economic risks with health risks and health system risks, and allowed for claims such as these: 'using the current version of the Life at Cancer Risk tool, the CSCC [Canadian Strategy for Cancer Control] is currently able to estimate the impact of cancer risk across many important socio-economic bases' (Canadian Strategy for Cancer Control, 2005).



### **Discussion: Communicating uncertainty, advocating action**

What we have presented here is simply a snapshot of how cancer risk was put together in a set of cancer policy documents, which we have treated effectively as a significant public ‘face’ for health expertise. We have not attempted an exhaustive exploration of how risk is conceptualized in cancer control in general, much less a complete representation of the sophistication and complexity that individual health experts and policymakers, including those who help write policy documents, would undoubtedly display if closely questioned on the subject. Throughout our analysis, we became increasingly conscious of the fact that risks are never merely empirical. Rather, the identification, and understandings, of risk generate implications for action.

The rhetoric and representations of risk in these documents served to advance a policy agenda that centered around classic health promotion strategies and around a complex management and governance strategy, comprehensive cancer control. These strategies may seem surprising in the light of the strong research commitments to high-tech cancer treatments and the genetic bases for cancer that have received much publicity over the past two decades. To policymakers, the approach taken in these documents may seem (and is) collectivist in comparison with investing in medical solutions, expensive cancer treatments, and gene manipulation. However, it also devolves most of the responsibility for preventing cancer to lay people as individuals.

To advocate for policy action the documents utilized the language and tone of authority, presenting all evidence and any uncertainties with certitude. We suggest that there is a tension between the imperative for action and the complexities of evidence that generates a significant challenge for health communication.

We identified a series of implications for how the public might encounter cancer risk as a result of our analysis. Firstly, although the focus and level of technical information varied across the sample, risk was primarily represented in terms of 6 behavioural risk factors. The dominant behavioural representation of cancer/risk is easily accessible to a lay population and, from what we can judge from preliminary research, closely aligned with some of the messages lay people identify around cancer. However, there was a broad range of conceptualizations of cancer/risk across the sample, from straightforward indeterminate statements of threat to very complex, highly sophisticated and technical calculations imported from the financial sector. Many of the latter, especially concepts that were population-based, developed from epidemiological research, or included detailed separations of the risks of incidence from those of diagnosis, screening, treatment, mortality and morbidity, might be anticipated to be reasonably inaccessible to a lay public. They may possibly provide a source of confusion to those seeking to relate their individual risk to the information contained in these and similar public health documents, especially given the discrepancies between different documents and the inconclusive nature of much of the evidence. Secondly, we identified competing ideas about risk within these documents – for example, between the dominant representation of cancer as dreadful and inevitably fatal, and the counter frames of opportunities for prevention and scientific progress in the fight against it. We suggest that some of the rhetoric around cancer risk that serves policy imperatives could be potentially damaging for individuals. For example, as we have already noted, representations of the risks of cancer in terms of death and suffering served to claim a high rank for cancer in the health policy agenda. Documents exploited the ‘fear appeal’ of cancer for this end.

We can only hypothesise about the potential effects of the competing patterns observed above. The dreadfulness of cancer was emphasised, which might be reasonably expected to help perpetuate high perceptions of cancer risk in the public and the same emotionally damaging metaphors that Sontag first identified. Dramatic quantification rhetoric regarding incidence clearly accessible to, and often intended for, a non specialist audience, of the 'one person in four will receive a diagnosis' variety, might increase perceptions of risk by making cancer more *salient*, and potentially make cancer seem inescapable. Such quantification rhetoric, especially the gap between population-based measures of risk and individual risk, also seems likely to suggest that cancer is unpredictable, and out of the control of the individual. Cancer rhetoric may generate fatalistic attitudes, and it might seem reasonable to an individual not to attempt to take preventive action.

We noted that in these documents risk was typically treated as an expression of population – that is, in terms of the percentages identified through epidemiological research – yet preventive action was largely aimed at individual behaviour. We also noted that risk was very often represented in terms of *outcomes* rather than in terms of *probabilities*. The aim of the documents – or more precisely, of the policies recommended in the documents – was expressed in terms of reducing incidence and mortality across the population, rather than in terms of reducing anybody's, or everybody's, 'chance' of getting cancer. We suggest that there is a symbolic corollary to these two forms of representation: that by identifying particular risk factors and utilizing the weight of cancer rhetoric to advance a policy agenda, the documents conveyed a promise of prevention. The documents explicitly promised that if the 6 risk factors were avoided, many cancers would be prevented. While this promise was presented as proportional, that is, that cancer *incidence* would be reduced by between one and two thirds, it could easily be inferred to apply to individuals as well.

Because they were making such a strong claim for the necessity of policy action, the documents' rhetorical strategies tended to elide uncertainty and complexity in their representations of risk. Despite the technical sophistication in the sample, the language of risk moved between 'risk', 'cause', 'determinant' and 'influence' in similar contexts and sections, and the documents tended to express uncertainties with certitude, thus creating a comparative conflict while appearing to remain authoritative within themselves. The variation in advice around diet and weight, for example, may prove a source of confusion for the lay public, and add to the impression that the causes of cancer are multiple and almost endless as well as to frustrations about an individual's inability to synthesise disparate information. We suggest that this problem reflects the disjuncture between the actual nature of science, which is incomplete, ever changing, and evinces nonlinear progressions, and the cultural functions of medical authority (control, reassurance, guidance) in health communication and policy.

The widest gaps between professional and public conceptions of cancer risk are likely to be found in the various possible representations of risk that were sidelined or excluded from these documents altogether. Genetic and chemical (or toxin) causes for cancer were explicitly regarded as minimal or non existent, significant only for a minor proportion of the population, while emotional and environmental concerns were not even considered. Equally interesting to us was our finding that despite the elapse of two decades since the Ottawa Charter, there was little attempt to work at the level of place or culture or even social inequality to understand or manage cancer risk for whole communities. There are various probable explanations for these exclusions, including: (1) that the documents concentrated on risks for which evidence was

available and easy to accumulate; and (2) that the documents concentrated on risks that have practicable and easily imaginable policy solutions (in fact this strategy was explicitly advocated under the rubric of comprehensive cancer control). However, these exclusions also reflect and reinforce the distance between public and biomedical worldviews and may very likely contribute to public dissatisfaction with orthodox health and medicine.

### **Conclusion**

In sum, these 32 documents both located cancer risk in five individual behaviours, and one state, related to consumption and exercise, and simultaneously revealed the extent of the uncertainty around the epidemiology of risk. Given the power invested in the metaphoric representations of the burden of cancer, and their habit of drawing on these powerful metaphors to build rhetorical support for cancer control, health authorities need to be cautious and responsible in their communication of cancer risk.

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