

London School of Economics and Political Science

## **Just health responsibility**

A comparative analysis focussing on the role of individual behaviour in relation to cancer and weight-control policy in German and US health care systems

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## Abstract

This thesis seeks to examine the appropriate role of individual behaviour and responsibility in relation to cancer and weight-control policy in German and US health care systems. It contains six main parts.

The first describes and compares the ways in which personal responsibility features in law and policy in both countries. It analyses salient differences in underlying motivation and characterization and highlights ethical tensions that arise from these provisions and their implementation.

The second part reviews what established normative theories can do to address the issues that have been identified. It argues that these frameworks lack specificity and are ill-suited as a basis for policy in pluralist societies. It provides an analysis of different notions of the concept of personal responsibility, and makes a proposal for an overarching framework, adopting a procedural justice account that draws on work by Norman Daniels, Jim Sabin and Thomas Scanlon.

The third part systematically reviews survey literature on the proper role of personal responsibility and develops an instrument for semi-structured interviews with physicians and population-level surveys in the US and Germany. The instrument complements this earlier survey work and explores key themes that arose in the analysis of policy documents and the philosophical literature.

Based on this instrument, the fourth part analyses the findings from twenty semi-structured interviews with primary care physicians and oncologists in Berlin, Germany and Philadelphia, USA.

The fifth part presents findings from three population level surveys of 1,000 respondents each. Two surveys with identical instruments were conducted with non-probability samples (census-adjusted proportional quota sampling with regard to income) in Germany and the US, and one, using a subset of questions, was administered to a probability-based sample in the US. Findings are discussed comparatively between countries and in view of the interviews with physicians.

The last part concerns the policy implications of the analysis, and applies the framework proposed in the thesis to the case of colon cancer screening. It seeks to defend an incentive policy that attaches financial advantage to attending counselling on the advantages and disadvantages of colon cancer screening, building also on findings from the surveys, and interviews with physicians. The final chapter highlights a range of general policy implications for the evaluation and implementation of programmes seeking to incentivise personal responsibility.

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## Acronyms

ACP: American College of Physicians  
 ANOVA: analysis of variance  
 BKK: Betriebskrankenkassen, Union of German employer-based sickness funds  
 BMA: British Medical Association  
 BMG: Bundesministerium für Gesundheit, German Ministry of Health  
 BMI: Body Mass Index  
 CAQDAS: computer-assisted qualitative data analysis software  
 CCA: Clinical Care Associates (primary care network of the University of Pennsylvania Health System)  
 CDC: Centers for Disease Control and Prevention  
 CDU: Christlich Demokratische Union Deutschlands, Christian Democrats  
 CSDH: Commission on Social Determinants of Health (of the WHO)  
 DHHS: US Department of Health and Human Services  
 DoL: US Department of Labor  
 DoT: US Department of Treasury  
 FDP: Freie Demokratische Partei, Free Democrats  
 G-BA: Gemeinsamer Bundesausschuss, Federal Joint Commission  
 GKV-FinG: Gesetz zur nachhaltigen und sozial ausgewogenen Finanzierung des Gesundheitswesens, Law for the sustainable and equitable financing of health care  
 GKV-WSG: Gesetz zur Stärkung des Wettbewerbs in der gesetzlichen Krankenversicherung, Law to strengthen competition among providers of statutory health-insurance  
 HDHP: High Deductible Health Plan  
 HIPAA: Health Insurance Portability and Accountability Act  
 HMO: Health Maintenance Organization  
 IOM: Institute of Medicine  
 MeSH: medical subject headings  
 NBGH: National Business Group on Health  
 OECD: Organisation for Economic Co-operation and Development  
 POS: Point Of Service plans  
 PPO: Preferred Provider Organization  
 QALY: Quality Adjusted Life Year  
 SGB V: Sozialgesetzbuch V, Book V of the German Social Security Code  
 SPD: Sozialdemokratische Partei Deutschlands, Social Democrats  
 WHO: World Health Organization

## **Preface and Acknowledgements**

The topic of personal responsibility for health raises a set of intricate issues in a range of different academic disciplines, including medicine, psychology, public health, health policy, law, political science, sociology, psychology and philosophy. As with most issues that demand an interdisciplinary approach, the analytic and explanatory powers of a single researcher are therefore limited. Here, the focus is on how to make progress with the oftentimes acrimonious debate around personal responsibility for health by examining what contribution philosophy and health policy analysis can make in clarifying the concept, and in assessing the appropriateness of specific rules or interventions. The philosophical approach is an applied one throughout, as I seek to set out a framework that specifies the areas in which justification is owed. This can help us decide when policies are acceptable and when it is reasonable to reject them, or to demand adjustments.

For better or worse, while I worked on this thesis I had plenty of opportunity to explore both theoretical and practical aspects of personal responsibility for health. Exercising in nearby Barnard Park in London before work I often saw a chubby boy walking to primary school. His breakfast, it seemed, consisted of a big bag of crisps that he dug into on his way through the park: we tended to look past each other casually, absorbed in our respective habits. Later, moving between the UK, the US and Germany, I had failed to keep up with dental check-ups, and narrowly avoided a painful root canal as a consequence. I initially missed the final appointment and was charged a substantial penalty when I came back, wondering, of course, whether this was reasonable or not. Chapter 4 was largely written with one hand, as I had broken the other when I fell off a branch doing pull-ups in New York's Central Park. As it happened, I was due to give a seminar on personal responsibility two days after the accident, and with my arm in a fresh plaster cast, at least we got to the topic instantly. The interviews with physicians were done after I had spent a year on a research fellowship in the US. Major health reform was passed then, accompanied by robust and, from a European perspective, oftentimes hard to comprehend, debate. I still remember walking inside a hospital in Berlin to meet with one of the oncologists for a research interview and being almost moved at the thought that no-one in Germany needed to fear personal bankruptcy due to medical bills. It did not

make me want to hug the patients smoking outside (some of them on intravenous drips), and of course, being German, the insight was not new to me. But in a relevant and new sense it made me appreciate how important universal and affordable access to healthcare is. Equally, it illustrated at a glance the point Thomas Scanlon made when he observed that in many situations where we are inclined to blame others, or wish to hold them accountable, our proper response ought instead to be: ‘there but for the grace of God go I’. Towards the final stage of the thesis, the irony was not lost on me that in one of the most busy periods I was not able to make as much time for exercise as I wished, nor enough time to cook or do other things that are more conducive to my overall wellbeing than generating p-values of survey findings, tracking down yet another insightful paper, or formatting tables. Among other things, what I take away from these experiences is that any framework seeking to address the question of personal responsibility needs to be compatible with the range of different ideas of a good life that people have; with the fact that opportunities of choice differ among people; and that talk about responsibility must be broader than just determining when we should blame and penalise people, as will hopefully become clear in the chapters that follow.

Much of the material included in this thesis has already been published, as is indicated in the first footnote of each chapter, which also lists conferences at which drafts of papers or chapters were presented, and individuals who assisted with technical questions that arose, with testing the instruments, or with discussions of issues that were insufficiently clear to me. Many friends and colleagues also provided most helpful guidance and advice in developing the initial approach of this thesis. Here I wish to thank again each of them: Johann Ach, Sandra Applebaum, Jorge Ayala, Tom Baldwin, Alan Balch, Ronal Barg, Gene Bishop, Jochen Breinlinger-O'Reilly, Berit Bringedal, James Brooke-Turner, Roger Brownsword, Johannes Bruns, Anna Bushan, Alena Buyx, Shawneequa Callier, Joseph Capella, Hanno Charisius, Zack Cooper, Tim Doran, Annette Dufner, Stefanie Ettelt, Nir Eyal, Ian Forde, Markus Grabka, Carmen Guerra, Rizwan Haq, Ingo Härtel, Peter Hasselblatt, Paul Henning, Ingo Höhr, Dirk Horenkamp-Sonntag, Karen Jochelson, Steven John, Martin Kaiser, Amit Kavnekar, Sabine Kies, Jeff Kullgren, Ian Forde, Tim Kennerly, Sabine Kies, Nicole Knaack, Jan Köser, Lore Korbei, Srinivas Kuruganti, Nilophar Lafrai, Karin Lange, Stefan Lenz, Kathy Liddell, Wolf-Dieter

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Special thanks are due to David Ash, Norman Daniels, Scott Halpern, Julia Kreis, Dan Wikler, Kristin Voigt and Kevin Volpp, all of whom had substantial impact on the way I approached central issues in this thesis and beyond. I am deeply grateful to them. I must also thank the *Nuffield Foundation* for support in beginning this thesis, as well as the *Commonwealth Fund*, and the *Kolleg-Forschergruppe Normenbegründung in Medizinethik und Biopolitik* at the University of Münster, as their fellowships not only enabled me to dedicate more time to it, but also connected me with expert thinkers. The *Penn CMU Roybal P30 Center in Behavioral Economics and Health* enabled funding for parts of this research, which would otherwise have been impossible, through the *National Institute on Ageing of the US National Institutes of Health*. At the LSE I could not have been more lucky or privileged than to be guided by Julian Le Grand, Elias Mossialos, and Alex Voorhoeve, who provided just the right balance of hands-on and hands-off advice, support and expertise, invaluable, always. Finally, I am grateful, beyond measure, for her support, encouragement and steady companionship, to Joy Wang.

I dedicate this thesis to my family, and especially to my Grandfather, Herbert Holter. He read and wrote and played tennis and skied until his last year of life, dying at the age of 88. He would have been immensely pleased to know that this work is done, at least until there was a Mahler Symphony on the Radio, or Schnitzel mit Kartoffelsalat, or a good glass of Zweigelt.

New York, March 2012

## Chapter 1<sup>1</sup>

### Introduction

[T]he conditions in which people are born, live, and work are the single most important determinant of good health, or ill health; of a long and productive life, or a short and miserable one.

Margaret Chan (1947–), Director-General, World Health Organization

Medicine is a social science, and politics is nothing more than medicine on a grand scale.

Rudolf Virchow (1821–1902), physician, anthropologist and politician

I did it my way.

Frank Sinatra (1915–1998), singer

#### 1.1 Background

The debate around responsibility for health, like many long-standing controversies, has become somewhat polarised. At one end of the spectrum, commentators make what might be called a “get-real” argument (Burd 2009): they point to evidence that suggests, for example, that lifestyle choices about physical exercise and the consumption of food and alcohol clearly do affect health outcomes and account for up to 40% of the burden of morbidity and premature mortality (Schroeder 2007)<sup>2</sup>; that chronic diseases are on the rise (Scheller-Kreinsen, Blümel, and Busse 2009), that successful treatment depends considerably on patients’ compliance (Atreja, Bellam, and Levy 2005); or that peoples’ behaviour matters in relation to keeping appointments and other interactions with the health care system (Halpern, Bates, and Beales 2003). Since it can make sense to say that in all these areas people are responsible for their actions, proponents then often assert that people should also be held responsible. This may entail that they suffer a penalty or disadvantage in cases

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<sup>1</sup> Text in this chapter draws on, and in part reproduces verbatim, material published in the following previous publications: Schmidt 2009d, 2011b.

<sup>2</sup> Drawing on prior work Steven Schroeder suggests for the US context that behavioural causes account for nearly 40% of all deaths, with the remaining causes genetics (30%), social circumstance (15%), inadequate health care (10%), and environmental factors (5%).



where they are judged to behave irresponsibly. Using such sanctions may also serve as an incentive for people to behave in the right way from the outset. In folk psychological terms such reasoning can fall on fertile ground. For the concept that one is responsible for the good and bad consequences of one's life, and that facing up to the choices one has made is a central part of what makes a life a good life, is deeply engrained in individual and autonomy centred societies (Jetten and Postmes 2006; McNamee and Miller 2009). Especially in the US, the notion of personal responsibility is integral to the concept of the American Dream, enshrined in the collective musical memory in Frank Sinatra's (and many of his epigones') rendition of *My Way*.

However, at the other end of the spectrum, commentators equally make a “get-real” argument when it comes to health responsibility. Here, it is stressed that the very concept of lifestyle choice can be cynical. The term seems to assume that it is equally easy for all to be healthy, with some simply choosing an unhealthy, as opposed to a healthy, lifestyle. But—leaving aside deeper philosophical debates about free will—there is much reason to doubt that this is the case. It is in this spirit that Margaret Chan cautioned that the environmental conditions in which people live are the single most important factor influencing health, when she presented the final report of the World Health Organization's (WHO) Commission on Social Determinants of Health (CSDH, Commission on Social Determinants of Health 2008).

The CSDH, as the WHO, has a global focus. Clearly the emphasis on the enabling conditions is of special relevance in this context. For there are stark contrasts in quality of life and life expectancy between developed and developing countries, and there is overwhelming historical evidence that traditional public health measures such as clean air and water, sanitation, and safe housing have a direct and highly significant impact on peoples' wellbeing. The German public health pioneer, physician, anthropologist and politician Rudolf Virchow was one of the first to emphasise this nexus, and work towards its implementation to improve health at the population level. In no small part, Virchow's work was prompted by his research regarding a typhus epidemic in a famine-ridden region of Prussia that he had been commissioned to carry out by the government. He was expected to make

recommendations for medical interventions and hygiene measures, but focused in his final report on the need for extensive social and political reform to improve health sustainably in the longer term.<sup>3</sup> For Virchow, the causes of the epidemic were as much due to poverty as to germs, and he argued that the most effective and sustainable way of responding to the outbreak was to improve social conditions.

Virchow's above-cited dictum that medicine cannot be reduced to a purely physical discipline, and that, conversely, political arrangements have very direct implications for people's health (Bauer A. 2005), is not only relevant for the living conditions in 19<sup>th</sup> century Prussia, and for developing countries lacking the ability to provide for peoples' basic needs. It is equally apt in relation to health inequalities in contemporary post-industrial developed countries, and the debate around personal responsibility for health.

Accordingly, researchers of social epidemiology and proponents of the social determinants of health view would argue that talking about a person's responsibility to maintain a healthy weight can be of relatively limited use in the case of a single unemployed teenage mother who grew up and lives in a deprived inner city borough with a high density of cheap fast food outlets, poorly maintained and unsafe parks, no affordable sports facilities, and so on. Holding her responsible for being overweight, by imposing some disadvantage or financial burden would be seen as a form of unacceptable victim-blaming. For not she, but the circumstances in which she lives, are seen as responsible for her poor weight. In the words of the CSDH report, and in line with Virchow's observations, instead of focusing on the causes of her poor health, more attention should be paid to the "causes of the causes" (Organization 2008).

Deciding on the appropriate balance of direct appeals to personal responsibility versus more indirect action at the level of the social determinants of health is of relevance to virtually any country with aspirations to operate effective and fair health and social policy frameworks.

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<sup>3</sup> These included: full employment, higher wages, the establishment of agricultural co-operatives, universal education, and the disestablishment of the Catholic Church. Note that Virchow's travel to Silesia in February 1848 coincided with the emergence of revolutionary movements in France and Germany (Taylor and Rieger 1984).

## 1.2 Personal responsibility in the US and Germany

In this thesis, the empirical part focuses on policy in the US and Germany, which, for several reasons, has the potential to be particularly instructive. First, as will be described in more detail in the following chapter, the concept of personal responsibility features centrally in Germany's social health insurance system and is intricately linked to that of solidarity, versions of which also underlie many other European health care systems (Prainsack and Buyx 2011; Houtepen and ter Meulen 2000; Ashcroft, Campbell, and Jones 2000). By contrast, as will equally be explained in more detail, the US has a far more fragmented system. The majority of insurance coverage is provided in a market-based system by employers. As one consequence of the American credo in the individual pursuit of happiness, there is less of a societal expectation that citizens should consider the impact of their conduct on the wider community. Equally, there is less of an expectation that one is owed, or can rely on, assistance from the community. It can hence be instructive to analyse how two countries with very different background conditions address the question of incentivising individual behaviour in dealing with similar problems of rising levels of chronic conditions.

Second, while the nature of the problem posed by chronic conditions is indeed similar in both countries, it differs in magnitude. Levels of obesity in the US are approaching critical levels, with 34% of Americans being overweight in 2011, and 34% obese (Centers for Disease Control and Prevention 2011). In Germany an equal 34% are overweight, but only around half as many (13%) are obese (Statistisches Bundesamt 2011b). Given that the need to respond to the prevalence of overweight in the US is perhaps the most urgent of all post-industrial countries, and given that obesity is in the views of many a matter of personal responsibility, an analysis of the policies that are viewed as appropriate regarding personal behaviour is particularly timely.

Third, while the difference between the US and the German system is indeed in many ways stark, and the countries can be seen as positioned on opposite ends of a spectrum, in other ways there is also some noteworthy convergence. A major trend in the German (and broader European context) over the past decade or so is a stronger belief in using competition among both payers and providers of health care

to promote efficiency—therefore adopting a salient element of the American approach (Le Grand 1999, 2007; Wendt, Rothgang, and Helmert 2005). On the other hand, in a development that without exaggeration can be described as historical, recent US health reform has introduced the individual mandate. In effectively requiring each American to have health insurance, and putting in place structures that make coverage affordable through insurance exchanges and a number of other arrangements, the US have removed what health reform advocates regard as the US' "moral stain" (Emanuel 2012), and positioned the country closer to European states. While opponents are challenging the constitutionality of this measure before the Supreme Court at the time of writing, and while a political change in the 2012 Presidential elections would be likely to lead to severe and unpredictable disruptions, the signal emanating from this reform is a significant one and can indeed suggest some convergence between US and European health care systems (Callahan 2008). In this context it can then be instructive to review the ways in which the concept of personal responsibility is conceived of within them, given that it is itself beset by many of the controversies that are raised by the justifications of the different health care systems as a whole.

Lastly, in practical terms a comparison between the US and Germany is attractive because providers in both countries levy income-dependent individual insurance contributions. This method of financing enables financial incentives to have some leverage, as, among other forms, they can be provided as insurance discounts or surcharges, or differences in applicable co-payments. By contrast, a largely tax funded single payer system such as the UK's National Health Service generally has no such options, and co-payments and other cost-sharing play only a peripheral role. While one could compare, for example, cash incentives that are independent of insurance contributions, such a comparison would only represent one of several possible uses.

Practical, as well as political, cultural and normative grounds then make a comparison between the US and Germany particularly useful for a better understanding of the extent to which health care systems should adopt policies that incentivise personal responsibility and behaviour change at the level of the individual, in particular as a response to rising levels of chronic diseases. As will be

described in the outline of the thesis below, this comparison between the two countries will be made along four main axes: an analysis of the respective legal and policy framework (including formal reactions by key stakeholders); semi-structured interviews with physicians, and population level surveys; focusing on obesity and colon cancer prevention as conditions with considerable impact on health and health care budgets, yet distinct elements of individual control. The analysis will be guided by an analytic framework that builds on the philosophical literature on responsibility for health and a systematic review of the survey literature.

### **1.3 Research questions**

Overall, the central objective of this thesis is to explore in more detail the zone that lies between the two extreme ends of the continuum between social and individual responsibility for health. I contend that this is appropriate and necessary because the often encountered polarization is misguided and unhelpful for making progress in the debate around responsibility for health. I suggest that to some extent, the current situation is due to confusions about the way we typically use the concept of responsibility, and I propose a more nuanced approach that permits a debate about personal responsibility beyond the blame-game.

More specifically, I intend to address in a comparative manner the following research questions:

#### **Main research question:**

In promoting health and striving towards an efficient delivery of health care, to what extent should German and American health care systems adopt policies that incentivise personal responsibility and behaviour change at the level of the individual?

#### **Sub question 1:**

In what way do principal US and German health care policies seek to influence the behaviour of individuals regarding health maintenance and contribution to efficient services, and what are the underlying implicit and explicit values?

#### **Sub question 2:**

To what extent can the philosophical literature on personal responsibility and the justification of norms in pluralist societies help clarify the normative principles underlying the policies in the US and Germany, as identified in the analysis following Sub RQ 1, and offer a constructive way forward?

**Sub question 3:**

In the views of members of the public and physicians in the US and Germany: which aspects of cancer care and obesity policies focussing on individual behaviour and contribution to efficient services are reasonable, and which ones are not?

**1.4 The thesis structure**

Chapter 2 addresses the first sub-research question and describes the way in which principal US and German health care policies seek to influence the behaviour of individuals with regard to promoting health and contributing to efficient delivery and use of health care. It has been observed that two principal ways of conducting comparative health policy or health systems research would be (1) to analyse the extent to which two (or more) countries achieve specific stated goals (such as providing health care access to the entire population, or meeting certain thresholds of effectiveness in terms of producing health gains); or (2), to consider health systems as a whole, and compare the relative inherent structural and normative strengths and weaknesses (Busse 2002: 1). Throughout this thesis, the approach is a hybrid version of both.

While later chapters compare attitudes in both countries by reference to a common interview and survey instrument, Chapter 2 begins by providing background to the respective health systems and, in an inductive manner, seeks to identify the underlying implicit and explicit values supporting the respective appeals to personal responsibility. The chapter also provides an initial conceptual characterisation of the concept of ‘incentives’ and discusses in the abstract different ways in which incentives can be framed. The relevance of these framing options is then illustrated by a review of actual incentive policies in both countries. The chapter describes shared interests in using incentives as well as differences in approaches between the countries, and also contextualises evolving policy developments by summarising official position statements of professional medical associations.

Chapter 3 responds to the second sub-research question and explores to what extent the philosophical literature on personal responsibility and the justification of norms in pluralist societies can help clarify the normative principles underlying the

policies identified in Chapter 2, and resolves possible conflicts that may emerge between the rationales that have been identified there. The chapter begins by situating the use of incentives in the broader context of public health ethics and the scope and limitation of coercion in relation to health. In the following, I seek to show that the literature on the concept of personal responsibility for health is disjointed, as there is a wide range of different notions that feature in separate contributions. I suggest that none of these is sufficiently nuanced to be of practical use in planning, evaluating, and justifying health responsibility policies in contemporary pluralistic societies, and instead I synthesise the different strands into a workable concept of *health responsibility as co-responsibility*. I attempt to show how, drawing on the procedural justice framework of accountability for reasonableness, developed by Norman Daniels and James Sabin, (Daniels 1999) and Thomas Scanlon's contractualism (Scanlon 1998), the concept can be operationalised to provide a framework that specifies seven areas in which people who are interested in identifying mutually acceptable policies regarding personal responsibility ought to provide justification.

The first part of Chapter 4 provides a systematic review of the survey literature regarding personal responsibility for health, and focuses centrally on attitudes of members of the public and physicians. Building on these data, and on themes emerging from Chapters 2 and 3, an initial instrument as a basis for subsequent qualitative and quantitative research is developed, to explore in more detail the range of relevant reasons that need to be considered in relation to two specific areas: weight control and colon cancer prevention. These areas have been chosen for three main reasons. First, both overweight and colon cancer result in significant burdens of disease and there are widely held views that prevention can significantly reduce morbidity and associated cost. Second, while overweight is often regarded as being largely under the control of individuals, colon cancer is viewed more as a condition that strikes like bad luck, and in this sense those suffering from it are not seen as responsible in the same way that the overweight or obese are. Third, as Chapter 2 will show, Germany instituted a particularly controversial colon cancer prevention policy, giving rise to a range of complex issues, which have so far not been explored specifically in the survey literature.

Chapter 5 addresses the third sub-research question and describes the conduct of 20 semi-structured half-hour interviews with primary care physicians and oncologists in Berlin, Germany, and Philadelphia, USA. A refined version of the initial instrument developed in Chapter 4, the 13-item questionnaire concerned, among other things: the relationship of personal behaviour to other factors that can determine health; the adequacy of a prominent analogy made by proponents of higher health care premiums for overweight people, suggesting that they should be seen like risky drivers, who equally face higher car insurance premiums; the question of how high incentives for different formats should be; whether physicians would lie if a patient requests this in order to receive an incentive in relation to weight-control and common cancer prevention; and the acceptability of a new and unique obligation to think about one's health, that the current German colon cancer policy has established. The Chapter focuses on describing and discussing the reasons physicians gave in support and against these policies, and closes by contrasting similarities and differences between the American and German respondents, as well as between primary care physicians and oncologists.

Chapter 6 equally responds to the third sub-research question and concerns population-level surveys in Germany and the US, using an adapted version of the instrument that was used for the interviews in Chapter 5. For methodological and cost reasons, one survey each was fielded to non-probability samples of  $n=1,000$  in the US and Germany, and in a separate survey, a subset of five questions was fielded to a probability-based sample of  $n=1,115$  in the US. The findings are grouped under five main questions:

- To what extent do respondents use incentive programmes?
- To what extent do respondents agree with rewards and penalties?
- To what extent do respondents value opportunity of choice, motivation and effort?
- What levels of incentives are acceptable for particular incentive programmes?
- Do incentive programmes interfere with the doctor patient relationship?

The discussion focuses on key similarities and differences between the American and German samples; similarities and differences between views of survey



respondents and physician views as per Chapter 5; and winners and losers of incentive programmes.

Chapter 7 draws together the discussion from Chapter 2 (policy), 3 (ethics), 5 (physician interviews) and 6 (surveys) by applying the approach set out in Chapter 2 to the specific case of colon cancer prevention, illustrating what work the framework can, and cannot do. Finally, Chapter 8 provides a summary of the findings and new insights that have emerged in response to each of the research questions. The chapter argues that the framework presented in this thesis provides a novel and useful way of structuring the controversial debate around personal responsibility health, enabling more progress in policy and practice than has so far been the case. It then comments on policy implications that are of relevance to both the US and Germany, and emphasises the need to bring behavioural economics more effectively to bear on the Realpolitik of health policy; to carry out effective public and consumer engagement; and to conduct robust and suitably comprehensive evaluations of ongoing incentive programmes. Specific separate issues arising in the US and German policy context are also addressed, and the chapter, and the thesis, closes with limitations and next steps.

## Chapter 2<sup>1</sup>

### Responsibility, ‘carrots’ and ‘sticks’ in health care policy in Germany and the USA

#### 2.1 Introduction

The epidemiological and medical evidence regarding the burden of disease that can be attributed to personal behaviour clearly suggest that people’s individual actions play a significant role for health outcomes at the individual and population level, as noted in Chapter 1. Among other things, this raises the question of how to respond in law and policy. Not mincing his words, John H. Knowles, an outspoken critic of the American health care system, and viewed by some as a moderate Republican, left no doubt about his take on the matter when he wrote in an article in *Daedalus* in 1977 that:

[t]he cost of sloth, gluttony, alcoholic intemperance, reckless driving, sexual frenzy, and smoking is now a national, and not an individual, responsibility. This is justified as individual freedom—but one man’s freedom is another man’s shackle in taxes and insurance premiums. I believe the idea of a ‘right’ to health should be replaced by the idea of an individual moral obligation to preserve one’s own health—a public duty if you will. The individual then has the ‘right’ to expect help with information, accessible services of good quality, and minimal financial barriers.

Knowles does not really fit the standard political left-right pattern, in which the left usually abhors the concept and is in favour of universal health care, and the right favours personal responsibility, but is typically against health care for all: Knowles, by contrast, is interested both in greater emphasis on personal responsibility for health, and in universal health care for all Americans. His view also differs from traditional libertarian positions that would hold that one has the right to conduct one’s life however one wants, but is not owed assistance from others in cases where the resulting harm is the consequence of one’s choices. Knowles’ proposal did not translate directly into US policy. But the question of how to conceptualise the relationship of personal responsibility and risk-pooling—that may cushion some, or

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<sup>1</sup> Text in this chapter draws on, and in part reproduces verbatim, material published in the following previous publications: Schmidt 2007a, 2007b, 2008a, 2008b, 2010; Schmidt, Stock, Gerber 2009; Schmidt, Stock, Doran, 2012. I am grateful for valuable discussion with Karen Jochelson and Joy Wang who reviewed drafts of the above papers and helped me better understand specific aspects discussed in them.

all of the negative effects of requiring treatment for conditions that may be said to be attributable to personal behaviour—is one any health care system has to answer, whether explicitly or implicitly.

In this chapter I seek to outline the ways in which two health care systems address the issue of personal responsibility for one's health: the German statutory health insurance system, and the employer-based insurance system in the USA. For both countries I first describe the overall framework that has been established in law and policy regarding the question of personal responsibility. In discussing the perspectives of important stakeholders, I then focus on two specific policies: incentives for cancer checkups in Germany, and wellness incentives for meeting Body Mass Index targets in the USA. This serves to identify the principal rationale behind these schemes and the concerns by those involved in their administration and use. The chapter also serves to prepare the ground for the discussion of ethical issues in the following Chapter 3, and the empirical work in chapters 4–6, which present a more in-depth analysis of attitudes of members of the public and physicians on particularly central aspects raised by personal responsibility policies. Before doing so, I begin with a brief conceptual clarification regarding the framing of health responsibility policies. This clarification is of relevance for the description as well as the evaluation of the policies that will be described later. For framing cannot be assumed to be simply a neutral background condition, but in many ways raises fairness issues by itself.

## **2.2 On 'carrots' and 'sticks': when is an incentive an incentive?**

There are a number of different ways in which personal responsibility can be promoted, as will be outlined in a more structured way in Chapter 3 (Section 3.2). On the one end of the spectrum, one could simply provide information about, for example, healthy eating. On the other, one might require people to exercise in a quasi-mandatory way, as in the case of the Chinese calisthenics programme, re-introduced in August 2010 in view of rising levels of obesity (Branigan 2010). Incentives, often called 'carrots', and disincentives or 'sticks', that form the centre of the discussion here, are two further means.

*Prima facie*, the distinction between ‘carrots’ and ‘sticks’ seems straightforward: one is a reward for behaviour that is judged to be positive, the other a penalty for behaviour that is judged to be negative. The use of incentives to influence individual behaviour has been implemented widely outside of health policy, especially for marketing purposes. For example, many airlines and supermarkets provide discounts for frequent flyers and shoppers in the hope that this will encourage customers to become more loyal. Levels of incentives are generally calculated in such a way that their cost is offset by customers’ more frequent purchases of goods and services. Programme enrolment is usually equally easy for all customers, and participation is often agreed at the point of purchase, with those not wishing to make use of the offer generally losing out on some benefits, such as reduced prices. On the whole, equal access, and the voluntary nature of the agreement means that no significant fairness issues are raised. However, problems can arise when this model is applied to the health care context. One of the main reasons is that it is not necessarily equally easy for all groups who are offered incentives to avail themselves of the opportunities. Depending on the size of the benefit, the question can arise whether losing out on a benefit can turn a ‘carrot’ approach into one that begins to have ‘stick’ character.

As the following discussion of real-world policy examples will show in more detail, the distinction between ‘carrots’ and ‘sticks’ is often far less clear than it seems. Much also depends on the way an incentive policy is *framed*. Conceptually, Dan Wikler set out one of the fundamental mechanism that is at work in implementing incentives as follows:

Suppose, for example, that the Government wants to induce the obese to lose weight, and that a mandatory national insurance plan is about to go into effect. The Government threatens the obese with higher premiums unless they lose their excess weight. Before the plan is instituted, however, someone objects that the extra charges planned for eager eaters make the plan coercive. No adequate justification is found. Instead of calling off the program, however, some subtle changes are made. The insurance scheme is announced with higher premiums than had been originally planned. No extra charges are imposed on anyone; instead, discounts are offered to all those who avoid overweight. Instead of coercion, the plan now uses positive incentives; and this does not require the kind of justification needed for the former plan (Wikler 1978: 330).

Let's assume that all those whose weight was in the range regarded as normal sign up for the discount rate, and all, or most of those who are overweight do not. Arguably, all plan members had an incentive to lose weight, and the switch in framing has transformed the policy from a 'stick' approach to a 'carrot' one—or has it?

I will not resolve this question here, but merely note that an answer is far from trivial. In the following, I will regard as the paradigm case of an incentive a situation where a population that has been offered certain services or goods at a specified price sees no changes in this baseline cost (leaving aside inflation-related adjustments and the like), but is offered a reduction in price, or another financial or in-kind benefit. I will call such cases 'genuine' incentives. In using this term, nothing is said about the ethical or other acceptability of the policy, it is intended merely to denote the mechanism that is at work. Because of the potentially misleading connotations, I will also not use the terms 'positive' or 'negative' incentives, which are commonly used in the literature (see, for example, Jochelson 2007). While, to some extent, these concepts also need to be seen as technical terms that seek to describe a mechanical aspect,<sup>2</sup> the adjectives 'positive' and 'negative' also imply a value judgment and may implicitly bias towards viewing an incentive scheme that works by offering a benefit as a good thing (or at least a better thing than a negative incentive programme). However, for much of the following analysis it is important to be open to the possibility that what might be described as a positive incentive may be bad (for at least some people) in some relevant way and equally, that a policy is not necessarily bad, just because it overtly uses penalties. Unless stated otherwise, I will therefore use a broad understanding of an incentive which encompasses both what is traditionally known as positive and negative incentives. On this view, knowing that one lives in a place that imposes the death penalty for murder can be as much an incentive not to kill someone as taxes can be incentives not to smoke, and a lump-sum of money may be to exercise regularly. It is now useful to review the characterisation of incentives to promote health and personal responsibility in law and policy.

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<sup>2</sup> Namely, whether the incentive consists in the option of securing a benefit – in the case of a positive incentive – or in avoiding a penalty – in the case of a negative incentive.

### 2.3 Health responsibility in the German statutory health insurance

Germany's social health insurance system is governed by Book V of the German Social Security Code (SGB V—*Sozialgesetzbuch*) of 1988, revised most recently in 2007 under the *Gesetz zur Stärkung des Wettbewerbs in der gesetzlichen Krankenversicherung* (GKV-WSG—“Law to strengthen competition among providers of statutory health-insurance scheme”) and in 2010 under the *Gesetz zur nachhaltigen und sozial ausgewogenen Finanzierung des Gesundheitswesens* (GKV-FinG—“Law for the sustainable and equitable financing of health care”). SGB V regulates the provision of statutory health care through the *Gesetzliche Krankenkassen*, or sickness funds. The concept of solidarity centrally underpins the statutory insurance scheme in three different ways. First, by pooling contributions and expenditures without individual or gender-specific risk assessments, those who are able to work, especially healthy and young persons, support the less healthy and older ones. Second, due to income-tested contributions, the better off support the less well off. Third, those without families support those with dependents, as family members may be insured through the main insurance contributor. The norms specified in SGB V are binding for some 200 sickness funds that provide care for approximately 90% of the German population (the remainder being covered by private insurance). People have free choice of fund, and those with a gross annual income of less than €47,700 are obliged to be insured by one of the sickness funds, while higher-income earners may opt out and elect to be insured privately (Busse 2005; Weide 2005).

In terms of financing, until recently, employers and employees split insurance contributions evenly, each paying around 6–8% of the employee's gross salary. However, reforms enacted in 2010 led to a change in this arrangement. Employers had complained for some time that the high health insurance contributions had a stifling effect on their competitiveness in the European and world market, and the then recently elected industry-friendly coalition of Christian Democrats (CDU) and the Free Democrats (FDP) implemented reforms that capped employers' contributions at 7.3%, and increased contributions for employees to 8.2% of their gross income, with all future increases being shouldered by the employees through a newly introduced capitated fee and future increases in insurance contributions. Sickness funds often differ in their benefit packages, although a mandatory set of

core services that all funds need to provide is set out in SGB V. Services are not entirely free for all, and cost sharing is required for, among other things, prescription medicines, doctor visits and hospitalisation (Riesberg and Busse 2003; Gericke, Wismar, and Busse 2004).

### 2.3.1 *Legal framework—health responsibility*

Article 1 of SGB V has overarching function and is entitled “Solidarity and personal responsibility”. A characterization of both concepts is provided in the wording of the article itself which reads as follows:

In the spirit of a mutually supportive community [*Solidargemeinschaft*] the task of the statutory health insurance is to maintain, restore or improve health of the insured. The insured have co-responsibility for their health; through a health-conscious way of living, taking part in appropriately timed preventative measures [and] playing an active role in treatment and rehabilitation, they should contribute to avoiding illness and disability, and to overcoming the respective consequences. The statutory sickness funds are to assist the insured persons through the provision of information, advice and services, and should encourage a health-conscious way of living [my translation, HS<sup>3</sup>].

The principal characterization of solidarity and personal responsibility is that the community as a collective, and people individually, are “co-producers” of health (Forde and Raine 2008: 1695). The notion of co-responsibility has two important facets in this respect. First, it states that the “mutually supportive community” has a certain degree of responsibility for the health of each individual. In this sense, individuals are entitled to claims against the community for assistance (Dixon and Hermesse 2004: 171; Ashcroft, Campbell, and Jones 2000: 381; Houtepen and ter Meulen 2000: 330). Second, it also implies that the community has certain claims against individuals. Leaving prudential benefits aside, the appeal to staying healthy has the aim of containing overall expenditure and opportunity costs. For all care needs to be financed by the solidaristic community, and the underlying assumption is that cost can be reduced or at least contained if demands on the health care system are limited. Using services unnecessarily may also deprive another person in need of resources or medical attention, exacerbating resource allocation dilemmas. Article 2 SGB V on “necessity, cost-effectiveness, and personal responsibility” is unequivocal in stressing people’s obligations in this respect:

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<sup>3</sup> Note that there is no official translation of SGB V. All translations therefore mine, HS.

Services ... are to be provided by the sickness funds with due respect to cost effectiveness [Wirtschaftlichkeitsgebot] ... and *insofar as the need for services is not attributable to the personal responsibility of the insured person*. [...] Sickness funds, service providers and insured persons must seek to ensure the clinical and cost-effectiveness of services, *which are only to be used insofar as necessary* [emphasis added, my translation, HS].

Article 2 SGB V raises the question of what exactly, in practice, the respective scope and limitation of solidaristic and personal responsibility should be. What forms will personal responsibility take: merely the demand for (co-)payments where the individual responsible for his own fate can pay? Or will there be a refusal of treatment when the person cannot pay for it by him or herself?

Article 52 SGB V sets out conditions under which statutory sickness funds may limit funding for services, and the health care reforms of 2007 included a noteworthy specification in this respect. In its pre-2007 version, Article 52 SGB V stated that insurers may demand a reasonable contribution to the costs of treatment if a person's need for health care is the result of engaging in a criminal activity. Solidarity and personal responsibility are interpreted in such a way that whoever harms the solidaristic community has lost the claim to having health care needs met at the community's exclusive expense.<sup>4</sup> In such cases, financing health care can become a matter of personal responsibility. However, this responsibility extends to the costs only: for solidarity still clearly requires the criminal person to be treated by the health care services. The 2007 reforms extended this principle to state that insurers may ask for equivalent contributions where people request treatment for complications arising from "cosmetic surgery, tattoos ... piercings," or another "non-medically indicated" measure. In its written justification of the bill, the Government argued that "since insured persons who decided to have [tattoos, cosmetic surgery, piercings] voluntarily exposed themselves to health risks, it is not appropriate to cover costs... through the collectively contributed funds" (Bundesregierung 2006: 300-301 [my translation, HS]). In addition to these provisions, there are a number of initiatives that are presented more explicitly as incentives for people to behave responsibly.

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<sup>4</sup> Additionally, since sickness funds also administer sick-pay, the policy also states that otherwise applicable sickpay may be denied in part or entirely, or requested to be paid back, where it has already been paid.



The oldest programme is set out in Articles 55 and 56 SGB V and relates to dental check-ups. According to these articles, sickness funds must cover 50% of the costs for required dental replacements, with the other half falling to the insured person. Insurance providers must up their contribution by 20% of their initial payment, if, over a period of 5 years, adults have taken part in annual check-up programmes (and under 18-year-olds in biannual ones). If there are no gaps over the past 10 years this is increased to 30%. However, if an individual has not taken part in such check-ups, he or she has to pay his or her full 50%.

Since 2004, Article 65a SGB V, entitled “Bonus for health-conscious behaviour” provides that sickness funds may offer incentives (known as ‘bonuses’) to insured persons who participate in quality assured prevention, health-promotion, screening, and check-up programmes. Some of these programmes are specified elsewhere in SGB V, but in practice sickness funds incentivise a wide range of activities. An overview of activities with bonus awards offered by members of the *Betriebskrankenkassen* (BKK), which insure employees of large employers such as *Daimler*, *Siemens* or the postal service, is provided at Appendix 2A. Article 65a SGB V also includes a noteworthy provision on financial aspects of bonuses. While no maximum limit is specified for incentives for particular activities, paragraph 3 states that:

in the medium term, resources for bonus awards must result from cost-savings and efficiencies that result from participation in the bonus programmes. Sickness funds are required to report in regular intervals, at least every three years, to the relevant authorities about any savings that are made. Where no savings are made, bonuses may not be awarded for the respective activities.  
[my translation, HS]

The reporting requirement extends to cost only, and there is no requirement to provide information on health improvement, which can, at best, be inferred from data on health care usage.

Insurers differ in the ways in which they provide bonuses. One common type consists in giving reward points of a nominal value for taking part in certain measures. Usually points can be redeemed for items thought to be conducive to a healthy lifestyle, such as sports equipment, or health books. More recently, some insurers such as the *Techniker Krankenkasse*, one of the four largest insurers with 4m

contributing members (6m including dependents), have included iPods and vouchers for music downloads. Many providers also offer the option of redeeming the collected points for cash. In case of the *Techniker*, incentivised activities have a value of between €5 and €30 (with a mean of €10.48).<sup>5</sup> A four person family may redeem between 100 and 200€ per year through such schemes, and programmes of other insurers offer bonuses of a similar level (Bödeker, Friedel, and Friedrichs 2008; Stock, Schmidt, Buscher et al. 2010; Friedrichs 2009; Dreier and Linger 2006).

A more recent addition introduced under the 2007 reforms takes a slightly different form and provides incentives for limiting ones use of health care services. Article 53 SGB V on personalised health care plans (*Wahltarife*) provides that sickness funds may offer significantly reduced contributions (or lower co-payments, where required) to those agreeing to take part in schemes thought to reduce the burden of morbidity and costs for the sickness funds, such as managed care programmes. Sickness funds may also offer what amounts to ‘no-claim bonuses’: If the insured requires no primary care consultation leading to a prescription, or hospitalization over a year, reductions of up to 20% of the annual contributions may be granted, capped however at €600 maximum (or €900, where several different bonus plans are combined). Subsequent policy issued in 2011 stipulated that sickness funds intending to offer these programmes must demonstrate in advance through actuarial modelling that bonuses can be financed through efficiencies, in parallel to the above-cited cost-saving requirement pursuant Article 65a SGB V (Meißner 2011).

A further new policy introduced in Article 62 SGB V under the 2007 reforms concerns participation in cancer check-ups and compliance in treatment. This Article and subsequent guidance by the *Gemeinsame Bundesausschuss* (G-BA, Federal Joint Commission<sup>6</sup>) states that patients who suffer breast, colon, or cervical cancer will

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<sup>5</sup> There are 31 measures, see: Techniker Krankenkasse [homepage on the internet]. “TK Bonusprogramme,” available in English from: [http://www.tk-online.de/centaurus/generator/tk-online.de/s07\\_english/dossiers/01\\_lexicon/tk\\_bonus\\_programme/tk\\_bonus\\_programme.html](http://www.tk-online.de/centaurus/generator/tk-online.de/s07_english/dossiers/01_lexicon/tk_bonus_programme/tk_bonus_programme.html) (accessed 20 August 2007)

<sup>6</sup> The G-BA is a self-governing body bringing together the payer community (the sickness funds), and health care providers (physicians, dentists, psychotherapists and hospitals) The body is tasked with determining the provision and reimbursement of pharmaceuticals, diagnostic and therapeutic procedures, medical devices and non-medical treatment for the statutory health insurance.

have to pay a maximum of 1% of their gross annual income as co-payments for treatments and medicines, provided they meet two conditions. First, they need to have attended counselling sessions on the advantages and disadvantages of the respective screens at the appropriate age. Second, they must not refuse treatment, should they require it. In case of non-compliance with either provision, the co-payment cap is 2%. Note, however, that both before and after introduction of this policy, the threshold for all other chronically ill was 1%.

In practical terms, all those insured<sup>7</sup> through the statutory sickness funds will be issued a ‘prevention-passport’ that documents their participation in counselling sessions. While people with severe mental diseases are exempt from the regulation, all others must attend counselling no later than two years after the recommended age for the respective disease to be eligible for the lower co-payments. Counselling is to be offered by medical professionals who are also qualified to carry out the respective screens. It is to be based on information brochures already available via the G-BA. Since this policy raises a number of interesting issues for the questions around the reasonable scope and limitations of personal responsibility that are of interest here, it will be discussed in somewhat more detail below in the consideration of the perspective of key stakeholders, as well as in the subsequent empirical chapters.

### 2.3.2 *Implicit and explicit rationales*

The different schemes outlined here have different rationales that may overlap:

- **Improving health.** In the most benevolent interpretation, programmes are simply intended to improve people’s health, and this notion is certainly emphasised in the written justification provided by the government in introducing the 2007 reforms, alongside the stress on individual’s personal responsibility to contribute to efficient services, as will be discussed in some more detail below (Section 2.3.3).
- **Lower expenditure.** There is the assumption that healthier people and those who limit their demand on the health care system over certain periods, will require less health care expenditure overall.

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<sup>7</sup> Inclusion criteria: women born after 1 April 1987, and men born after 1 April 1962 – the point being that the policy should only apply to people who had the opportunity to chose to comply with it (or not) at the age at which screening is recommended.

- Competing for healthier customers. In a somewhat more indirect way, incentive programmes function similarly to schemes such as air miles or store loyalty cards (Müller 2003; Knaack 2008). If programmes are designed in such a way that they appeal in particular to the better off and healthy, incentives can help sickness funds attract and retain ‘good risk’ customers, who are likely to require less care, and contribute disproportionately more, as insurance contributions are income-dependent. In this way, incentive programmes may help insurers secure a competitive advantage. It is noteworthy that schemes such as the no-claims-bonuses (Article 53 SGB V) were introduced under the 2007 Reforms that signalled the aim of improving competition among sickness funds explicitly in the title.

Ideally, all three goals can be achieved, and the result of participation in bonus programmes is better health, lower health care cost, and improved competition between providers. However, tensions can clearly arise if sickness funds are guided more by one line of thought than by another. For example, Wolfgang Bödeker and colleagues noted that evidence on the initial evaluation of bonus programmes for the *BKKs* suggested that cash incentives are more effective than in-kind ones in motivating people to take up incentive schemes, although in-kind schemes provide the highest financial returns (Bödeker, Friedel, and Friedrichs 2008: 218). In principle, this may tempt insurers to focus on in-kind incentives that are less likely to promote behaviour change, but have more potential to reduce cost.

In a similar vein, the general emphasis on cost savings might turn out to be problematic. As noted, Article 65a SGB V assumes that healthier people are less costly to the health care system than sick ones, and specifies that bonuses may be paid only when savings are achieved.<sup>8</sup> Evidence from different evaluations indicated a return-on investment ratio of roughly 3:1 (Bödeker, Friedel, and Friedrichs 2008: 216; see also Baicker, Cutler, and Song 2010: 305; Stock, Schmidt, Büscher et al. 2010: 52). The normative implications of the cost-saving rationale will be taken up again in Chapter 3, Section 3.5.1. For now it can be observed that the assumption that bonus programmes will always lead to cost-savings can be problematic. Table

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<sup>8</sup> It is interesting to note that the initial response from the sickness fund community to the requirement to demonstrate savings in three year intervals was more than skeptical, as it was feared that no such savings could be shown over such a short time frame (Bödeker, Friedel, and Friedrichs 2008).

2.2 shows the findings from an evaluation pursuant Article 65a SGB V of the *Techniker Krankenkasse*, a large sickness fund insuring approximately 9% of the German population. Overall, the mean difference for the sum of three cost categories (hospital spending, medication spending, and additional benefits) between matched pairs of bonus programme users and non-users over the three-year evaluation period amounted to €177 (£147) savings per insured enrolled in the incentive programme per year. If programme costs were taken into account, overall savings were reduced to €101 (£84). However, a subgroup analysis comparing the costs of participants and non-participants with no health care utilization in the year prior to introduction of the programme found differences in all three areas of spending, with those participating in the incentive programme having significantly higher costs overall (if lower, in both cases, than the mean cost in the complete intervention and control group). One implication of this finding is that it would seem odd to wind up programmes that have been shown to achieve behaviour change, simply because they may not have reduced costs: an unbalanced cost-saving requirement can therefore be problematic.

**Table 2.2: Mean health care costs among incentive program participants and their matched controls, 2006 (Evaluation of Bonus programmes of the *Techniker Krankenkasse*)**

	Total study population		Subgroup analysis: Participants without any health care costs in 2003	
	Incentive Programme Participants (Intervention group) (n=70,429)	Incentive Programme Non-Participants (Matched control group) (n=70,429)	Incentive Programme Participants (n=4,822)	Incentive Programme Non-Participants (n=4,822)
Hospital spending (2006 mean)	€469	€613	€576	€226
Medication spending (2006 mean)	€365	€413	€34	€26
Other medical benefits*(2006 mean)	€88	€81	€155	€108
Total**	€922	€1,107	€765	€360
*Other medical benefits include massage, physiotherapy, walking aides, etc. **Note: the amount of €177 (£147) mentioned in the text reflects the difference in the mean of the individual increase in cost in each cohort between baseline and the end of the study. This sum therefore differs from the aggregate of the three cost categories summarised here. Source: (Stock, Schmidt, Buscher et al. 2010; Schmidt, Stock, and Doran 2012)				

### 2.3.3 Stakeholder views

When Parliament passed the 2007 reforms, a heated debate raged over the issue of personal responsibility, and in particular over Articles 52 and 62 SGB V, concerning the chronically ill, and the question of whether the revised law might unduly burden

the chronically ill and force them to undergo screening. In introducing the bill, the government argued in its written justification of the provision, that those who benefit from expensive medical care had “special personal responsibilit[ies]” (Bundesregierung 2006: 305). Accordingly, the initial proposal envisaged that the lower co-payment threshold of 1% (which, as noted above, is the default threshold for all other chronically ill people) should be available only if women and men underwent the screens for colon, cervical and breast cancer at the recommended age (and subsequently in the appropriate intervals), and took an active part in complying with schemes such as disease management programmes. Otherwise they should face the 2% threshold (i.e.: twice the amount that all other chronically ill faced).

In the final debate on 2 February 2007, Brigitte Bender of the opposition Green party (Die Grünen) argued that this constituted a “a punishment... of severely ill people... in the form of increase in contributions... that is irrational.” (Deutscher Bundestag 2007: 8032). Gregor Gysi of the left (Die Linke) equally described the policy as a “penal fine” that he perceived as undermining the principle of solidarity, and as introducing a questionable principle of responsibility that could also be found in the new policy of requesting contributions to the treatment of people suffering from complications arising from piercings (as described above, regarding Article 52 SGB V, *ibid.*: 8015). By contrast, Elke Ferner, a member of the then governing Social Democrats (SPD), defended the policy, arguing “I do think that, if chronically ill are not willing to play an active part in treatment, then we do have to set appropriate incentives” (*ibid.* 8019), and her colleague Jens Spahn of the CDU, who formed a coalition government with the SPD, equally argued: “the bill says that if people do not come forward to the recommended checkups... they simply don’t get the reduced copay, and stay with the standard. So, it is not true that there is a ‘penal fine’, as you [the opposition] have been calling this provision over the recent weeks and months. It’s only that you don’t get a reduction. [...] Not getting a reduction is not the same as being made worse off [by this policy]” (*ibid.*: 8036, all translations mine, HS).

The provisions of Article 52 and 62 SGB V came to be nick-named “snitch-Articles” (Petzparagrafen), in some discussion fora of health professionals as they required physicians to inform sickness funds about people requiring treatment for

tattoo complications etc, and about non-compliant cancer-prevention behaviour. The provisions also received strong opposition from the medical profession. At the 2007 General Assembly of the *Bundesärztekammer* (BÄK, German Medical Association), delegates noted significant concerns about the concept of responsibility implied in Article 52 SGB V, and called for a critical debate about the role of physicians in relation to Article 62 SGB V, which, they feared, sought to assign them the role of “therapy-police” (“Therapiepolizei”) of the sickness funds (Bundesärztekammer 2007: 3).

The controversy could not be resolved in passing the law, and it was agreed that the precise content of the new requirement would be specified at a later stage by the G-BA. In its final report, the G-BA cautioned strongly against making co-payments conditional on actual participation in the respective screens and noted several areas of concern that spoke against more directive screening approaches. Further to the reservations expressed by the BÄK, these included an overall high ratio of numbers-needed-to-screen for each of the screens; the absence of evidence that screening programmes will lead to net savings; the importance of shared decision making and informed consent in view of the risk-benefit balance of the screens; and the “right not to know,” which was seen as widely accepted by ethicists, health professionals, and lawyers and backed up by the German Constitution (Gemeinsamer Bundesausschuss 2007), and perceived to be infringed if insured persons underwent screening simply to evade the higher co-payment.

Instead, the G-BA proposed the abovementioned policy, which leaves intact the fundamental architecture of establishing higher co-payment thresholds for the three types of cancer patients, but changed the requirement of undergoing screening to taking part in counselling sessions on the advantages and disadvantages of screening, and also relaxed the compliance requirement, as non-compliance would only be attested in cases where patients refused treatment—the latter shift was largely in response to opposition from physicians who viewed the possible policing function they were given under the initial law as incompatible with the doctor-patient relationship.

The then Minister for Health, Ulla Schmidt, welcomed the new regulation in her formal announcement, stating:

Early diagnosis enables better treatment. This is why the statutory sickness funds offer a range of screening and disease-prevention measures. I would like more people to make use of them, and the most recent reforms have created new incentives. It is important that all take more responsibility: for their own health, and also towards the community of people who jointly fund health care and ultimately pay for the treatment of chronic diseases. (Bundesministerium für Gesundheit 2007) [my translation, HS]

Arguably, as discussed initially in the review of structural issues around the concept of incentives, the policy still represents an incentive for people to consider the advantages and disadvantages of screens, and of refusing treatment should they require it. However, it is also clear that the approach is far from a genuine incentive: for, in principle, it could equally have been implemented by, for example, holding the 1% threshold constant for all chronically ill, and offering a 0.5% co-payment for those complying with the requirements.

In summary, then, salient features of the German situation are, first, the explicit reference to personal responsibility and its connection to solidarity. The characterization of these values in the provisions following Article 1 SGB V is that solidarity requires assistance for those with health care needs, but that such assistance is not unconditional. Several policies seek to prevent burdening the solidaristic community with costs that may be attributable to individuals' personal responsibility, even though it is unclear whether such a burden exists. A wide range of incentive schemes has been put in place, with the distinct, but often also overlapping aims of (1) promoting responsibility toward keeping oneself healthy, and regaining health in the case of sickness; (2) respecting the health of others (for example, in the case of bonuses for prenatal or childcare checkups, or vaccinations, which have a population-level benefit); and (3) contributing to cost-reduction and an efficient operation of the health care system (without direct cost-shifting among insurers). From the perspective of health care insurance providers, incentive programmes are also attractive as they may confer a competitive advantage in their effect on the composition of the risk pool. Some of the schemes have an overtly 'stick' character, while others are presented in the form of 'carrots'. However, the example of the provisions pursuant Article 62 SGB V regarding cancer prevention also illustrated that incentives can be framed in very different ways, and that 'carrots'



can also have a 'stick' character. In the responses of stakeholders to the 2007 reforms that introduced many of the more controversial new policies, the reaction of the medical profession is particularly noteworthy, both in view of the fact that they rejected aspects of the policy because of lack of insufficient evidence (as in the case of the Government's proposal to increase the number of people undergoing cancer screens under Article 62 SGB V) and their opposition to be given policing functions that they viewed as incompatible with their professional roles.

#### **2.4 Health responsibility in the US employer-based insurance system**

In contrast to Germany, the provision of health care in the USA is organised in a far less centralised fashion, and there is, as yet, no universal coverage, even though an individual mandate has been introduced under the 2010 health reforms. Overall, there is a mix of private and public provision of health care. Large employers often offer their own health insurance and use insurance companies mainly for administrative purposes, while designing their own benefit packages (Institute of Medicine 2012). Federal programmes such as *Medicaid* provide services for the least well off. People older than 65, and some who meet special criteria, are eligible for *Medicare* coverage. The *Veterans Health Administration* provides services for former military personnel. There are also significant differences in the way in which the different states provide services under Medicaid or Medicare, and while some view this diversity as an excellent opportunity to learn from different approaches, many view it as inequitable and problematic. The vast majority of Americans access health insurance through their employers, who may offer a range of different plans. A somewhat more detailed description of the way in which employers facilitate access to health care is necessary both because the system is significantly more complex than the German one, and because the impact and relevance of incentive schemes can be understood more clearly against this background.

In 2010, a total of 157 million Americans received health benefits through their employers. However, not all employers offer health insurance, and there are significant differences between large and small employers, the latter often leaving it up to employees to purchase coverage individually. In 2010, 34.6% of workers were employed in firms with more than 5,000 employees constituting 36.9% of those received coverage through their employers, whereas 8.3% of all workers were

employed by companies with 3 or less employees, constituting 5.5% of those receiving coverage. The average annual premiums in 2010 were \$5,049 for single coverage (with workers contributing on average 19% of this sum) and \$13,770 for family coverage (with workers' contributions amounting to 30%, on average), although there is significant variation around this figure. Seventeen per cent of covered workers have a single premium that is at least 20% higher than the average single premium, and 20% of covered workers have a single premium that is less than 80% of the average single premium (Kaiser Family Foundation 2010: 9, 69; Wallen and Williams 1982).

Price and benefit packages also depend significantly on the type of plan that employers offer. While 84% of employers offer only one type of plan (Kaiser Family Foundation 2010: 59), the four principal options are:

- Health Maintenance Organizations (HMOs: services are covered within specified networks only, and referrals are made within the network. This type usually has the lowest co-payments);
- Preferred Provider Organizations (PPOs: these have more flexibility and permit use of some out-of-network services, although patients usually need to pay co-insurance in such cases);
- Point Of Service plans (POSs: combining HMO and PPO features—an in-network physician is the primary provider, and out-of network services are covered as long as the primary care physician initiates a referral), and
- High Deductible Health Plans (HDHPs: these have generally the lowest premiums, but the highest deductibles, and most attractive for people of good health and/or in strained financial situations), see also Table 2.3.

While the differences in cost of coverage between the different plan options is relatively moderate, the amount workers contribute directly varies more significantly and can be almost twice as high on a HMO plan (\$1,028) compared to a HDHPs (\$632, see Appendix 2B). In the US employers therefore pay a much larger share of health care cost than in Germany, and co-payments and other forms of cost-sharing play a more prominent role, enabling the use of financial incentives that are coupled directly with the cost of coverage. To a significant extent, the employer-based health insurance system is governed by standard (insurance) market mechanisms of supply,

demand and risk-adjustment, although there is also some overarching regulation that imposes some limitations on the activities of insurance companies.

#### *2.4.1 Legal framework—health responsibility*

Not least because of the diversity in providers of health care, and the multitude of plans that may be offered in the private market and through employers, there is currently no explicit single set of norms that would specify responsibilities of health care users in different areas. However, similar to the German initiatives on health promotion and incentives, there is some federal guidance on the conditions under which particular types of incentives may be offered. The background to this regulation is the 1996 *Health Insurance Portability and Accountability Act* (HIPAA) which, among other things, sought to improve continuity of health insurance when individuals moved between providers because they changed employers (or lost employment). Prior to the act it was possible that someone who previously had coverage was denied insurance by another company, or charged a significantly higher premium, for example because of pre-existing conditions. HIPAA established that a group health plan may not demand higher premiums of individuals than of other “similarly situated” insurance holders, with comparisons based on a range of health-risk related factor such as medical history or disability.

But HIPAA also clarified that this did not prevent insurers from offering incentives for participation in health promotion and disease prevention programmes. Subsequently, the Departments of Labor (DoL), Treasury (DoT), and Health and Human Services (DHHS) issued guidance in 2006 to address the scope and limitations of this provision in guidance entitled *Nondiscrimination and wellness programs in health coverage in the group market* (in the following: Nondiscrimination rules, Departments of Labor, Treasury and Health 2006).

The *Nondiscrimination Rules* distinguished two different kinds of incentives. First, in the case of what can be called ‘participation-incentives’, a premium discount, rebate, or cash payment may be given simply for participating in a programme, for example one relating to weight-loss or smoking cessation. Second, in the case of what can be called ‘attainment-incentives’, a reimbursement may be

given for meeting certain health status targets, relating to risk factors such as Body Mass Index (BMI) or blood pressure. One important difference between these two types is that practically all people will be able to use participation-incentives, whereas many will not be able to use attainment programmes, whether for health, or other reasons. The Departments therefore considered it necessary to set a ceiling for the level of incentives that may be offered for attainment-incentives. Drawing on evidence from a leading benefit design consultant who suggested that premium discounts offered by insurers at the time ranged from around \$60 to \$480 annually in 1998, the departments calculated that this equated to approximately 3% or 23 % of the total cost of an employee's coverage (i.e., the employee's premium plus the employer's contribution). They subsequently specified three alternative thresholds of 10, 15 and 20% as incentive ceilings, that became the subject of a formal consultation (Departments of Health and Human Services 2001). In finalising the guidance the departments opted for the upper end of this scale, justifying as follows:

The final regulations provide that the amount of the reward may not exceed 20 per cent of the cost of coverage. The percentage limit is designed to avoid a reward or penalty being so large as to have the effect of denying coverage or creating too heavy a financial penalty on individuals who do not satisfy an initial wellness program standard that is related to a health factor. Comments from one employer and two national insurance industry associations requested that the level of the percentage for rewards should provide plans and issuers maximum flexibility for designing wellness programs. Comments suggested that plans and issuers have a greater opportunity to encourage healthy behaviors through programs of health promotion and disease prevention if they are allowed flexibility in designing such programs. The 20 per cent limit on the size of the reward in the final regulations allows plans and issuers to maintain flexibility in their ability to design wellness programs, while avoiding rewards or penalties so large as to deny coverage or create too heavy a financial penalty on individuals who do not satisfy an initial wellness program standard that is related to a health factor. (Depts of Labor, Treasury, Health 2006: 75018)

The question of the scope and limitation of wellness incentives, and of appropriate thresholds was revisited during health reform in 2009 and 2010. Both the House of Representative's *Affordable Health Care for America Act* (Section 112) and the Senate's *Patient Protection and Affordable Care Act* (Section 2705) included further proposals, with the latter proposing to increase the level of reimbursements for attainment-incentives to 30%, with the option of 50% for particular initiatives, subject to approval by the DoL, DoT and DHHS. Echoing earlier regulation, the proposal emphasised that for individuals for whom it is "unreasonably difficult due to a medical condition.... [or] medically inadvisable" to take part in the programmes,

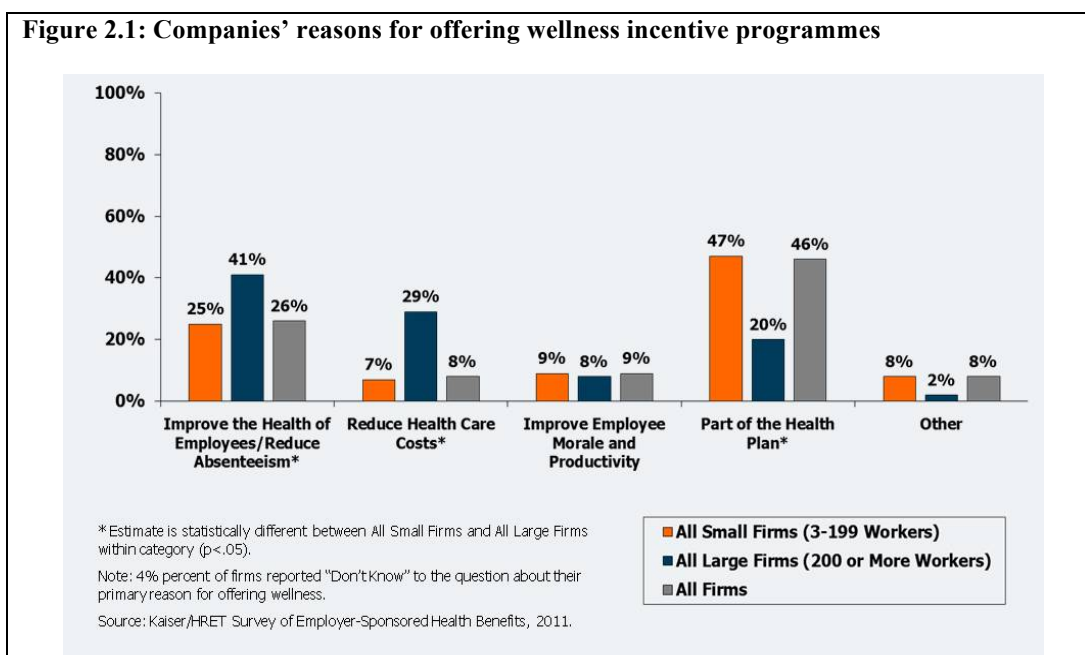
a reasonable alternative standard must be provided for reimbursements to be made, as long as plans were able to request the employee's physician to confirm the existence of a relevant condition. The Senate Bill's provisions passed unaltered into the final *Patient Protection and Affordable Care Act*, passed in March 2010.

In practice, there are several ways in which these provisions can be implemented. In the form of genuine incentives, contributions for insurance holders could be held constant, and those who are willing and able to seek to achieve attainment thresholds could be offered reductions up to 30 or 50% of the cost of coverage. In this case, cost for the incentive would need to be offset by savings resulting from healthier employees, or otherwise be absorbed by the employer. Alternatively, the model envisaged in Wikler's thought experiment (that could also be found in the German cancer prevention regulations pursuant Article 62 SGB V) could be used, by increasing contributions for all, and offering the option of returning to previous levels as an incentive. The *Nondiscrimination Rules* explicitly note that incentives may be implemented by imposing, in effect, differential premiums, as programmes may shift costs "from plan sponsors to participants who do not satisfy the standards, from participants who satisfy the standards to those who do not, or some combination of these." (Depts of Labor, Treasury, Health 2006: 75027). In this case the financing of incentives would result, at least in part, from cost-shifting, rather than gain-sharing. Depending on the type of health plan and the willingness of companies to risk controversy, in principle this provision can permit for substantial differences in cost of health care to employees, as Table 2.3 illustrates.

<b>Table 2.3: Wellness incentives and cost-shifting options: impact on cost of coverage as passed on to consumers</b>		
	30%	50%
Assuming the average cost of coverage of \$4,700, then incentives up to the following amounts may offered:	\$1,410	\$2,350
<i>Scenario A:</i> (genuine incentive) Initial cost of coverage remains unchanged. Incentive amount reduces overall cost of coverage	$\$4,700 - \$1,410 = \$3,290$	$\$4,700 - \$2,350 = \$2,350$
<i>Scenario B:</i> Initial cost of coverage changes: it is made up of previous cost + incentive amount. The incentive is to return to previous contribution levels	$\$4,700 + \$1,410 = \$6,110$	$\$4,700 + \$2,350 = \$7,050$

It is somewhat ironic that one of the major achievements of the 2010 health reforms was finally to end medical underwriting (further to the aforementioned restrictions already resulting from HIPAA), and that the same law should then, in principle, enable significant cost variation in a very similar vein under the guise of wellness incentives.

The extent to which employers will in fact make use of the new opportunities is not clear at this stage, although a marked increase over time can be noted. According to a survey by the National Business Group on Health, 36% of large employers (with at least 1,000 employees) used incentives in 2009. In 2011 this figure rose to 54%, and 80% plan to use incentives in 2012. The use of incentives as penalties over these time points has increased almost fivefold: levels more than doubled from 8% in 2009 to 19% in 2011, and then doubled again to an expected 38% in 2012 (National Business Group on Health and Towers Watson 2011). An earlier survey by the Group found that that 56% of large employers see wellness incentives as one of the top three priorities for curbing cost<sup>9</sup> (National Business Group on Health 2011), and a survey by the Kaiser Family Foundation indicates clear interest in using wellness programmes for health care cost control and improved productivity through reduced absenteeism (Figure 2.1).



<sup>9</sup> The other two being cost-sharing and consumer-directed plans.

While the discussion so far has been somewhat abstract and dealt mainly with what is legally possible, it is also instructive to consider a representative real world example that illustrates the concerns about cost-shifting are not merely armchair philosophy. The BeniComp® Advantage scheme, offered by the benefit design consultant BeniComp is intended to work with a HDHP, and its mechanics are set out clearly on the website, both for employers and employees, and is reproduced in full at Appendix 2C.

The information BeniComp provides for employers opens candidly:

What haven't you tried?... You've increased employee contributions, raised copays and coinsurance, ... We all have tried to shift the cost of health care with plan design changes and by having our employees share in the cost. It simply has not worked.

The company then praises its product which is alleged to be the “first plan that rewards employees for managing their own health”. The function is described as follows: “If an employee maintains or improves their health, BeniComp® Advantage offers a financial reward. For those employees who choose not to modify their lifestyle, they do not receive these rewards and will incur higher out of pocket cost.” The framing of “reward” used here follows directly Wikler’s thought experiment introduced in Section 2.2 and the company acknowledges that the plan “does shift cost, but only to those who have lifestyles that threaten controlled premiums for the rest of the population<sup>10</sup> [...] Either way, costs are allocated more fairly”.

An illustration then shows how the plan works. If employees previously had a deductible of \$500, this is increased to \$2,000. Employees can reduce this by achieving four attainment-incentives, relating to not smoking, and meeting BMI, cholesterol, and blood pressure targets.<sup>11</sup> Each has a value of \$500, and the information emphasises: “Unearned credits=employer savings!”, suggesting that savings of between 12–30% can result from better employee health and higher

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<sup>10</sup> Regarding the population perspective it needs to be born in mind that this, of course, only refers to the population that is covered by employer-based insurance, and not to people outside of it, nor to people over 65, as employers typically only provide coverage until retirement at which point employees are covered by Medicare (which can lead employer-base plans to adopt a more short-term perspective regarding health promotion and cost-savings).

<sup>11</sup> “Blood Pressure: <120/80, Cholesterol LDL: <100, Body Mass Index (BMI): <24.9. While these are established national guidelines, your employer may choose to modify these parameters”, source as below.

deductibles, as well as from employees “who choose other health care options”, i.e. leave the health plan. The programme may also lead to selection effects if prospective unhealthy employees are aware of it in the application phase, and decide to seek employment at a comparable company that does not operate this kind of incentive programme.

Under the heading “This seems aggressive. How do most employees react?” BeniComp suggest that employees understand that companies “cannot continue to provide rich benefits with plan expenses outpacing profits 5:1”. Furthermore, it is suggested to pitch the programme in an analogy to “auto insurance [:] those employees who are doing what they can to lower their risk of serious illness receive the equivalent of a ‘safe driver discount’. Employees understand this concept and receive it very well”.<sup>12</sup> BeniComp’s programme is fully compatible with the legal and regulatory framework, as the information materials also emphasise. Despite the far more obvious potential for inequalities in abilities to use programmes such as these, the US has no reporting requirement whatsoever, neither regarding actual cost-savings that may result from the initiatives, (as in the German case), nor on health improvement or user profiles in terms of health or income groups.

#### 2.4.2 Stakeholder views

Perhaps the most remarkable change in the US policy framework on health incentives is the most recent increase in levels of permissible incentives. It is useful to review the debate that led to it in some more detail. The provisions found their way into draft health reform legislation first in the Ensign-Carper amendment, passed in winter 2009/10 by a vote of 18:4 in the Senate Finance Committee’s work on *Americas Healthy Future Act* that was to become the *Patient Protection and Affordable Care Act* (Ensign 2008). The amendment was also known as the *Safeway-amendment* as, according to Sen. Carper (D-Del.), co-sponsor of the amendment, Sen. John Ensign (R-Nev.) is “a big advocate of the Safeway program” (Ross 2008; Hilzenrath 2010). Steve Burd, CEO of supermarket chain *Safeway*, had published an OpEd entitled “How Safeway Is Cutting Health-Care Costs: Market-

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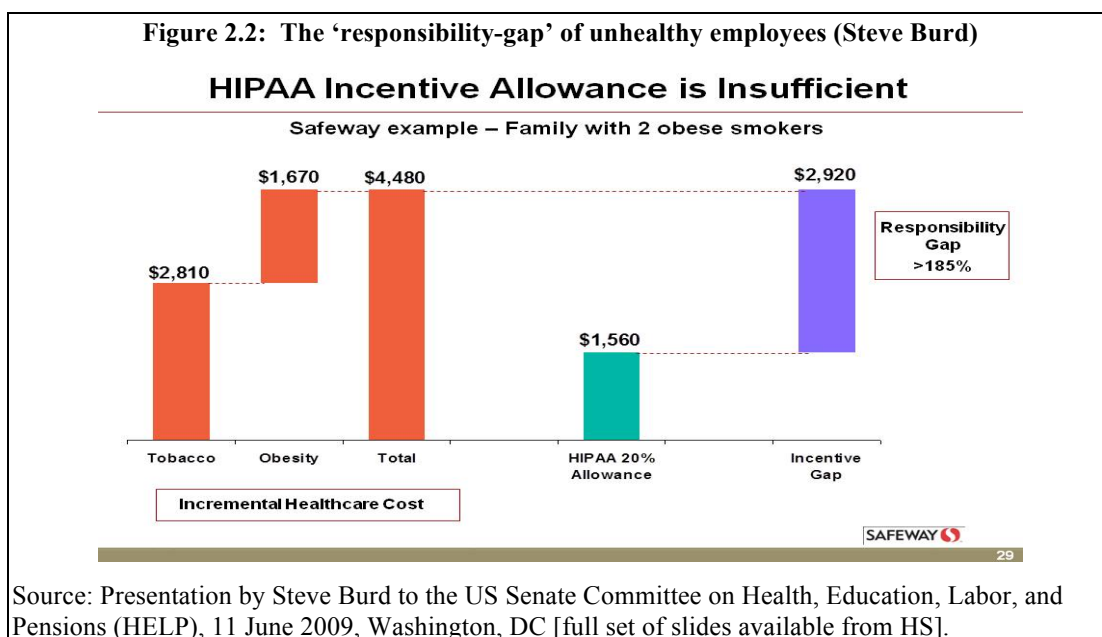
<sup>12</sup> All quotations from: BeniComp® Advantage, “Detailed overview”, available at: [http://www.benicompadvantage.com/index.php?option=com\\_content&view=article&id=8&Itemid=4](http://www.benicompadvantage.com/index.php?option=com_content&view=article&id=8&Itemid=4), accessed 18 February 2012



based solutions can reduce the national health-care bill by 40%” in the *Wall Street Journal* in June that year, claiming that the wellness programme implemented by his company had helped keep health care expenditure constant over the previous four years by varying premiums by as much as \$780 for individuals and \$1,569 for families (Burd 2009). In his commentary Burd also set out the line of argument that can be found in BeniComp’s explanation of the company’s *Advantage* programme:

For decades, driving behavior has been correlated with accident risk and has therefore translated into premium differences among drivers. Stated somewhat differently, the auto-insurance industry has long recognized the role of personal responsibility. As a result, bad behaviors (like speeding, tickets for failure to follow the rules of the road, and frequency of accidents) are considered when establishing insurance premiums. Bad driver premiums are not subsidized by the good driver premiums.

Burd also received considerable attention from policymakers in Washington, and discussed his insights, among other occasions, in a presentation 11 June 2009 to the US President’s Domestic Policy Council, in which he reiterated many of the points made in the *Wall Street Journal* OpEd. Criticising the permissible premium variation under HIPAA, he also set out what he termed the ‘responsibility-gap’, arguing that the incremental health care costs of a family with two obese smokers amounted to a total of \$4,480, of which HIPAA only allowed employers to recoup \$1,560, see Figure 2.2.



Burd’s view is frank, but also somewhat at odds with the declared intention of wellness incentives to focus on health promotion, as well as with the DoL’s, DHHS’ and DoP’s emphasis that the initial 20% threshold was acceptable, as otherwise there

was the risk of incentives having “the effect of denying coverage or creating too heavy a financial penalty” as stated in the above-cited section from the *Nondiscrimination Rules*.

Unsurprisingly, Burd’s intervention attracted criticism from several quarters. First, on the grounds that he has so far not been forthcoming with actual evidence for the cost-reductions that he claims have been achieved through *Safeway’s* programmes. David Hilzenrath, a journalist with the *Washington Post* argued that the case showed how “the untested claims of interest groups can take on a life of their own and shape national policy” (Hilzenrath 2010). Hilzenrath reviewed *Safeway* policy documents and interviewed senior staff, finding that health care costs had in fact not been kept flat for four years. Costs had dropped in 2006 by 12.5 % as a result of the company overhauling its benefits, according to *Safeway* Senior Vice President Ken Shachmut, one of Hilzenrath’s interlocutors. However, this decline had nothing to do with the company’s incentive programme, which had not been implemented until 2009, according to Shachmut, and after 2006 costs began to climb again. According to company spokesman Brian Dowling it would also be difficult for premium incentives to have such an impact on the company’s overall workforce of about 200,000, because the Health Measures programme had been open to only 28,000 of whom 17,000 to 18,000 had enrolled, mainly general office workers rather than store personnel (who are covered by union contracts).<sup>13</sup>

Regardless of similar concerns that had been circulating among informed circles as health reform was being debated, the *Safeway Amendment* still received much support, including from medical leaders such as the Cleveland Clinic’s chief executive, who acknowledged that more evidence would be helpful, but equally suggested that “the lack of empirical third party data does not preclude moving forward” (Hilzenrath 2010). At the same time, a sign-on letter to members of Congress authored by the *American Heart Association* and endorsed by more than one hundred health care advocacy groups including *AARP* (formerly the American Association of Retired Persons), the *American Cancer Society-Cancer Action Network*, the *American Diabetes Association*, the *American Public Health*

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<sup>13</sup> Hilzenrath points out that “Burd’s assertions about flatlining costs pertained to those workers eligible for Healthy Measures, as did the projected 8.5 per cent increase for 2009.” (Hilzenrath, *ibid.*)

*Association, Consumers Union, and the Obesity Action Coalition* urged Congressmen and women to abandon the amendment because of concerns that cost-shifting can be used to penalise sicker employees; because there was lack of clarity of what constitutes a “reasonably designed” wellness programme; and because the ‘alternative standard’ is only provided for people with a medical condition (and not others who may have reasonable concerns, for example about sharing their health information with people other than their doctor, see: American Heart Association 2009).

A position paper on wellness incentives issued in September 2010 by the *American College of Physicians (ACP)* equally expressed concern about approaches along the lines envisaged by Burd. The ACP supported “the use of positive incentives to motivate behavior change” but also cautioned that any discriminating potential needed to be avoided, and that the “incentive structure must not penalize individuals by withholding benefits for behaviors or actions that may be beyond their control” (American College of Physicians 2010: 1-2). Regarding possible impact on the doctor-patient relationship the ACP noted that incentives:

should support appropriate patient autonomy and participation in decision making, including the right to refuse treatment, without punitive consequence [and that programmes] should be designed to recognize and support the physician’s ethical duty to provide care, the physician’s ethical responsibility to discuss all appropriate care options with the patient in a culturally sensitive manner and the physician’s professional obligation to make recommendations on the basis of medical merit. (American College of Physicians 2010: 1-2)

While relevant stakeholder groups therefore do not oppose the principle of using incentives for health improvement, the reforms eventually introduced under the Patient Protection and Affordable Care Act are viewed as problematic due to lacking evidence that would support the change, as well as because of concerns regarding the impact on vulnerable populations and the doctor-patient relationship.

#### *2.4.3 Implicit and explicit rationales*

In the USA, as in Germany, there is a clear interest by policymakers and health care professionals in using wellness programmes and incentives for health promotion, and Figure 2.2 showed that one third of large employers think that they are a suitable means for this purpose, with the added benefit of reducing absenteeism and improving productivity. Almost as many think that such initiatives can help reduce

health care expenditure (see also NBGH 2010). In principle, cost-reduction may be achieved in different ways. One option would be that better health will lead to lower health care usage, as noted regarding the potentially problematic German requirement, that bonuses may only be paid, if savings result from the programmes (Section 2.3.2). Another option, emphasised, for example by BeniComp, who advise that their Advantage scheme will result in “immediate” savings, is to shift cost to employees, or to motivate high-cost enrollees to seek coverage elsewhere. Although American employees have far higher contributions than their German counterparts, employers still cover the larger part of health care costs, which may explain some of the interest in using incentives to shift cost back to employees. Another, perhaps more implicit, and more value-laden rationale for such initiatives may be found in an appeal to fully embrace the ethos of ‘live free or die’. As Schachmut, *Safeway’s* Senior Vice President observed: “I have no problem with a smoker having a 10-pack-a-day habit and killing him or herself... I mean, it's a personal choice. It's a free country. I just don't want to have to pay the health-care costs of that personal choice... and the same thing is true for obesity” (Hilzenrath 2010).

## **2.5 Conclusion**

In part for overlapping reasons, in part for distinct ones, individual-level incentives are of considerable interest to policymakers and different stakeholders in Germany and the USA. There is universal agreement that they may be suitable tools to promote better health and efficiency of health care services in principle, although their acceptability depends considerably on the specific details of their implementation.

In the German context, goal conflicts can arise as incentives can be used by sickness funds not just for health promotion or efficiency purposes, but also to secure a competitive advantage over other providers in attracting ‘good-risk’ insurees. The fact that in the American context employers are far more directly involved in the provision of health care introduces a different kind of potential goal conflict, as outlined above, leading to higher willingness to shift cost and achieve reductions in absenteeism. In both countries health care professionals observed that incentives had the potential to interfere with the doctor patient relationship, with German doctors in particular opposing being given a policing function.

A major difference between the German and the US approach is that while, *prima facie*, both countries intend to use the schemes for health promotion, the levels of incentives differ significantly and are far lower in Germany. A more conceptual difference that is however directly related to issues around the permissible level of incentives is that US policy recognises that attainment-incentives are generally not open to all, whereas this is more likely the case with participation-incentives. Such a distinction is not recognised in Germany, where both types are mixed (see Appendix 2A). Equally, while US policy requires that alternative standards be provided to those who (for medical reasons) are unable to meet attainment-incentive targets, there is no such provision in Germany. While Germany imposes a reporting requirement on the financial impact of incentives, this is not required in the US, and neither country requires evidence that incentive programmes lead to health improvement.

The framing of incentives plays a significant role in both countries, and a number of different approaches can be distinguished. The implementation of the German cancer policy pursuant Article 65 SGB V was officially introduced as an incentive intended to assist responsible behaviour, but was widely criticised as a penalising approach, and not perceived as a merely benevolent encouragement. The perception of a penalty had less to do with the absolute size of the difference (2% instead of 1% of one's annual gross income), which is unlikely to result in financial hardship, but with the mechanics of creating the incentive by doubling the baseline.

The German framework is generally careful to minimise cost-shifting, and explicitly requires that bonus payments must not be financed by those not taking part in the schemes—instead, bonuses should be paid through gain-sharing as a proportion of the win that results from having achieved more efficient services. In contrast to this approach, US policy explicitly permits cost-shifting, and proponents such as Burd clearly see this option as the principal attraction of the policy. His statement regarding the 'responsibility-gap' revealed (see Figure 2.3) that his interest in higher levels of incentives is not driven by, for example, a view that the next stage in making a major step forward in terms of achieving behaviour change and helping people lead healthier lives can only be made if incentive levels are increased from

20% to 30% (or 50%—nor has anyone else ever made such a claim), but that he wants to reduce his company's payments for the obese and smokers. The latter, he feels, unduly burden the community of more responsible and healthy enrollees, and it is hence inappropriate that they should be required to fund care that is required because of avoidable health risk behaviour (in the same way that the community of prudent and careful motorists should not have to pay for the risks that reckless speeding motorists incur because of their actions).

Table 2.4 provides a summary overview of the principal arguments in favour and against personal responsibility in US and German policy. These arguments, as well as the influential views by commentators such as Steve Burd make a number of non-trivial assumptions in relation to concepts such as voluntariness, attributability, causation, praise and blame, and not least the concept of responsibility itself, which will be considered in more detail in the next chapter.

<b>Table 2.4: Principal arguments for and against promoting personal responsibility for health in policy</b>	
Note: Items in “for” and “against” cells are not generally supposed to correspond (i.e., “against” cell is no attempt at countering directly the “for” argument)	
<b>For</b>	<b>Against</b>
<b>Both US and Germany</b>	
<b>Coproduction:</b> Personal action is one of several determinants of health.	<b>Discrimination/victim-blaming:</b> personal responsibility for health (PRH), can become unduly penalising, especially where people are held responsible for factors beyond their control.
<b>Cost-reduction:</b> belief that ‘an ounce of prevention saves a pound in cure’ explicitly underlies German legal requirement that incentive payments may only be made if savings are achieved.	<b>No economic case:</b> Initial German idea for getting more people to cancer screens was not judged cost-effective. In the US, no evidence for claims that influential Safeway wellness programs achieved savings. Overall it’s unclear over what timespan savings should be demonstrated and whether they are realistic, especially longer term.
<b>Voluntary self-harm:</b> Ok to ask users for higher contributions where they require services as result of voluntarily chosen health risks.	
<b>Germany</b>	
<b>Solidarity:</b> Solidarity demands PRH: (1) sickness funds cant ‘make’ people healthy, so cooperation is required (2) more needs can be met if users limit demands, use services only where necessary.	<b>Solidarity:</b> Solidarity can demand limiting PRH: some costs of unhealthy behaviour are absorbed by the solidaristic community, and cost-shifting is not seen as compatible with the principle of risk-sharing.
<b>Compliance/physician-patient relationship:</b> Partly overlapping with cost-reduction argument, but also part of duty to cooperate in treatment/rehabilitation: lacking compliance in cancer prevention can double copay from 1–2%.	<b>Physicians forced in policing role/ physician-patient relationship:</b> checking on compliance and meeting health standards is viewed as incompatible with primary obligation to patients.
<b>Chronically ill have special responsibilities:</b> as they use more services, can be asked to contribute to efficiency.	<b>Arbitrary penalty:</b> not ok to single out group of cancer patients with compliance regulation: other chronically ill are on 1% threshold.
	<b>Coerciveness:</b> Initial idea for getting more people to undergo cancer screens seen as coercive (high false positive/negative rates in breast cancer screens).
<b>US</b>	
<b>Polluter-pays principle/‘Live free or die’ ethos:</b> Individualism demands PRH: people are responsible for their choices, and this includes the consequences of their choices. I am not my neighbour’s keeper, no solidarity. Auto-insurance analogy.	<b>Continuation of medical underwriting/ discrimination:</b> Initial laws on wellness incentives permitted cost-shifting up to 20% of cost of coverage. More was seen as giving rise to discrimination issues. But 2010 reforms increased this to 30% and 50% in exceptional cases, while ending refusal of insurance for pre-existing conditions. Can be seen as medical underwriting by the backdoor.
<b>Fairness/no free-riding in risk-pool:</b> similar to German solidarity conceptualization: because of limited resources it’s ok to penalise those who (allegedly) free-ride. US law explicitly permits cost-shifting from plans to unhealthy, or from healthy to unhealthy.	
<b>Promote productivity, reduce absenteeism:</b> Employers pick up majority of health care cost and feel ‘cheated’ by employees not pulling their weight (eg because of excess weight... )	

## Chapter 3<sup>1</sup>

### **An ethical framework for evaluating health responsibility policies**

#### **3.1 Introduction**

Chapter 2 showed that in policy and practice, proponents of health responsibility draw on different rationales and have different goals in mind, be they to promote the health of people individually and at the population level, to enhance competition between payers of health care, to improve the efficiency or fairness of health care services, to increase productivity in the workplace, or to select for healthy and against unhealthy individuals in the pool of individuals covered by a given company or insurance provider and thereby lower health care expenditure. While it is not necessarily impossible to achieve all of these rationales or goals to a reasonable extent, it also became clear that tensions can arise when they come into conflict. In this chapter I approach the question of how such conflicts might be resolved, and examine more closely the concept of personal responsibility for health from a philosophical perspective. In part, this matches closely with some of the arguments employed in the policy discourse, but in part it also goes beyond this and will hopefully help to explicate some of the confusion and polarization that besets the debate.

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<sup>1</sup> Text in this chapter draws on, and in part reproduces verbatim, material published in the following previous publications: Schmidt 2007b, 2008a, 2009a, 2009b, 2011a, Schmidt, Halpern, Ash 2012, Schmidt, Voigt, Wikler 2010. Earlier versions of these papers were also presented at several academic meetings: the Priority in Practice Conference, Philosophy Department, University College London, UK, March 2008; the Ninth World Congress on Bioethics, International Association of Bioethics, Rijeka, Croatia, September 2008; the Responsibility & Health Workshop, Hughes Hall Centre for Biomedical Science in Society, Cambridge University, Cambridge, UK, March 2009; the Fourth International Jerusalem Conference on Health Policy, The Israel National Institute for Health Policy and Health Services Research, Jerusalem, Israel, December 2009; at a meeting of the National Institute for Health and Clinical Excellence's Citizen's Council, May 2010, a seminar at the Kollegforschergruppe "Normenbegründung in Medizinethik und Biopolitik" in Münster, January 2011, and a seminar at the The Centre for the Study of Incentives in Health, London, March 2011. I am grateful for valuable discussion with participants at these meetings, and equally for comments from, and discussions with Annette Dufner, Stefanie Ettelt, Nir Eyal, Elias Mossialos, Nicole Knaack, Julia Kreis, Kristin Voigt, Alex Voorhoeve, Joy Wang, James Wilson and Dan Wikler, who reviewed drafts of the above papers, or of this chapter, and helped me better understand specific aspects discussed in them.



I begin by contextualising the use of ‘carrots’ and ‘sticks’ for personal responsibility for health in the broader philosophical debate around the scope and limitation of coercion in the health context. This is followed by a conceptual analysis of the core concept of health responsibility: I seek to show that characterizations found in the literature are insufficiently nuanced to be of practical use in planning and evaluating health responsibility policies in contemporary pluralistic societies. In setting out the concept of *health responsibility as co-responsibility* I then present a proposal for a more nuanced concept of personal responsibility that takes up the oftentimes disconnected strands in the philosophical debate, and is nonetheless compatible with the needs of real-world policy.

### **3.2 Personal responsibility and behaviour change in the spectrum of coercion and ‘doing nothing’**

One of the seminal philosophical contributions regarding the question of how to reconcile tensions between state power and individual liberties that is directly applicable to the health care context is John Stuart Mill’s so-called ‘harm principle’, set out in his essay *On Liberty*:

The object of this essay is to assert one very simple principle, as entitled to govern absolutely the dealings of society with the individual in the way of compulsion and control, whether the means used be physical force in the form of legal penalties, or the moral coercion of public opinion. That principle is, that the sole end for which mankind are warranted, individually or collectively in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. (Mill 1989 [1859] : 13)

It is not uncommon that the citation ends here, and the quote is seen as synonymous with the paragraph’s equally famous conclusion: “Over himself, over his own body and mind, the individual is sovereign” (e.g.: Gillon 1985: 1807; Callahan 1981: 21). However, the section between these two parts is also noteworthy. Thus, before the concluding sentence, immediately following the above section, Mill says:

These are good reasons for remonstrating with him, or reasoning with him, or persuading him, or entreating him, but not for compelling him, or visiting him with any evil, in case he do otherwise. To justify that, the conduct from which it is desired to deter him must be calculated to produce evil to someone else. The only part of the conduct of any one, for which he is amenable to society, is

that which concerns others. Over himself, over his own body and mind, the individual is sovereign. (Mill *ibid.*)

For the present context, the full quote is relevant as it illustrates that even drawing on a liberal philosopher as Mill one can accept that there are further options between the two poles of hard paternalism<sup>2</sup> on the one hand, and the complete *laissez-faire* of a libertarian minimal state on the other, that we may consider in efforts aimed at behaviour change: for Mill clearly sees it permissible to ‘remonstrate, reason, persuade or entreat’. A recent report by the *Nuffield Council on Bioethics* that was concerned with setting out an ethical framework for broader public health initiatives represented these different options along a so-called ‘intervention ladder’ that ranked interventions by their degree of intrusiveness, see Box 3.1.

**Box 3.1: The intervention ladder (Nuffield Council on Bioethics)**

The range of options available to government and policymakers can be thought of as a ladder of interventions, with progressive steps from individual freedom and responsibility towards state intervention as one moves up the ladder. In considering which ‘rung’ is appropriate for a particular public health goal, the benefits to individuals and society should be weighed against the erosion of individual freedom. Economic costs and benefits would need to be taken into account alongside health and societal benefits. The ladder of possible policy action is as follows:

*Eliminate choice.* Regulate in such a way as to entirely eliminate choice, for example through compulsory isolation of patients with infectious diseases.

*Restrict choice.* Regulate in such a way as to restrict the options available to people with the aim of protecting them, for example removing unhealthy ingredients from foods, or unhealthy foods from shops or restaurants.

*Guide choice through disincentives.* Fiscal and other disincentives can be put in place to influence people not to pursue certain activities, for example through taxes on cigarettes, or by discouraging the use of cars in inner cities through charging schemes or limitations of parking spaces.

*Guide choices through incentives.* Regulations can be offered that guide choices by fiscal and other incentives, for example offering tax-breaks for the purchase of bicycles that are used as a means of travelling to work.

*Guide choices through changing the default policy.* For example, in a restaurant, instead of providing chips as a standard side dish (with healthier options available), menus could be changed to provide a more healthy option as standard (with chips as an option available).

*Enable choice.* Enable individuals to change their behaviours, for example by offering participation in an NHS ‘stop smoking’ programme, building cycle lanes, or providing free fruit in schools.

*Provide information.* Inform and educate the public, for example as part of campaigns to encourage people to walk more or eat five portions of fruit and vegetables per day.

*Do nothing or simply monitoring the current situation.*

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Full excerpt from: (Nuffield Council 2005: 41–42)

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<sup>2</sup> Joel Feinberg defines as follows: “Hard paternalism will accept as a reason for criminal legislation that it is necessary to protect competent adults, against their will, from the harmful consequences even of their fully voluntary choices and undertakings. [...] Since it imposes its own values and judgements on people ‘for their own good’, it seems well named by the label of ‘paternalism’. It is not as clear that ‘soft paternalism’ is ‘paternalistic at all [...] Soft paternalism holds that the state has the right to prevent self-regarding harmful conduct... *when but only when* that conduct is substantially non-voluntary, or when temporary intervention is necessary to establish whether it is voluntary or not” [Emphasis in original] (Feinberg 1986; Dworkin 2010).

The Nuffield Council's mapping can provide a helpful contextualization of health responsibility policies that take the form of 'carrots' or 'sticks', as outlined in Chapter 2. As we saw there, in presentational terms, *prima facie*, most incentive schemes take the form of non-coercive encouragements, suggesting that people are free to take them up or not. That is, on the Nuffield Council's ladder, incentives rank as more intrusive than the options of doing nothing, enabling choice, and guiding choices through changing the default policy. The latter approach has recently attracted some attention under the label of, first, "libertarian paternalism", and then "nudging" (Sunstein 2003; Thaler 2008; Thaler and Sunstein 2003; see also: Marteau, Oliver, and Ashcroft 2008). In contrast to these measures, the hope of those advocating incentives is that they will have more traction, while avoiding the controversies surrounding the more invasive and potentially liberty-infringing measures higher up on the ladder, such as using 'sticks' or disincentives, or restricting or eliminating choice.

Theoretically, the underpinnings of using incentives rest on the same principles of behavioural economics that underpin Cass Sunstein's and Richard Thaler's work, and have also become known as "asymmetric paternalism" (Loewenstein, Brennan, and Volpp 2007; Camerer et al. 2003). The starting point is to challenge the *homo economicus* model of classical economics which holds that people are self-interested rational agents who are generally able to identify the means necessary to achieve goals worthy of pursuit, and to act accordingly. The case of health behaviour, along with other situations, such as retirement planning, complicates this assumption considerably. Even though the desire to lose weight, to drink less or to stop smoking is felt strongly by many, many also fail in acting on it, despite being quite clear about the means that are required, such as eating less, and exercising more.

Researchers in the field of behavioural economics have begun to systematically map these constraints affecting behaviour change. The concepts of "present preference bias" and "quasi hyperbolic discounting" have been coined in response to a series of experiments demonstrating that people generally prefer rewards in the present or near future to ones further in the distance (Laibson 1997; Frederick, Loewenstein, and O'Donoghue 2002; Madden et al. 1997). In other words, the pleasure of an extra helping of cake today will often be preferred over the option of

being healthier later—even if one’s future self would prefer the alternative. The underlying mechanisms that often lead to inertia and procrastination can, however, be turned around by exploiting the very principles that fuel them, for example, by providing immediate feedback and rewards for behaviour change that might not be perceived as rewarding by itself. A further important concept established in observational and experimental research relates to loss aversion (Kahneman and Tversky 1979). What is meant here is that people disproportionately prefer avoiding losses to making gains (of equivalent value). These and further principles of behavioural economics (Loewenstein, Brennan, and Volpp 2007) have led to a range of studies exploring the potential of using losses and gains in motivating behaviour change through fixed sum discounts, cash rewards, lotteries, or deposit contracts in areas such as medication adherence, smoking cessation, weight loss or substance abuse management (Volpp, John et al. 2008; Volpp, Loewenstein et al. 2008; Volpp et al. 2006; Volpp, Troxel et al. 2009; Lussier et al. 2006; Giuffrida and Torgerson 1997; Paul-Ebhohimhen and Avenell 2008; Jeffery 2012; DeFulio 2012; Higgins et al. 2012). Research also suggests that incentives have the potential to benefit low-income groups (Marteau, Ashcroft, and Oliver 2009; Oliver and Brown 2011).

Conceptually, then, it is clear why incentives, in particular, are attractive as tools for promoting health responsibility: while interventions focusing on improving the infrastructure of the environment still depend on people making use of these improvements, incentives seek to focus peoples’ attention more directly on making use of available opportunities, and similar offers that are viewed as having positive value, in a way that seeks to be sensitive to the need to minimise force or coercion.

However, Chapter 2 also illustrated that the extent to which policies can be said to be successful in achieving these goals depends significantly on the way in which incentives are implemented, and I will return below to a framework that seeks to assist in deciding which policies are reasonable, and which ones are not. However, before this step it is also necessary to take a closer look at the very concept of health responsibility. For some of the confusion in the debate arises not only from the fact that people have different rationales in mind when they speak about responsibility, or different ideas about the legitimacy of using policy tools that may entail persuasion or coercion, but also because they have different ideas about the extent to which the

concept of responsibility for health is primarily descriptive or normative, as will be shown next. Clarity on all aspects is required to make progress with the responsibility debate in academia, policy and practice.

### **3.3 Personal responsibility: conceptual analysis**

Why should we talk about personal responsibility in health or other contexts of social policy at all? Alexander Brown suggested that plausible arguments can be made that appeals to responsibility and policies enforcing it rest on five separate rationales. Accordingly, responsibility-sensitive policies may enhance fairness in the distribution of resources, maximise utility of available resources for all, or promote individual self-respect, autonomy, and human flourishing (Brown 2005: 28-33). Some of the policies to realise these rationales may entail penalties, but not all do.

However, for many commentators, ascribing responsibility is intrinsically linked to holding people responsible, and proponents argue that responsibilities without sanctions appear pointless, while opponents caution that imposing sanctions often entails the risk of misunderstanding the fundamental determinants of health, and risks penalising people unduly. Further to the *Black report* (Black 1980) and the *Whitehall studies* (Marmot, Shipley, and Rose 1984; Marmot et al. 1991) which paved the way for much research on the social gradient in health, the 2008 report by the WHO *Commission on Social Determinants of Health* emphasises the importance of the environment in which people live, showing, for example, that a boy growing up in the deprived Glasgow suburb of Calton will live on average 28 years less than a boy born in nearby affluent Lenzie (54 vs. 82 years, see: World Health Organization 2008). This suggests strongly that the role of individual behaviour alone in relation to health outcomes is limited, to say the least (Venkatapuram and Marmot 2009). Further, following Geoffrey Rose's seminal paper "Sick individuals and sick populations" (Rose 1985), the argument can be made that a focus on individual behaviour, consumerist models and "over-dependence on individual choice will not achieve changes in society norms" (Doyle, Furey, and Flowers 2006: 396).

Given the important role of environmental factors, then, many commentators argue that focusing on broader political and public health measures is, first, a more efficient approach for health promotion, and second, more appropriate in fairness

terms, than seeking to get individuals to change their behaviour (Resnik 2007: 445; Minkler 1999: 126-131; Raikka 1996: 360). For, even if all people are held responsible for the same type of health outcomes—say, being overweight and experiencing associated poor health—such policies would raise problematic equity issues and could amount to “victim-blaming”, where people who are already in disadvantaged social positions are held responsible for factors that are largely beyond their control (Minkler 1986: 551; Wikler 2004: 336; Daniels 2007: 67-68, 148). In particular, there are worries that responsibility-emphasising policies may stigmatise people individually or particular socio-economic groups (Roemer 1995: 21; Minkler 2000: 18).

In addition, a branch of feminist theory, traditionally concerned with an analysis of obligations and entitlements against a background of the structure of (power-)relationships between people, has emphasised the “social cooperation model”. On this view, people are embedded in different webs of interconnectedness, which makes it difficult to attribute full responsibility to individual people alone. Susan Sherwin, for example, has argued against appeals to responsibility that penalise people, although she appears to accept that personal responsibility may be a meaningful concept if it has an empowering effect (Sherwin 1998: 165).

Clearly, these lines of argument, research and evidence need to be taken seriously, and it would be naïve to ignore the constraints and opportunities associated with a particular upbringing, geographical location, or income bracket, as opposed to another. However, as noted in Chapter 2, not all responsibilities are concerned with penalising people for bad health outcomes, and it would be short-sighted to reduce the debate about personal responsibility to this one form.

Moreover, as a review of the literature shows, there is a range of different things commentators may mean when they say that “person X is responsible for p”. Sometimes, distinct notions are made explicit, but other times, several meanings may be in use simultaneously, whether explicitly or implicitly. Not all authors seem to be aware of previously published conceptualisations, in part, perhaps, because discussions have taken place in different specialist philosophical, medical and health policy publications, with insufficient interdisciplinary exchange. Irrespective of the

reasons for the sources of the range of different meanings it is crucial to be aware that much confusion arises from not distinguishing clearly between these different senses, or from not being explicit about which sense is intended in endorsements or criticisms of particular responsibility-related policies.

In the following I seek to provide an overview of the different notions that have currency in the literature. In a second step, I will present a synthesis that aims to illustrate that it is not useful to reduce the concept of personal responsibility to just one meaning, as it is, by necessity, multi-faceted, due to the different roles that health behaviour plays in, among other things, medicine, health policy, law, sociology, philosophy, and politics. While a reduction to one single meaning has a certain aesthetical and methodological appeal, I contend that this approach is of little use in making progress with the debate around personal responsibility as it fails to acknowledge that the concept plays a role in more than one discourse.

In terms of concepts that have been set out to be applied in the context of health care (or are otherwise directly applicable), the following influential examples, roughly in chronological order, stress different aspects. Daniel Wikler differentiated between “causal ... responsib[ility versus] responsib[ility] ... [as] being at fault and accountable” (Wikler 1978: 333) and therefore makes a principal distinction between behaviour as having contributed to a health outcome that is judged as negative, and considering sanctions for this outcome. The first may lead to the latter, but there is no intrinsic connection: separate justification is required in moving from one to the other. In a similar vein, Ronald Dworkin distinguished between three senses: one’s purely functional role as a biological organism (“role responsibility”), the effect of personal choices (“causal responsibility”), and claims others may have against people whose health behaviour leads to avoidable cost (“responsibility based on liability”, Dworkin 1981: 28). Thomas Scanlon proposed a split between “substantive responsibility ... [and] moral responsibility” (Scanlon 1998: 21-22, 248, 272, 278), where substantive responsibility is relevant for questions of distributive justice as it demands us to consider centrally the opportunities a person has had, and the choices that she made, in assessing what we owe her, and what she owes the community. Moral responsibility, by contrast, is concerned with the circumstances that determine when it is appropriate to take a person’s attitudes or actions as the basis for moral

appraisal. More recently, Zofia Stemplowska defined “agent responsibility” as meaning that one has responsibility for having brought about a certain state of affairs (thus overlapping with Wikler’s “causal responsibility” and Dworkin’s “role responsibility”), which is separated from “consequential responsibility”, meaning that “the burdens (or benefits) that come with or constitute [an action] are justly one’s to bear (or to enjoy)” (Stemplowska 2008: 241).

The key distinctions made in these four approaches hence differentiate between descriptive and evaluative senses of personal responsibility that may be, but are not necessarily connected: we may say someone is responsible for an outcome simply because her behaviour played a causal role in bringing it about, and we may also find that such behaviour makes her praise or blameworthy, but such assessments can be separate from seeing legal or otherwise retributive sanctions justified.

Distinctions are also made regarding different types of responsibilities that may or may not be deserving of sanctions. Alexander Cappelen and Ole Norheim distinguish two different senses in separating “responsib[ility] for ... choices ... [from] responsib[ility] for the consequences of ... choices” (Cappelen and Norheim 2005: 478). They argue that within a liberal egalitarian approach it can be acceptable to hold people responsible for the choices they have made regarding health risks, but not directly for the actual consequences of their choices. This is so because of complications around determining exactly the degree to which certain health outcomes can be said to be under the control of individuals, both in terms of epidemiological factors and those generally discussed as relevant in the aforementioned literature on the social determinants of health. Therefore, as argued earlier along identical lines by Julian Le Grand, Cappelen and Norheim see tobacco taxation justified on the basis that it is a penalty for taking a health risk, even if no demonstration is required as to the extent to which an individual’s action *de facto* led to cancer (Le Grand 1991: 121). Without suggesting new terminology John Roemer also made a noteworthy contribution on the subject of how to determine the extent of an individuals’ substantive responsibility in the context of considerable variation of social and epidemiological factors. According to Roemer, responsibility assessments should be linked to the degree to which a person’s risk behaviour departs from standards that are typical for the kind of group a person might be assigned to in view



of their health risk propensity (Roemer 1995: 20; see also: Roemer 1994; Roemer 1993).

A separate attempt for conceptual clarity and progress regarding the questions of which kinds of responsibilities can justifiably attract penalties can be found in proposals that suggest that the central distinguishing feature is to do with whether responsibilities relate to past or future actions. Hence Micha Werner, Henk ten Have, Georg Marckmann, Eli Feiring and others separate between “prospective ... [vs.] retrospective responsibility” (Werner 2002: 525; ten Have 1994: 120; Marckmann 2005: 302; Marckmann 2007: 111), or “forward-looking ... responsibility [vs.] backward-looking ... responsibility” (Feiring 2008: 33), generally arguing that retrospective responsibility attributions should be avoided because of their potential to hold people responsible for factors that are in fact beyond their control, and that, instead, the focus should be on (non-penalising) prospective responsibility. Shlomi Segall, by contrast, does not seek to negate that in some cases—including retrospective or backward looking responsibilities—people may reasonably be said to be responsible for a poor health outcome. He has sympathies for a classical luck-egalitarian account, that holds, broadly, that distributional equality does not require equality of outcome, but merely the elimination of inequalities that are beyond people’s individual control (see: Arneson 1989). However, Segall suggests that the value of solidarity may act as a waiver in some cases, requiring us not to abandon people if they are in a position of disadvantage even if this is, to some extent, reasonably attributable to their actions (Segall 2007: 197; see also Buyx 2008: 1515).

These and further characterisations have been set out for different reasons: some sought to address particular policy issues, others evolved from certain problems that arose in theoretical political philosophy, notably the problem of abandonment in (luck)egalitarian frameworks (Anderson 1999; Arneson 2000). Here, the purpose is not to settle deeper theoretical disputes, but to bring the rich and nonetheless to some extent surprisingly disconnected literature on health responsibility to bear on the issue at hand. This is necessary to make progress with actual policy proposals that, in very direct ways, set out responsibilities that often have significant penalties and rewards attached. In addition, I also wish to

demonstrate that for purposes of health promotion and routine interactions of people with health professionals, it is crucially important to understand that talk about personal responsibility is not necessarily connected with the discourse about rewards and penalties.

With several of the above commentators, I hence agree that at the most basic level, it is conceptually important to distinguish whether we are ascribing responsibility in a backward-looking sense (where, for example, we assess someone's past behaviour that is correlated to some health outcome, be it positive or negative) or in a forward looking one (where we may want to specify what people should do in the future). The distinction is central for framing more clearly the issues at hand. However, I have less faith than the cited commentators that a focus on prospective responsibilities alone will avoid thorny fairness issues, or be sufficient to preserve a meaningful concept of personal responsibility for health promotion and health policy. Nor am I persuaded that reference to solidarity alone will be sufficient to attenuate the potentially penalising elements of responsibility ascriptions. As Chapter 2 has shown, solidarity can cut both ways and may undermine, as well as support, understandings of responsibility that can entail penalties.

In both forward and backward looking perspectives, several different things can plausibly be meant when we ascribe responsibility, as has emerged from the above review of different concepts. In a backward-looking sense, the phrase "person X is responsible for p", with "p" standing for a health outcome that is judged to be negative, may mean:

- (1) X's behaviour has played a certain causal role in having brought about p.
- (2) X's behaviour has played a certain causal role in having brought about p, and should recognise this.
- (3) X's behaviour has played a certain causal role in having brought about p, should recognise this, and try to avoid doing so in the future.
- (4) X's behaviour has played a certain causal role in having brought about p, should recognise this, and make good any costs (with or without being blamed) for reasons of distributive justice.

- (5) X's behaviour has played a certain causal role in having brought about p, should recognise this, try to avoid doing so in the future, and make good any costs (with or without being blamed) for reasons of distributive justice.
- (6) X's behaviour has played a certain causal role in having brought about p, should recognise this, try to avoid doing so in the future, make good any costs, and, in cases where X requires treatment, may be given a lower priority than patients whose behaviour played none or a lesser role in contributing to their health care needs (typically with attribution of blame).

As can be gleaned from the brief review above, it is not uncommon for commentators to focus on the last type only, and/or to jump straight from the first to the last type, assuming that having established some degree of causal or role responsibility, a person must also be held responsible (see: Daniels 2007: 67-69; Heath 2008: 787; Cappelen 2005: 477). But this is far from necessary.

There are several reasons why we may find it adequate and useful to draw on some notion of non-penalising retrospective responsibility, whether in abstract policy, specific prevention campaigns, or consultations with health care professionals. For example, in a given case where a person is responsible in one of the first three senses above, there may remain some degree of freedom for personal action and behaviour change even if environmental constraints have played a role, perhaps even a major one. Realising the scope for action in this area is important for avoiding fatalism and resignation, which may have a powerful grip on people struggling to maintain or improve their health. While it is difficult to disagree with the strong emphasis that proponents of the social determinants of health approach put on the general need for improving environmental conditions, an exclusive or overly strong focus on the environment can overlook the degrees of freedom that people have, even in constrained conditions. For people to take action, then, it is necessary for them to realise the extent to which they contributed to, say, a bad health outcome, and, in this merely functional sense, to realise that they are, and can be, responsible for good or bad health. An important qualification is of course Kant's old adage of "ought implies can", which has particular relevance in this context. For it would be pointless, if not outright Kafkaesque or cynical, to specify responsibilities where, due

to strong environmental constraints, it is simply impossible for people to act accordingly.

It is also important to recognise that talk of responsibility in a forward looking sense is in many ways quite different from the more common backward-looking perspective. Hence, what we may mean here when we say that “person X is responsible for p”, and “p” is an action judged to be conducive to good health, may be:

- (1) X should do p as no-one else can, in principle (or will, practically) do p for X (e.g., exercise more, eat less).
- (2) X should do p, as this will be good for the health of X.
- (3) X should do p, as this will be good for the health of others, or the operation of the health care system, even though X won't be penalised if p is not done.
- (4) X should do p, as this will be good for the health of others, or the operation of the health care system, and X knows that a penalty will be imposed if p is not done (or a reward given, if p is done).

Again, it is far from necessary that the first or second type of responsibility, which may be said to relate primarily to prudential obligations, automatically leads to the last type, which, together with the third, also invokes notions of justice. Some health-related behaviours simply require that people individually do them, as no-one else will do them for them, and not even the most optimal environmental conditions will ‘make them do them’, in some sort of mechanistic way. It is in this somewhat banal, but nonetheless crucially important sense, that a range of health-related behaviours are personal responsibilities. Noting them and appealing to them in health promotion activities is relevant since—environmental constraints permitting—in a significant sense it is up to us to decide on whether we wash our hands regularly, brush our teeth, exercise, see our GP when we are sick, are honest about our health-relevant information, take part in public health programmes, and so on. Advocating such responsibilities can result in clear personal benefits and is also likely to complement the social determinants of health approach as it can help identify particular social or other structural constraints that make it difficult for people to live healthily.

Prospective and retrospective responsibilities can, as some of the above commentators suggest, be advocated in an either/or fashion—for example, with Wikler it would clearly be possible to argue that (retrospective) personal responsibility should at best play a peripheral role (Wikler 2004: 134), but that a prospective notion of non-penalising responsibility in the sense of (1)–(3) above may nonetheless be permissible. But it would be more difficult to advocate retrospective responsibilities without prospective ones. For in the case of penalties it seems reasonable to hold people responsible only if they have had knowledge of the penalty that is attached to certain choices or behaviours at the point of time where they acted in ways that were likely to put them at a disadvantage. Yet, this principle seems not heeded universally in policy: as we have seen in Chapter 2, in the case of the German policies on repaying cost of treatment for complications arising from tattoos, piercing or non-medically indicated plastic surgery (Section 2.3.1), the penalty was introduced both for people who may decide to undergo one of these procedures after introduction of the law, and for all those who happened to have done so in the past (not knowing, clearly, that at some point these actions would incur a penalty). By contrast, the policy on higher co-payments for sufferers of breast, colon, or cervical cancer patients—introduced in the same law—did specify an age cut-off, meaning that the policy will not retrospectively punish those who failed to behave in ways that are deemed legally appropriate. Even if commentators are likely to continue to differ about the role that opportunity of choice should have in holding people responsible, it is clear that advocates of personal responsibility policies would have a stronger case where they set out and justify explicitly prospective responsibilities first, before implementing retrospective ones, in particular where significant rewards or punishments are associated with the measures.

### **3.4 Personal responsibility as co-responsibility**

So what would a plausible concept of health responsibility look like? Further to the above analysis, I draw on Werner's general characterisation of responsibility in seeking to answer this question (Werner 2002: 521-527). Werner separates four dimensions of responsibility: *someone* (a subject of responsibility) is responsible for *something* (the object of responsibility) towards *someone* or some *entity* (the judicial authority) in view of particular *normative standards* (the normative background). To

unpack this approach for the present context in somewhat more detail, it then follows that:

- *Subjects of responsibility* are, first, patients, and much of the literature focuses on patient obligations (see, for example: English 2005; Gauthier 2005; Kelley 2005; Resnik 2005). However, as the analysis in Chapter 2 showed, people in other health states may also have obligations. These are the healthy; those who are unwell, but not yet in need of treatment; and those who are recovering from an illness.
- *Objects of responsibility* are typically past or future actions that relate to one's own health, the health of others, or the operation of the health care system. All three dimensions again being commonly found in policy and law.
  - Self-directed responsibilities may concern leading a healthy life as part of a conception of a 'good life', or, in a more instrumental sense, to achieve particular life plans.
  - Responsibilities towards others can take the form of not harming them. They may also relate to caring for health needs of those under one's guardianship, such as children, protecting and promoting their (future) opportunity ranges. Donating blood or organs are further forms of obligations towards others, if arguably much weaker ones than not harming them.
  - Responsibilities towards the health care system concerns contributing to its fair and efficient operation so that it can serve as many people in need as possible. For example, missing appointments, or not cancelling them in time may deprive others of medical attention, and may have considerable financial cost, as may wasting medicines or using services unnecessarily.
- *The judicial authority*: Where health responsibilities are codified explicitly, the issuing authority or its agents (health care providers or medical professionals) may carry out assessments of whether the obligations have

been met, and whether some form of positive or negative response should follow. But obligations may also be set out merely as ideals or aspirations.

Before turning to the remaining question of the normative standards, that determine which responsibilities are acceptable and which ones are not, I will summarise the key elements of the discussion so far in order to set out the core of what I take to be an appropriate concept of responsibility in the health care context: *health responsibility as co-responsibility*.

Health responsibilities concern one's reasonable prospective and retrospective obligations as a healthy person, patient or convalescent, to lead a healthy life, to respect the health of others, and to contribute to an efficient health care system, insofar as available choices and external factors permit this. Prospective responsibilities relate to appeals to act in a certain way in the future, whether in a purely descriptive or functional sense ('no-one else will go jogging for you, brush your teeth', etc) or in a way that appeals to an obligation to realise certain values, which may or may not entail rewards or penalties. Retrospective responsibilities relate to an assessment of past behaviour in relation to obligations that, ideally, have been specified earlier and were known to the addressees. Retrospective assessments can have a purely descriptive explanatory meaning, for example, where a certain degree of causal responsibility for poor health is conveyed, or appeals are made for behaviour change, on the grounds that this is likely to improve a person's health. Retrospective assessments can also have positive consequences in the form of praise, or financial or other bonuses that may have been offered as incentives. Equally, they may have a potentially negative character, for example, using measures such as not-for-payment bills to convey the cost of treatment; requiring (higher) co-payments; or assigning lower priority in treatment.

Since health is affected both by personal behaviour and factors generally beyond immediate individual control (socio-economic status, access to health care, infrastructural arrangements, etc), it is neither an exclusive matter of personal or social responsibility. As the element of personal control admits of degrees, conceptually, substantive responsibility also needs to admit of degrees. By necessity,

health responsibilities are therefore *co-responsibilities*.<sup>3</sup> This is relevant both for the assessment of the causal factors that led to a particular health state, as well as for attributions of praise or blame, and decisions about possible positive or negative sanctions.

In one sense, this concept might seem disappointingly vague and bland. However, it appears to be the most appropriate model to capture the various interwoven dimensions of health responsibility that can reasonably be subsumed under the term, and to do justice to the fact that an overly narrow focus on blame and punishment detracts from preserving an important core of the concept that can be independent of sanctions. I also contend that both conceptually and in practice, attributing responsibility must admit of degrees, despite the fact that holding people accountable must often be a matter of either/or, and I turn next turn to the question of how particular forms of health responsibility might be justified.

### **3.5 Assessing the reasonableness of health responsibility policies**

In one sense, the question of health responsibilities might simply be a matter of choosing “the right” normative framework. Various political perspectives have different ways of explaining which of the above notions of responsibility should be central, and which ones should be more peripheral, as is clear from the background discussions to the policies discussed in Chapter 2. Equally, as already alluded to in the discussion of the core concept of personal responsibility above, there are different accentuations in philosophical contributions, such as luck-egalitarian ones (Arneson 1997; Dworkin 2000; Roemer 1994; Roemer 1995) or communitarian (Callahan 1998), or libertarian accounts (Engelhardt 1981). However, there are two principal problems with resorting to a single foundational normative theory. First, in value pluralistic societies, agreement about what constitutes the right framework remains generally elusive: saying, for example, that people should be held substantively

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<sup>3</sup> Note that the concept of co-responsibility also features in Article 1 of the German Social Security Code (SGB V), although in a somewhat different and narrower sense, as responsibility for health is there characterised as shared between the health care system and patients. See also Ian Forde’s and Rosalind Raine’s characterisation of health as co-production: “Responsibility for better health should be shared between society and the individual, ... society’s efforts for health improvement should be dovetailed with individuals’ and families’ efforts.” Central to their discussion is that policies are required that “support ... people to engage with decisions about their own health” (Forde and Raine 2008).



responsible for choices that lead to poor health because a certain luck-egalitarian theory says so will appeal to luck-egalitarians—but not to those who do not share its premises. Second, and perhaps even more significantly, even if we suppose that we are able to find a country in which all residents (or just citizens) can agree on a single monolithic theoretical account, whether political or philosophical, such value systems are typically of a very general nature, and do not tell us *ad more geometrico* how to decide in designing and evaluating concrete policies which, as Chapter 2 showed, have a great number of design features each of which can give rise to distinct normative issues.

Of course, this situation is not unique to the health responsibility debate. For example, regarding the controversial question of just resource allocation, which, according to Norman Daniels, is: “How can we meet health needs fairly when we can’t meet them all?” we are equally faced with a range of substantive positions that offer different perspectives. To make progress in practice, Daniels suggested a proceduralist approach in which general principles of justice are supplemented with fair processes for limit-setting, drawing on the framework of Accountability for Reasonableness, that he initially developed with Jim Sabin (Daniels 2000; Daniels 1999, 2007). This approach requires that policies meet four conditions concerning (1) publicity (making publically accessible decisions and their rationales), (2) relevance (providing a reasonable explanation for decisions, see below), (3) revision and appeals (putting in place mechanisms for challenge and dispute resolution), and (4) regulation (voluntary or public regulation to enable the three aforementioned conditions). The relevance condition is specified in its briefest form as follows:

The rationales for limit-setting decisions should aim to provide a reasonable explanation of how the organization seeks to provide “value for money” in meeting the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be “reasonable” if it appeals to evidence, reasons and principles that are accepted as relevant by [fair minded] people who are disposed to finding mutually justifiable terms of cooperation. Where possible, the relevance of reasons should be vetted by stakeholders in these decisions ... (Daniels, 2007: 110)

While the approach has been the subject of some criticism,<sup>4</sup> I adopt the Accountability for Reasonableness approach to make progress with the debate

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<sup>4</sup> A relevant charge for the present context has been pressed by Richard Ashcroft. Qualifying his attack somewhat by calling it a polemic he is concerned that the widespread interest in policy circles

around personal responsibility for health in a pluralist society. Moreover, I also see this approach as compatible with Thomas Scanlon's contractualism which can provide a particularly fitting normative anchoring.

Contractualism is based on the idea that people seek to justify to each other actions, principles or policies that govern their conduct. It is typically both a theory about the legitimacy of authority, and about the motivation, form and content of particular moral norms (Ashford and Mulgan 2009). Two principal types can be distinguished. A contractarian branch traces its roots to Hobbes' assumption of a so-called 'natural state' in a pre-social society, characterised by the *bellum omnium contra omnes*. With Jan Narveson, the argument is hence that social contracts and morality more broadly would be accepted by self-interested individuals, "first because we are vulnerable to the depredations of others, and second because we can all benefit from cooperation with others" (Narveson 1988: 148).

Contractualism proper differs from contractarianism in motivation and method. Here, the focus is not on self-interested bargaining individuals, but on people who

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in procedural justice accounts often amounts to "the adoption of a 'presumption of undecidability'", eschewing robust normative defence: "If bioethicists have anything distinctive to contribute to formation of public health policy and planning, it is in our training in the analysis of complex ethical problems and argument about normative conclusions. If we act on a presumption that the ethical problems of resource allocation, pandemic response and so on, are too complex or controversial for us to illuminate other than by listing principles and describing, once again, principles of procedural justice, then we are abrogating our responsibilities—or admitting our redundancy" (Ashcroft 2008: 7). It is indeed regrettable when the rigorous analysis of problems and argument about normative conclusions is abandoned. However, it is not clear that a procedural justice account requires, or by necessity leads to this consequence. Quite the contrary, as is clear from the above-cited quotation setting out the relevance condition, it explicitly invites such activity. The approach is, however, more modest in accepting that a single comprehensive normative position is not likely to be supported by all members of a value pluralist society, and that hence some trade-offs are required, that people who are interested in finding mutually agreeable terms of cooperation would find acceptable. Therefore, while there are, as noted immediately above, comprehensive normative (luck-egalitarian, communitarian, or libertarian) positions that could provide broad guidance on how to conceptualise the concept of personal responsibility for health, it is not clear which of these we should accept as the master theory, superior to a procedural justice account (and Ashcroft provides no guidance on this difficulty). I therefore proceed here on the assumption that setting out a procedural justice-based list of tests or areas in which justification is owed is the most appropriate way forward, since established comprehensive normative frameworks do not command universal support, lack sufficient specificity, and because it appears that a number of relevant ethical issues can be addressed effectively without recourse to first principles (such as the impact of programmes on the doctor patient relationship, or the acceptability of different rationales, for example in relation to cost-saving). This does not mean that normative theory should be ignored, but rather, that it is one input among many, and that those holding particular normative positions need to accept that there can be competing positions, and that a procedural justice account provides a better basis for making progress in policy and practice than the attempt to persuade everyone to become luck-egalitarian, utilitarian, etc.

share a commitment to justify publicly the standards of morality applicable to all (Scanlon 1998: 191-194), offering a far more promising basis for the context of public health ethics than the contractarian approach (Ashcroft 2006: 11).

Historically, contractualism can be traced to Kant's emphasis that moral principles must be such that they can be justified to all, and to Rousseau's notion of the 'general will' that would be adopted by all free and equal citizens. John Rawls' work is widely regarded as influential in resurrecting this form of social contract, and Scanlon has presented a distinct form in his 1998 book *What We Owe to Each Other*.

Scanlon's contracting parties are not placed behind a Rawlsian veil of ignorance, but should be understood as agents who are aware of their circumstances, with distinct "generic reasons" regarding their willingness to accept certain "principles that may affect them. Generic reasons are reasons that people have in virtue of their situation, characterised in general terms, and such things as their aims and capabilities and the conditions in which they are placed" (Scanlon 1998: 204). These reasons feature prominently in the concept of "reasonable rejectability" that is central to Scanlon's approach:

[Contractualism] holds that an act is wrong if its performance under the circumstances would be disallowed by any set of principles for the general regulation of behavior that no one could reasonably reject as a the basis of informed, unforced general agreement. (Scanlon 1998: 153) [...] In order to decide whether a principle could be reasonably rejected, we need to consider it from a number of standpoints. From the point of view of those who will be its main beneficiaries there may be strong generic reasons to insist on the principle, and to reject anything that offers less. From the point of view of the agents who will be constrained by it, or of those who would be beneficiaries of an alternative principle, there may be reason to reject it in favor of something different or less demanding. (Scanlon 1998: 213)

Scanlon asserts that his approach offers an accurate description of moral motivation, which rests on "the positive value of living with others on terms they could not reasonably reject" (Scanlon 1998: 162). Justification is hence important not merely in formal or strategic terms, as for contractarians (because it enables a person to bring others to do what serves her interests), but *substantively*: justifying actions to others is "to embrace the value of mutual recognition" (Stratton-Lake 2004: 15). It is what makes one a moral agent, and Scanlon emphasises that in this sense his view has "substantive moral content" (Stratton-Lake 2004: 134).

It was said above that the approach pursued here would be not to draw on a particular moral theory in order to justify health responsibility policies, and it may therefore be surprising to see this anchoring in a substantive normative theory. However Scanlon's contractualism offers a formal, rather than a prescriptive structure, and is well suited to underpin approaches such as Daniels' and Sabin's Accountability for reasonableness approach, and other institutions found in democratic arrangements, such as consultations in the case of potentially controversial planning projects, whether these relate to new railways, buildings, or health policies. In all cases the fundamental motivation of such enterprises is to elicit a broad range of relevant reasons, to ensure that the changes in view of reasonable concerns are made, or otherwise, that explicit justification is provided why particular objections were not deemed relevant.

In this process Scanlon draws particular attention to reasons that may be cited to reject a policy, and this is of particular relevance to the present context, as it is possible that those who may be disadvantaged by health responsibility policies are to be found among societal groups that have no strong lobbies to argue their case. Making genuine efforts at understanding what reasons those have who object to certain policies, and agreeing that mutual recognition is a product of justifying to each other why one design should be more acceptable than another, can hence been seen as substantively rich approach, but it is nonetheless one that aligns closely with procedural justice arrangements in place in most democratic societies. However, despite this helpful general guidance, and in common with other normative approaches, Scanlon's contractualism of course does not give us a finer grid that would help us see in which areas exactly we should ascertain whether people might have reasons to reject health responsibility policies.

In order to specify the areas in which justification is owed, I set out below seven "tests" that concern the impact of a policy in the planning, monitoring, or evaluation phase on key normative and structural values and components that are integral to practically all health care systems.<sup>5</sup> These tests concern evidence,

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<sup>5</sup> This framework was first published in Schmidt, H. 2008. Bonuses as incentives and rewards for health responsibility: a good thing?, *Journal of Medicine and Philosophy* 2008, 33:198–220. Note that by coincidence Julian Le Grand and Divya Srivastava set out a similar approach in a Report for

rationale, and feasibility; intrusiveness; equity; solidarity/risk-pooling; attributability and opportunity of choice; affected third parties; and coherence (see Box 3.2).

**Box 3.2: Seven tests to evaluate the appropriateness of health responsibility policies**

***Evidence, rationale, and feasibility***

What are the policy's principal rationales and goals? Have they been justified in an open and transparent manner, with opportunity for comment by all those affected by the policy? How sure can we be that the policy will achieve its aim(s), in principle and in practice? Are the required efforts and cost proportionate in view of the goals?

***Intrusiveness and coerciveness***

Are there ways in which the goal of the policy could be achieved in less intrusive ways? If not, is the extent of intrusiveness justifiable in view of the expected benefits?

***Equity***

Are there some groups (such as particular socio-economic, ethnic, or regional subgroups) who are likely to experience disproportionate benefits or burdens as a result of the policy? At what point would it be reasonable to reject a policy because of inequitable impact?

***Solidarity/risk-pooling***

Insofar as the health care system has an implicit or explicit principle of solidarity or risk-pooling: how does the policy affect it? If it should undermine solidarity or risk-pooling: are all affected clear about this, and can the effect be justified?

***Attributability/opportunity of choice***

To what extent are penalties or rewards based on actions that can be attributed to people's free and voluntary choices? Where peoples' opportunity of choice is limited: can waivers or alternative standards be implemented? Should rewards be given, even if people have not changed their behaviour, but just happen to satisfy the policy's criteria?

***Affected third parties***

Does the policy have an effect on the relationship people have with, for example, their physicians or employer? Insofar as physicians are involved in assessing whether or not someone has complied with their responsibilities: is their involvement justifiable and accepted by them and their patients? What information should employers have (or not) about people's compliance with responsibilities?

***Coherence***

How does the policy compare with standards of responsibility, attributability, and blame in other areas of social policy and the law? Since tensions can be resolved in more than one way: in which way should they be addressed?

I illustrate their relevance by focusing on financial incentive systems introduced in chapter 2, which are also the subject of the research in the subsequent chapters. To some extent, this illustration is somewhat general, as the framework is not applied to a single specific policy, but instead comments on overarching features of the schemes described there. However, an example of a direct application can be found in Chapter 7, where the framework is used to show how an incentive policy seeking to improve the uptake of colon cancer prevention might be justified. For now, the discussion should help illustrate how the approach can be used in practice in general terms.

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Health England (Le Grand and Srivastava 2009: 35), scoring incentive schemes using the following criteria: effectiveness, (low) cost, equity, feasibility, local/individual autonomy, which, in different guise, are also included in the framework presented here. However, my framework also goes further in recognising the importance of assessing the impact on solidarity/risk-pooling, affected third parties, and attributability.

### *3.5.1 Evidence, rationale, and feasibility*

In Chapter 2, several different rationales were shown to underlie the policy initiatives in Germany and the USA. The first step in planning personal responsibility measures is hence to justify these publicly, and to enable those affected by them to contribute their views, which includes possible arguments they would make to reasonably reject them, or request modifications.

Insofar as incentive programmes are offered on a voluntary basis, people might not be concerned about the rationale of using them to improve health. However, in practice, the implementation of incentives typically means not just that some people are offered an additional ‘carrot’, but that those not taking part are denied one, and, in effect incur higher health care costs, as the description of the US incentives schemes clearly showed (see Section 2.4.1). The German programmes generally operate on far lower levels, but in principle the same issues are raised. In both cases, what is offered as a ‘carrot’ will seem to many far more like a ‘stick’. In view of this situation it is desirable to justify implementations such as the above explicitly, and it is especially important to provide evidence that the programmes have a reasonable chance of success, both in terms of helping people change their behaviour, and in terms of achieving goals such as cost reduction, that, as noted, also feature prominently.

While much of the focus in the debate around incentives and personal responsibility is focussed on hard questions of distributive justice, the acceptability of programmes may well turn to a significant extent on an empirical analysis of the effectiveness of incentive programmes in practice, and the actual costs associated with particular risk factors and ageing populations, which are often simply assumed.

In this context it needs to be noted that consensus remains elusive regarding the question of whether, overall, prevention (whether achieved through incentive programmes or other means) will curb cost over time, and there is an as yet unresolved dispute about whether increasingly longer life expectancy will in fact lead to higher levels of morbidity and care needs (known as the ‘medicalisation thesis’), or whether longer life will mean that the period in which care is needed is simply condensed over a shorter time than previously (the ‘compression thesis’) with some

arguing that this will not lead to overall increases in health care expenditure and others less convinced about possible savings (Kühn 2005; Metz 2001; see also: Busse et al. 1999).

For example, Pieter van Baal and colleagues used a dynamic population model to analyze health care data from the Netherlands in order to estimate lifetime health care cost conditional on the presence of risk factors. They found that expenditure was highest for the healthy (defined as: non-smoking, BMI between 18.5 and 25: health care cost from age 20 was estimated to be €281,000) and lowest for smokers (€220,000), with obese people in an inter-mediate position (€250,000), largely due to differences in the longer life expectancy of healthy people, and associated cost for care (van Baal et al. 2008). Better health at older ages may condense health care costs over a shorter time, and possibly reduce costs, but longer life at good health may also lead to higher absolute levels of morbidity and need for care (Woolf 2009; Russell 2009; Cohen 2008). If evidence to this effect should become irrefutable, it would seem that from a purely economic perspective that focuses on health care expenditure only, we ought to be more concerned about the lifestyle associated cost-impact of muesli-eating jogging seniors, than about smokers who drink excessively, and are overweight. Of course, the mere fact that prevention programmes may not lead to cost savings in the longer term does not mean that they should not be carried out. But it would seem that other reasons would need to be given in their support.

### *3.5.2 Intrusiveness and coerciveness*

Incentive systems are generally framed as not being particularly intrusive or coercive, as it is commonly suggested that people are free to use them or not. However, high levels of reimbursement, especially where combined with cost-shifting, as illustrated above (see Sections 2.2 and 2.41), can raise doubts about the extent to which people are free not to make use of the offers. Providers also differ in the way they advertise their programmes, and it is not uncommon for insurance holders to receive frequent reminders by mail or other means. Such initiatives may be perceived as “nannying” or forms of “healthism” (Levin 1987; Steinbrook 2006) or perhaps bribery (Ashcroft 2011: 195) and may have a counterproductive effect on health responsibility attitudes and the development of personal autonomy. Programmes that reward participation in pre-symptomatic check-ups, such as cancer

screens, may also be intrusive in the sense that they bring uncertain and unwelcome knowledge about disease susceptibility, possibly leading to anxiety or confusion, even if the degree of intrusiveness can be mitigated by focusing on providing information with appropriate confidence intervals and the option for people to discuss any questions they may have with independent experts. The level of intrusiveness or coerciveness therefore needs to be considered carefully, and is closely linked to the questions regarding evidence and rationale: poor evidence and rationales combined with highly coercive or intrusive measures would make for rather bad policy.

### *3.5.3 Equity*

The fairest way of providing health interventions is often simply to make them available universally for all: this avoids stigmatization and leaves uptake to people who are suitably motivated. On the other hand, such approaches can be prone to problematic self-selection biases. For the present context, not only the penalising effect resulting from cost-shifting that has been noted above needs to be considered (which is likely to disadvantage most those who are generally poorer in health and income), but also the question of whether unequal reaping of benefits should be acceptable.

Certainly, based on data from the Bertelsmann Gesundheitsmonitor, initial evidence from Germany suggests that this is the case: 19%, or almost twice as many people belonging to the fifth (least poor) quintile, used incentive programmes in 2004–2005 as opposed to 11% of the first (poorest) quintile (Braun et al. 2006: 22). An analysis over time, using the same survey data, suggests that overall participation in wellness incentive programmes almost doubled between 2004 and 2008 from 13% to 25% of the insured population. With regard to health status, this doubling could also be observed in the subgroups of those with fair health or better, but usage among those with poor health changed very little over time and remained between 14–17%. Uptake also remained relatively unchanged for the lowest income group (between 10–17%) while all other groups more than, or nearly doubled (Schmidt, Stock, and Doran 2012, see also Figure 8.12). In the US, a recent study examining the health status user profile of new enrollees of Medicare plans that had added gym membership benefits also found that 6% more of those responding to this offer



reported excellent or very good health, compared to the prior situation, in which no such benefits were offered (Cooper and Trivedi 2012), suggesting that selection effects are real.

It is useful, then, to think more clearly about differences between people regarding their existing motivation, actual behaviour change, and factors that may make behaviour change more challenging, when it comes to assessing the fairness of who receives advantages associated with incentives, and who loses out. To approach this question in a structured manner, I suggest here that it is instructive to consider the responses of the following five groups to incentive programmes that are offered universally to all enrollees of a health plan: (1) ‘the lucky ones’; (2) the ‘yes I can’ group; (3) the ‘I’ll do it tomorrow’ group; (4) the ‘unlucky ones’; and (5) the ‘leave me alone’ group.<sup>6</sup> Depending on the exact characteristics of particular schemes, the impact on these groups varies, of course. Nonetheless, a somewhat more abstract consideration is useful for bringing clarity to the question of ‘who benefits’ that is central to equity considerations. The framework also shows that there are significant differences regarding whether or not programmes promote behaviour change among enrollees. What I suggest might be called the ‘five groups problem’ therefore concerns the following question: at what point do inequalities in the capacity to use incentive programmes constitute unfairness, and how should we respond in policy?

### 3.5.3.1 ‘The lucky ones’

For practically any incentive programme there will be people who would qualify for associated reimbursements without any form of behaviour change. Some people simply enjoy eating healthily and exercising regularly, and do so quite effortlessly. Their behaviour is hence compatible with the spirit of an incentive programme, even if the benefit—say, a participation-based reimbursement for going to the gym regularly, or an attainment-based one for meeting certain Body Mass Index (BMI)

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<sup>6</sup> My analysis is based on a review of the public health literature on incentive use and behaviour change, personal insights resulting from involvement in the evaluation of incentive programmes, and conceptual analysis of the characteristics of incentive users. I began with established concepts and developed a more nuanced framework that can be applied directly to wellness programmes in planning, practice, or evaluation. Differentiation between the five groups is not intended to provide an exhaustive and exclusive model, to suggest that beliefs are never shared across groups, or to imply individuals may not belong to different groups in different stages of their lives. My purpose is to illuminate plausible distinguishing features between different groups of users in the context of incentive programmes.

thresholds—does not lead them to change their actions. Others whose actions may remain unaffected include people whose dispositions are not as well aligned. For example, some people may eat in the most unhealthy ways, never exercise, and still have a favourable BMI values. Despite the dissonance between their motivations and the programme's spirit, they may reap the exact same benefits as their health-conscious counterparts, without any change in behaviour or motivation.

#### 3.5.3.2 The 'yes I can' group

Other people would not normally have performed the benefit-qualifying behaviour, but they may see the incentive as a welcome occasion—though perhaps not the sole reason—for trying to overcome inertia or weakness of the will. The incentive benefit's 'nudge,' coupled with their underlying motivation, provide an effective basis for action. Here, incentives are likely to feel like a deserved reward. They may help initiate behaviour change in the first place, or sustain it, where intrinsic motivation is not yet sufficiently developed. Conceptually and in practical terms, this group is also generally known as the 'group of responders' in the literature—yet, it cannot be assumed that all, or even the vast majority of those offered incentive programmes, are, in fact, responders. It is also plausible to assume that people's responses differ with regard to the mode of incentive. Some may find that a 'soft' participation -incentive that merely requires them to partake in an activity is most effective nudge, feeling overly pressured by a 'hard' attainment-incentive, that requires meeting, for example, BMI targets. For others it may be the other way round, and they may respond better to a more robust challenge that requires them to meet set thresholds. Designing an effective incentive for the 'yes I can' group therefore requires an assessment of what is likely to be the most effective and acceptable approach.

#### 3.5.3.3 The 'I'll do it tomorrow' group

Others, like those in the 'yes I can' group, also have a desire for behaviour change, but, for a range of reasons, often simply cannot bring themselves to act on it. They may simply feel unable to try, or where they try, find that they often fail. The reasons may include unfavourable opportunities in their everyday circumstances, such as poor access to affordable and healthy food, or insufficient time to prepare it. Or they may lack access and time for physical exercise in a safe environment. Such

factors can render attainment-incentive schemes, such as achieving BMI values, significantly more challenging. And people have been brought up differently: some received more encouragement to be self-motivated and -efficacious, and others less. Therefore, even participation-incentives such as lower health care cost in return for gym attendance may be taken up more readily by some than by others. For many in this group, incentives may be extremely tempting, yet they can be as far out of reach as the branches of the fruit-laden trees were for the proverbial Tantalus.

#### 3.6.3.4 The ‘unlucky ones’

For biological, medical or other reasons that are completely external to their volition, some people face such strong constraints that, whatever they would do, they are simply unable to meet the criteria associated with specific attainment or participation-incentives such as BMI targets or gym participation. For example, some people with genetic mutations will always be obese, regardless of how much they exercise or control their energy intake. As with the ‘I’ll do it tomorrow’ group, incentives that are simply out of reach will make little sense for the ‘unlucky ones’.

#### 3.6.3.5 The ‘leave me alone’ group

A last group of people comprises those who would qualify in principle for wellness incentives but may voluntarily decide not to use them. They may already meet targets, or could do so easily, or could effortlessly participate in incentivised activities, but still resist. Reasons may include that they feel patronised or ‘nannied’ by wellness schemes; or concerns that incentives introduce an inappropriate element of competition in health plans that they think ought to be based on a principle of mutuality and fair risk-sharing. Or, on quite practical grounds, they might judge the effort required to register for schemes to be too burdensome.<sup>7</sup>

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<sup>7</sup> Of course, such reasons may also play a role in the deliberations of the ‘I’ll do it tomorrow’ group and the ‘unlucky ones’. The purpose of setting out the groups in this way was, however, to bring out the clearest distinguishing features between the main groups, rather than to try and provide a wholly exhaustive and exclusive set of categories. For example, a further group (that, to some extent, may also be viewed as a sub-group of the ‘Yes I can’ group) could be called ‘the grumpy ones’: here people are able and successful in securing the incentive premium, but they resent the fact that they did so, for example, where they do not care about the supposed health benefit, but participate because they felt ‘bribed’ by the level of the incentive.

As this conceptualization shows, universally offered wellness incentive programmes can give rise to several general problems, including the following:

- Some people may receive benefits, even if their motivation and behaviour runs counter to the spirit of an incentive programme;
- Behaviour change is not always required, and some people may receive benefits for default behaviour—whether this is the result of deliberate prior choice, or unreflective habit;
- Some people face constraints due to weakness of the will, poorly developed self-efficacy, or strong medical or societal constraints. Meeting targets, or participating in health promotion activities, requires a much greater effort of them, compared to others. Still, where they fail to begin or complete an incentive programme, they must forgo the benefit in the same way as those who had sufficient opportunity of choice, but who voluntarily decided against taking part.

Ethically and in policy terms, this raises the question of how significant such differences are—both quantitatively, regarding the actual number of people in each of the five groups for a given policy, and qualitatively, regarding the question of how possible differences in numbers between groups should be addressed. While the other elements of the overall framework proposed here would clearly also need to be considered, and while the costs of redressing inequities always need to be balanced against other central goals of a health care system (Le Grand 1984: 40; Oliver, Healey, and Le Grand 2002: 566) the principal options would be (1) to continue to offer incentives universally, regardless; (2) to offer them universally but with some modifications that make it easier for people who, for example, face more challenging environments to avail themselves of the options; (3) to offer targeted, instead of universal schemes; and (4) to abandon incentive programmes altogether. Appendix 3A illustrates what these different policy options would mean for the different groups.

#### *3.5.4 Solidarity*

Solidarity, as noted in Chapter 2, is a value that explicitly underlies the German statutory health insurance system. In practice it means that the healthy support the

sick; the young support the old; the employed the unemployed; and the better off the worse off, as insurance contributions are income-tested. More normatively, the concept can be seen as an expression of the recognition of human vulnerability, and it is plausible to describe those brought together in social health insurance systems as being in a solidaristic relationship with others, which has the aim of providing mutual protection against the negative consequences of sickness and disease. To a significant extent, key aspects of the principle can be found in other insurance systems that rely on risk-pooling, even if the value would be more implicit in such cases.

The general concept of solidarity is highly complex. Recent work examining its motivation, function, and role in different European health-care systems has analysed it, among other things, as attitudes of individuals or descriptions of communal arrangements, and has explored notions of fellowship, compassion, charity, altruism, universal or group-specific brotherhood, friendship, interest coalitions, civic duties, or mutual recognition and interdependency of individuals (Prainsack and Buyx 2011; Houtepen and ter Meulen 2000; Ashcroft, Campbell, and Jones 2000). Although there are hence a range of different candidates that might explain why solidarity should matter, it is clear that a functional baseline description of solidarity in public health-care systems would be focused around the notion of achieving collectively a degree of security that could not generally be achieved individually. In this sense, solidarity (and, by extension, the less value-laden concept of risk-sharing) has also been characterised as “the ‘beating heart’ of a social health insurance approach” (Saltman 2004: 29). It is equally clear, then, that any evaluation of appeals to health responsibilities, whether in the form of bonus systems or policies that have a more negative character, needs to consider whether they are likely to enhance this central concept, or will be to its detriment.

### *3.5.5 Attributability and opportunity of choice*

As highlighted above, there are a number of ways in which it can make sense to attribute a good or bad health outcome to a person without linking this assessment to questions of praise or blame, or reward and punishment. Often, causal attributability will only be partial, as a number of other factors, typically arising from the environment within which a person lives or works also need to be considered.

Where negative sanctions are contemplated—whether framed as incentives or disincentives—there needs to be good evidence that the people concerned had a reasonable range of opportunities to avoid what is regarded as a poor health outcome. In this regard the requirement in the US regulations that an alternative standard must be provided for those who feel unable to meet the standards required by particular attainment-incentives programmes are a useful way of acknowledging that peoples' circumstances and opportunities of choice are central and can differ (Le Grand 1984: 46), and that some programmes will simply be incompatible with the choice sets people have in their daily lives. However, the provision is also very narrow in focusing on medical conditions only (or, following the stratification under the five groups problem, the situation of 'the unlucky ones') and hence ignores much of the data that come from the social determinants of health literature, which demonstrates that the socio-economic situation of a person can imply equally powerful, and often directly linked, constraints (i.e. affecting many in the 'I'll do it tomorrow group'). Care is hence required in devising policies that offer fair chances to all.

### *3.5.6 Affected third parties*

Depending on implementation, incentive systems may not involve any third parties; for example, in the case of the German incentives for regular dental check-ups, reception staff may log a visit electronically, and the patient then receives the rebate for any work that needs to be done. However, the determination of other types of incentive-qualifying behaviour may involve health care staff; for example, they are required where rewards are made if key health data, such as blood pressure, stay within a certain range over a year. Those on no-claim plans may wish that health care staff was not involved if they require treatment before completion of the qualifying period, and issues may arise where patients appeal to staff not to record their appointment. Equally, the US requirement that a physician needs to attest that a person is unable to meet a standard for an attainment-incentive can lead to similar situations. Most of these situations are likely to lead to awkward situations, but depending on the size of the incentive at stake, more serious tensions may arise, and health care professionals may not be pleased with being put in an actual, or perceived, policing position, which may have a detrimental effect on the doctor-patient relationship (Bishop 2006: 757) or the trust relationship (Marteau, Ashcroft, and Oliver 2009: 984).

Another relationship that needs to be considered is that between incentive programme participants and their employers, in particular in cases where incentive programmes are offered in the work place. For obvious reasons, employers are likely to be interested in their employees' health status, and while most countries have in place data protection legislation that regulates access, the implementation of wellness programmes provides opportunity to review compliance and adequacy.

### *3.5.7 Coherence*

The coherence test asks how benefits or disadvantages that result from a personal responsibility policy fit in with the wider context of social policy and law. It is probably more relevant for cases where explicitly penalising sanctions for contributions to a bad health outcome are envisaged. For example, the concept of contributory negligence as applied in jurisprudence regarding road traffic accidents offers an approach where similar questions are addressed on a day-to-day basis. However, while coherence across different areas of social policy and the justice system more widely is clearly desirable, possible conflicts can be resolved either by aligning a particular health responsibility policy with the wider context, or, alternatively, it may be that the health context shows the relevance of significant constraints that require us to re-assess the justification of other policies, provided they are similar in all relevant aspects.

The seven tests set out here in the context of a contractualism-based procedural justice account are intended to enable policy makers, practitioners and ordinary citizens to scrutinise and evaluate in a clearly focused way policies seeking to promote personal responsibility for health. Applying the framework can therefore help in agreeing mutually acceptable justifications for particular policies. At the same time, the process may also mean that some constituents of basic evaluative reference points shift, as the analysis may indicate that revisions are necessary. The process of applying one's reference framework to specific cases, and reviewing whether in the case of clashes the framework, or the case at hand needs to be adjusted, is sometimes described as striving to achieve a "reflective equilibrium" which consists:

in working back and forth among our considered judgments (some say our 'intuitions') about particular instances or cases, the principles or rules that we

believe govern them, and the theoretical considerations that we believe bear on accepting these considered judgments, principles, or rules, revising any of these elements wherever necessary in order to achieve an acceptable coherence among them. The method succeeds and we achieve reflective equilibrium when we arrive at an acceptable coherence among these beliefs. An acceptable coherence requires that our beliefs not only be consistent with each other (a weak requirement), but that some of these beliefs provide support or provide a best explanation for others. [...] The key idea underlying this view of justification is that we “test” various parts of our system of beliefs against the other beliefs we hold, looking for ways in which some of these beliefs support others, seeking coherence among the widest set of beliefs, and revising and refining them at all levels when challenges to some arise from others. (Daniels 2011)

Thus, agreeing which policies that seek to promote personal responsibility are reasonable requires us not only to apply our personal normative reference framework to this specific matter but, in doing so, to accept the possibility that some parts of our reference framework may require revision. In this sense willingness to engage in such a process can also help refine ethical theories, in addition to providing a workable vehicle for making progress in a particularly controversial area of health care policy and practice.

### **3.6 Conclusion**

It must be admitted that the approach of *health responsibility as co-responsibility* set out here is somewhat less clear-cut than one of the for-or-against personal responsibility stances often encountered in the literature, and especially in political debates. With a number of different types of forward and backward-looking responsibilities, a procedural justice account supplemented with seven tests to specify the areas in which justification is owed (without a single test whose outcome would necessarily “trump” all others) the situation seems to be messy.

Still, I contend that this situation is far preferable to any of the alternative options, if we want to avoid the victim blaming potential that personal responsibility policies are prone to have, and equally if we want to bypass the potentially fatalistic implications that an exclusive focus on the social determinants of health can have, and instead seek to preserve a meaningful concept of health responsibility that is appropriate in descriptive, epidemiological, and moral terms. Particular policies that seek to implement personal responsibility standards hence depend on a holistic justification in a number of different areas. These areas, as circumscribed by the



seven tests outlined above, concern central values that are integral to the provision of health care, and I believe that much progress can be made in policy and practice if, in a transparent and open process, valid and explicit reasons, and sound evidence to support them, are given in the design and evaluation of personal responsibility policies.<sup>8</sup>

The following chapters will examine attitudes of the public and of health care professionals regarding central normative elements of this framework, to assess the relevance of this analysis, and the importance of central features. While this chapter only set out the framework in general terms, Chapter 7 will apply it to the specific case of colon cancer prevention, which will show more clearly the scope and limitations of the approach.

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<sup>8</sup> See also footnote 4 in this chapter on the question of why a procedural justice based account is the most promising way forward, despite inevitable shortcomings, as highlighted by Ashcroft 2008.

## Chapter 4<sup>1</sup>

### **Incentivising individual behaviour: review of the survey and interview literature, and development of an instrument for new research**

#### **4.1 Introduction**

The previous chapters have demonstrated that internationally there has been an increasing focus on personal responsibility in health care policy and practice, with interventions ranging from benevolent encouragements to genuine financial incentives and explicit penalties. To date, policies in both countries have been shaped largely by discourse among politicians, policy makers, employers and academic health policy analysts, including ethicists. While physicians have also been active participants in the debate, the voice of those most directly affected by the interventions, i.e. the public, has not been heard in equal measure, although different forms of public or consumer engagement have been used in other health policy and research contexts.<sup>2</sup>

While it appears that there is no systematic work that engages consumers in the design or implementation of incentives, key rationales for public engagement that are found elsewhere, including identifying consumers' preferences to improve the effectiveness of interventions and maximise the acceptability and legitimacy of potentially controversial policies through engagement (Kreis and Schmidt 2013), apply just as strongly in the case of wellness incentives (Daniels 2009b; Schreier and Diederich 2008; Institute of Medicine 2003; Merzel and D'Afflitti 2003). For the present context, knowing more about views of the public and physicians is certainly of relevance in view of the approach set out in the previous chapter, that seeks to adapt

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<sup>1</sup> Text in this chapter draws on, and in part reproduces verbatim, material drafted by HS and published in Kreis and Schmidt 2013.

<sup>2</sup> Including priorities for health research (Caron-Flinterman et al. 2005; Brown et al. 2006; Gooberman-Hill, Horwood, and Calnan 2008; O'Donnell and Entwistle 2004), designing randomised controlled trials for specific diseases (Koops and Lindley 2002; Langston et al. 2005; Marsden and Bradburn 2004; Helfand 2010), community-based participatory research (Dalal et al. 2009; Gray et al. 2000; Savage et al. 2006), medical device development (Bridgelal Ram, Grocott, and Weir 2008), guideline development (Boivin et al. 2010; Jarrett L. and the Patient Involvement Unit 2004), systematic reviews (Helfand 2010; Braye and Preston-Shoot 2005; Serrano-Aguilar et al. 2009) and health technology assessment (Facey et al. 2010; Gauvin FP et al. 2010; Abelson et al. 2007; Lehoux et al. 2009).

Norman Daniels and Jim Sabin's accountability for reasonableness framework to questions of responsibility.

It was proposed there to assess policies at the planning, implementation or evaluation phase by examining evidence, rationale, and feasibility; intrusiveness; equity; solidarity/risk-pooling; attributability and opportunity of choice; affected third parties; and coherence. It is obvious that the broad set of reasons that will typically be drawn on in justifying policies would be incomplete without any information on how those directly affected by them experience them. This seems certainly plausible regarding questions around the acceptability of particular rationales, and, for example, the degree to which interventions are felt to be intrusive and their expressive or symbolic value, e.g. whether they are demeaning. Moreover, as the conceptual analysis has suggested, some incentive programmes carry the risk that they may disproportionately disadvantage groups of lower socio-economic status, who are often marginalised and without strong lobbies that would ensure that their views are heard. Engagement, or research on the attitudes of this group of people, can therefore help to achieve a more balanced set of reasons that are relevant for the assessment of incentive programmes. In a more pragmatic sense, understanding the public's views is also relevant for an effective use of incentive programmes: for they are likely to have the greatest chance of success where views about the reasonableness that employers or policy makers may have are aligned with similar assessments by the public.

Part of the intention of this thesis is therefore to carry out original research into views of members of the public on salient aspects that determine the acceptability and effectiveness of incentive programmes. Equally the plan is to gain a better understanding of the views of physicians, as, again, the previous chapters have indicated that their active support is required for incentives to be effective (but cannot always be presumed). To ensure that the empirical work carried out here will not duplicate previous work, and instead builds on it, the first part of this chapter presents an overview of themes from the recent survey and interview literature that is relevant for the questions being addressed here. The second part develops an instrument for the empirical work being carried out in the following chapters.

## **4.2 Key themes in relevant survey and interview work so far**

This section describes the structure of the review and presents findings regarding attitudes towards the role of responsibility in the special case of organ transplantation, and then in health care more generally, focussing first on views of the public and patients, and then on those of physicians.

### *4.2.1 Structure of review*

The review of the published literature on survey and interview work follows broadly the useful proposal for structuring systematic reviews in bioethics that Daniel Strech, Matthias Synofzik and Georg Marckmann set out, building on earlier related work (Strech, Synofzik, and Marckmann 2008; see also: McCullough, Coverdale, and Chervenak 2007). Strech et al. reviewed the related, but far more general, field of empirical work on rationing, and were puzzled by the difficulty of establishing a coherent pattern of conclusions from different qualitative research findings, due to factors such as heterogeneous methodologies, sample compositions and angles of research questions. Adapting the approach of systematic reviews as used in medical research, they proposed that progress could be made by adopting the following seven step approach: (1) careful definition of the review question; (2) selection of relevant databases; (3) application of ancillary search strategies (review of bibliographies from relevant references, hand search of journals not or not completely captured by databases used); (4) development of search algorithms (through index mapping, i.e.: identifying database-related search terms by reviewing indexes of articles already known from prior non-systematic literature reviews, and cluster modelling, i.e.: combining database-specific search terms with Boolean operators); (5) relevance assessment of the retrieved references (through blinded reviewers, predetermined inclusion and exclusion criteria); (6) quality assessment of included studies (including a justification and explication of the assessment tools); and (7) data analysis and presentation (including a justification and explication of methods).

The review here does not attempt to present an exhaustive systematic review of qualitative research findings on personal responsibility in the literature, nor does it aim to weigh the relevance of different arguments. Rather it seeks to ensure that the work to be carried out here in relation to discrete issues arising in the context of incentive programmes will not duplicate previous efforts, and instead will build on these, by

being sensitive to themes that emerge from previous related research. It is therefore not necessary strictly to follow the approach outlined above, in particular regarding steps 5–7. Nonetheless, the framework provides a helpful general approach which was adapted as follows.

The general review question was: “what empirical research is there on attitudes of the public or physicians to using incentive systems as tools for promoting personal responsibility for health, and has work similar to that proposed here already been done?” Based on previous research on conceptual issues around personal, and confirmed by informal consultations with colleagues working in the field, it was clear that in terms of databases PubMed, which comprises more than 20 million citations for biomedical literature from Medline, life science journals, and online books, would be an appropriate resource (step 2). 10 relevant papers were already known prior to the search and these papers and the cited literature were reviewed to establish an initial list of search terms. Most papers were included in PubMed, which allowed an identification of the relevant data-base specific search terms, called “medical subject headings” (MeSH) in the case of PubMed (step 3 and 4). Box 4.1 lists the characterizations of 5 MeSH terms that stood out as particularly relevant. While for an exhaustive review it might perhaps be appropriate to screen all results using these MeSH terms individually or in combination, as they are likely to have a high degree of sensitivity, the strategy would be poor in terms of specificity, as it would identify a far too wide range of hits. For example, apart from “Health Care Surveys” and “Public Opinion” each term individually identifies more than 100,000 sources.<sup>3</sup> The MeSH terms resulting from the index mapping exercise were therefore combined with relevant title keywords in five cluster models.

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<sup>3</sup> Health Surveys: 314,766; Attitude of Health Personnel: 100,287, in combination: 3195.

**Box 4.1: MeSH terms for literature on empirical work relevant for questions around personal responsibility**

Health Surveys: “A systematic collection of factual data pertaining to health and disease in a human population within a given geographic area”

Health Care Surveys: “Statistical measures of utilization and other aspects of the provision of health care services including hospitalization and ambulatory care.”

Questionnaires: “Predetermined sets of questions used to collect data—clinical data, social status, occupational group, etc. The term is often applied to a self-completed survey instrument”

Public Opinion: “The attitude of a significant portion of a population toward any given proposition, based upon a measurable amount of factual evidence, and involving some degree of reflection, analysis, and reasoning”

Attitude of Health Personnel: “Attitudes of personnel toward their patients, other professionals, toward the medical care system, etc.”

Attitude to Health: “Public attitudes toward health, disease, and the medical care system.”

Note: while a MeSH term “social responsibility” exists (“The obligations and accountability assumed in carrying out actions or ideas on behalf of others”), this is the only term identified in the MeSH browser when searching for “responsibility”. There is no MeSH term “personal responsibility”, or “individual responsibility”, see: <http://www.nlm.nih.gov/mesh/mbinfo.html> (accessed Sept 2009)

Based on familiarity with the conceptual literature and informal consultation with colleagues working in the field, it seemed that relevant studies could be identified by using “responsibility”, “incentive”, “priority setting”, “rationing”, and “allocation” as title key words in combination with the MeSH terms. It is plausible to assume that the first two terms would occur in a publication that presented findings from work concerned with personal responsibility and/or incentive use, and equally, since personal responsibility is often discussed as one of several criteria in rationing, that publications on this topic might include findings on views of the public or physicians on personal responsibility or incentives.

The search was conducted from 2–10 December 2010, using the PubMed online search tool in Endnote X3, limiting results to the last 15 years, i.e. 1995–2010. As Table 4.1 shows, the cluster models produced a total of 1,190 hits. After the first screen (titles only) 184 remained, after the second screen (review of abstracts) 47 were identified as potentially relevant. These 47 publications (which include the previously known publications) were retrieved, and after a third screen (full text analysis) 18 remained.<sup>4</sup>

<sup>4</sup> All searches are available as archived Endnote libraries.

<b>Table 4.1: Quantitative findings from literature search on empirical work relevant for questions around personal responsibility</b>				
<b>Title key word/MeSH combination</b>	<b>Hits</b>	<b>1st screen</b>	<b>2nd screen</b>	<b>3rd screen</b>
Title: Responsibility [and MeSH]				
- Health Surveys	46	11		
- Health Care Surveys	6	1		
- Questionnaires	116	7		
- Public Opinion	18	5		
- Attitude of Health Personnel	157	19		
- Attitude to Health	215	22		
Total	558	55		
Title: Incentive [and MeSH]				
- Health Surveys	12	1		
- Health Care Surveys	13	0		
- Questionnaires	40	2		
- Public Opinion	1	1		
- Attitude of Health Personnel	13	0		
- Attitude to Health	41	18		
Total	100	22		
Title: Priority setting [and MeSH]				
- Health Surveys	12	5		
- Health Care Surveys	3	0		
- Questionnaires	22	6		
- Public Opinion	15	13		
- Attitude of Health Personnel	22	5		
- Attitude to Health	19	0		
Total	93	29		
Title: rationing [and MeSH]				
- Health Surveys	14	6		
- Health Care Surveys	5	0		
- Questionnaires	19	8		
- Public Opinion	32	10		
- Attitude of Health Personnel	39	5		
- Attitude to Health	61	17		
Total	170	46		
Title: allocation [and MeSH]				
- Health Surveys	91	4		
- Health Care Surveys	13	2		
- Questionnaires	57	4		
- Public Opinion	20	9		
- Attitude of Health Personnel	31	5		
- Attitude to Health	57	8		
Total	269	32		
Grand total overall	1,190			
Grand total after screening title		184		
Grand total after screening abstract			47	
Grand total after reading paper				18

The relevance assessment (stage 5 in the above approach) for all three screens drew on the following predetermined inclusion and exclusion criteria: publications should:

- (a) provide data through interviews, focus groups, surveys or polls;
- (b) present an analysis of views of physicians, the public or patients, with patients needing to suffer from conditions relevant to those considered here, i.e. cancer and obesity-related diseases, or ones raising similar issues (such as alcohol-associated diseases<sup>5</sup>);
- (c) be conducted in a developed or high-income country;
- (d) have at least one question on either personal responsibility or incentive use, where surveys or interviews are primarily concerned with broader rationing or resource allocation questions; and
- (e) studies concerned with intensive care situations were excluded, because the situation was viewed as too dissimilar to the types of situations considered here.

#### 4.2.2 Findings

In analysing the full text versions of the articles it became clear that only 18 were accessible, relevant, and presented new and original research.<sup>6</sup> None of the remaining studies were concerned with questions that could be seen as overlapping directly with the research planned here, i.e., there was no interview or survey work that would have examined attitudes of the public or physicians towards incentives to promote weight loss, or incentives for promoting participation in cancer screening and compliance in treatment. Four of the 18 studies addressed responsibility in the context of organ transplantation; the remainder considered it as part of broader questions around resource allocation. Six studies focussed on analysing views in Germany, five on the UK, two compared various countries, two examined the US, and one each concentrated on Norway, Finland, and Australia. Thirteen studies related to views of the public, one to those of patients,<sup>7</sup> two to physician attitudes, and one with a

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<sup>5</sup> As will be explained below, there are however some significant differences regarding normative responsibility assessments in the context of organ transplantation as opposed to obesity policy. Therefore, only a subsection of transplant-related papers that were particularly relevant was included in the review here.

<sup>6</sup> The remainder turning out to be concerned with broader ration issues or specific responsibilities of physicians (14); more narrow aspects arising in the context of organ donation (4); evaluations of survey or engagement methods (3); presenting preliminary findings of research for which final reports were also available (2); not accessible (2); or in commentary form (1).

<sup>7</sup> Note that a several papers that were identified in the first screen (title only) also concerned patient views, and while it was clear that the papers concerned interview or survey work, the diseases in question were viewed as too dissimilar to warrant further inclusion, and were therefore excluded (2 studies on Alzheimer, 2 on HIV, 1 on rheumatoid arthritis, 1 on asthma, and 1 on schizophrenia). Other



combination of aforementioned. In the following, three summaries will be provided of themes emerging from, first studies focussing on organ transplantation, second, on views of members of the public and patients, and third, of physicians. The second section also includes three particularly relevant studies that have been published after completion of the review, one (by Judith Long, Marie Helweg-Larsen and Kevin Volpp) presenting survey findings from patients in waiting rooms in two US primary care clinics; another relating to a representative sample of the US population (by Sarah Gollust and Julie Lynch) and a third comparing attitudes to incentives in a more experimental setting of US and UK residents (Marianne Promberger, Rebecca Brown, Richard Ashcroft and Theresa Marteau), bringing the total to 21.

#### 4.2.2.1 Responsibility and organ transplantation

The case of organ transplantation differs in significant ways from the conditions that form the focus of the research intended here, but also has some relevant parallels, which is why it seemed appropriate to discuss this area separately. The salient difference between discussions about personal responsibility in the case of organ donation, on the one hand, and responsibility for body weight or participation in screening and complying in treatment, on the other hand, is that in the case of organs, the resource that is to be distributed, viz., transplants, are scarce to the extent that many people on waiting lists will die while waiting for an organ. Some people require an organ because of natural pathologies that are independent of their behaviour, whereas in the case of others, behaviour may have played a significant role. Thus, there are some people on waiting lists who had some opportunity to change their behaviour, but failed to do so. Had they behaved differently, they might not have required a donor organ. Moreover, they would not have come in a situation where they might deprive a person who equally needs a donor organ of receiving it, in cases where they are given preference over people who had no way whatsoever of avoiding their need. While in some case this merely means that they have a longer wait because

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papers excluded at that stage were 6 that focused on developing country, or specific minority group settings; 22 that were on topic, but not surveys or interview based; 41 that fitted methodology-wise but were clearly not concerned with personal responsibility or incentives (mainly general rationing issues, or using rationing as an example to study certain methodological issues); 4 that concerned the use of incentives at the physician or institutional, but not individual level; 14 that assessed the clinical or otherwise scientific (in the narrow sense) effectiveness of particular incentive programmes; and 39 that were either off-topic, inaccessible, clearly irrelevant, or in a language other than English, French or German.

others failed to behave in ways that are regarded as responsible at an earlier stage, in other cases they may die. Such consequences generally do not materialise in the same way when it comes to failing to maintain a healthy body weight, participating in screenings, or complying with treatment: here, the costs are primarily financial. Even though opportunity costs may result due to attention of health care staff being unavailable for people who require treatment because of events that are wholly beyond their control, this will hardly ever lead to death.

This preface is necessary to understand that although findings on normative assessments of responsibility for smoking or alcohol consumption leading to the need for an organ transplant share some similarities with responsibility assessments regarding excessive food intake (or insufficient energy expenditure), people may feel more strongly about responsibility for transplant needs because of the more immediate life or death consequences for people who had no opportunity whatsoever to influence their need. It is not surprising, then, that Peter Ubel and colleagues found in a questionnaire-based study of 407 prospective jurors in the US that subjects allocated significantly fewer than half of the organs to those with unhealthy behaviours and worse prognoses, and that significantly fewer organs were allocated to patients viewed as responsible for causing their diseases<sup>8</sup> (with subjects who never smoked being the most likely to follow this pattern, Ubel et al. 2001). Equally, Georg Schomerus and colleagues found in a telephone survey involving the adult German population (randomised sample, weighed results,  $n=1,012$ ) that out of nine conditions alcoholism was considered to be particularly “self-inflicted”, evoking a high desire for social distance, and being clearly associated negatively with resource allocation decisions<sup>9</sup> (Schomerus, Matschinger, and Angermeyer 2006). Eve Wittenberg and colleagues,

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<sup>8</sup> Subjects were presented with four scenarios and asked to distribute 100 transplantable organs among two groups of 100 patients each. In each scenario, one group of patients, but not the other, was described as having a history of unhealthy behaviour (alcohol or cigarette use) associated with a poorer prognosis. In some scenarios, alcohol or cigarette use was said to cause the organ failure. In others, it only contributed to the patients’ transplant prognosis.

<sup>9</sup> Participants were asked to name three out of nine conditions (Cancer, myocardial infarction, AIDS, diabetes, Alzheimer’s disease, rheumatism, depression, alcoholism, schizophrenia) for which they would prefer resources not to be cut should general cutbacks within the health care budget be necessary. For all conditions respondents were asked about personal attitudes and illness beliefs. The authors note that the “perceived personal responsibility was highest with alcoholism compared to all other diseases. More than 8 out of 10 respondents rated alcoholism with ‘4’ or ‘5’ on a five-point Likert scale with the extreme ‘depends very much on oneself’, followed by AIDS, where in a similar manner seven out of 10 respondents held sufferers responsible for their illness.” (Schomerus, Matschinger, and Angermeyer 2006: 207)

who administered a questionnaire with two scenarios relating to liver disease and asthma to a cross-sectional sample of 800 randomly selected US residents (response rate 43%) also found that

respondents who believed that alcohol-induced liver disease and asthma caused by in-home air pollution were the result of personal responsibility allocated fewer treatment resources to these patients than to the patients with inherited liver disease and those with asthma related to outdoor air pollution. (Wittenberg et al. 2003: 197)

The two principal reasons for allocating livers to patients with inherited disease were “alcohol consumption is voluntary” (17%) and “alcoholics are responsible for their illness” (15%, *ibid.*: 200–201).

However, a recent systematic review of studies that explored community preferences for solid organ (heart, lung, liver, and kidney) allocation by Allison Tong and colleagues was less certain that assessments of personal responsibility outweighed other considerations in allocation decisions. The research team analysed fifteen studies involving more than 5,563 respondents (including Ubel et al. 2001, but not including Wittenberg et al. 2003, or Schomerus et al. 2006<sup>10</sup>), and identified seven themes that could describe community preferences for organ allocation. These were maximum benefit; survival and quality of life; social valuation; moral deservingness; “the ‘worthiness’ of recipients based on their social standing and lifestyle decisions”; prejudice; ‘fair innings’; ‘first come, first served’; and medical urgency. The authors conclude that “[d]espite the emergence of these general themes, there was no evidence of an emerging consensus with evidence rather suggesting conflicting preferences between individuals” (Tong et al. 2010: 803), although it might be said that the discussion of the relationship between the themes could have been made more explicit. The authors also observe—similar to Strech et al.’s above-noted commentary—that generalizations across studies may be complicated by differences in underlying methodologies and theoretical frameworks (*ibid.*).

For the purposes here it is not necessary to adjudicate the question of the salience of the criterion of personal responsibility in the case of organ transplants over other criteria. But it can be noted that it certainly is one that has particular relevance at the sharp end of rationing decisions, drawing attention to the importance of assessing the

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<sup>10</sup> Regarding the reason for why the remaining papers were not considered here, see footnote 4.

extent to which a need can in fact be said to have been avoidable, which requires an assessment of the opportunities of choice that people concerned have had. Equally, the case of organ transplants highlights that the magnitude of the ‘cost’ of failing to behave in ways that are regarded as responsible requires scrutiny. For while it might be argued that the consequence of people dying gives strong reasons to appeal to personal responsibility (in whatever way: verbally, or through some sort of sanction), there might be less reason to do so if the consequences are less significant. The next section will shed some light on the relationship between responsibility and other goals.

#### 4.2.2.2 Responsibility and views of members of the public and patients

As attitudes around responsibility are often influenced by developments in politics and policy, and since recent years have seen an increased focus on responsibility, the summary of studies concerned with views of the public and patients will proceed backwards in time, beginning with the most recent work, citing other work where fitting. This approach also has the advantage that it begins with some of the most relevant studies for the questions that are of interest here.

Marianne Promberger, Rebecca Brown, Richard Ashcroft and Theresa Marteau focused on the acceptability of financial incentives and examined attitudes through an analysis of data from two non-probability-based convenience samples, with respondents being members of online access panels in the UK and US, n=88, 100, (Promberger et al. 2011). The team asked respondents to evaluate the acceptability and fairness of using medical interventions (pills and injections) versus financial rewards and penalties (levels of rewards or penalties were not specified). Respondents were told to assume that medical and financial interventions were equally effective, and asked to state which type of intervention should be funded by a health care system in relation to five health-related behaviours (weight loss, smoking cessation, and adherence to treatment programmes regarding drug addiction, serious mental illness, and post-operative physiotherapy). While only the case of weight loss is directly relevant for the research planned here, it is nonetheless noteworthy that the authors conclude from their finding that across all five conditions, and in both the US and the UK samples, “financial incentives, whether rewards or penalties, are judged as less acceptable than medical interventions” (Promberger et al. 2011: 4). They hypothesise that the reasons may be that financial incentives constitute a violation of a cultural

norm, or that a sense of injustice may lead people to find it inappropriate to offer financial advantages to people who could have avoided poor health through behaviour. For weight loss, participants in both samples overall favoured pills and injections over rewards and penalties, but were most opposed to the latter, preferring reward schemes. Respondents in both samples also strongly agreed that smokers were responsible for the consequences of their behaviour, whereas assessments were less clear-cut with regard to overweight.

A study by Sarah Gollust and Julie Lynch concentrated on the US and examined the extent to which cues about a person's race, income, gender or responsibility for poor health mattered in relation to the perceived deservingness of care (Gollust and Lynch 2011). The authors also used an online access panel, albeit a larger one, with the sample being representative of the US population (two waves with a total of three vignettes were fielded with  $n=1,334$  completing both surveys). With regard to health, the authors note that respondents were more likely to blame diabetes patients for their condition if respondents were provided cues that patients had poor diet and exercise habits than when they were said to have had a family history of the disease. However, less blame was attributed when patients were characterised as working class, compared to middle class, with no difference in this pattern between higher income and lower income respondents. Equally, both groups agreed that poorer patients who suffered diabetes should shoulder a smaller burden of health care cost.

Judith Long, Marie Helweg-Larsen and Kevin Volpp fielded self-administered surveys to a convenience sample of 515 patients in waiting rooms of two university-based primary care centres in Philadelphia, USA, focussing on incentives to quit smoking, lose weight, and control blood pressure, diabetes and cholesterol. Overall, acceptance of using incentives was found to be equivocal, with 36–42% agreeing that incentives were a good/excellent idea, and 41–44% finding that it was a bad/very bad idea. 'Carrots' were preferred over 'sticks' for smoking and weight loss (smoking 67% vs. 54%, weight loss: 43% vs. 32%).<sup>11</sup> With regard to blame attributions, 76–79% of people disagreed with the statement that people with hypertension or diabetes had themselves to blame for poor health, with markedly less in the case of obesity

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<sup>11</sup> No data on effectiveness was given for the other conditions.

(55%), and smoking (24%). Thirty per cent agreed that paying smokers to quit maybe one of the only effective ways to achieve behaviour change (smokers showing statistically significant higher odds) with 47% disagreeing.<sup>12</sup> Sixty-two per cent found it acceptable if companies offered incentives for health improvement, but 53% agreed that people should not be paid for behaviour they should display anyway. Regarding appropriate levels of incentives, respondents were presented with three brackets, \$0, \$50–500 and >\$1,000 for each of the four conditions. There was little variation across these, and 51–53% opted for \$0, 35–40% for the middle bracket and 10–13% for the highest; the median was \$0 for all four conditions. Acceptable levels for incentives in the form of ‘sticks’ were not assessed (Long, Helweg-Larsen, and Volpp 2008).

Adele Diederich, Margrit Schreier and colleagues carried out a number of different interviews and survey studies as part of a larger interdisciplinary research collaboration on priority setting in health care, funded by the German Research Foundation.<sup>13</sup> In a nationwide representative survey of 2,032 Germans, 34 questions in ten clusters that concerned different aspects of rationing-related issues were posed. One of the clusters addressed health behaviour and included three questions on higher co-payments where skin cancer may be correlated with prior solarium use; where other potentially risky behaviours are given, or where there is lack in compliance in treatment, see Table 4.2.

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<sup>12</sup> No data on effectiveness was given for the other conditions.

<sup>13</sup> Priorisierung in der Medizin – DFG-Forschergruppe FOR655, see: <http://www.priorisierung-in-der-medizin.de/> (accessed 16 Dec 2010)

**Table 4.2: Health behaviour attitudes/Germany: findings from a representative survey (Diederich/Schreier 2010)\******Solarium use***

To what extent do you agree with the following statement: ‘people who frequently use a solarium and subsequently suffer from skin cancer should pay a proportion of the cost of treatment’

Agree completely	Tend to agree	Tend not to agree	Disagree completely	Don't know	Answer refused
45.7	26.2	13.2	12.9	1.4	0.6

***Importance of potentially risky behaviours***

There are many behaviours that have a negative effect on health and can increase the risk of illness. In your view, in which cases should patients incur higher co-payments?

	Yes	No	Don't know	Answer refused
Consuming unhealthy foods	45.9	45.9	7.2	1.0
High use of alcohol	70.9	25.6	3.1	0.4
Smoking	67.8	28.7	3.1	0.4
Adventure sports	74.2	23.3	2.3	0.1
Sunbathing/solarium use	65.0	31.1	3.5	0.3
Use of illicit drugs (e.g. heroin)	76.4	21.1	2.0	0.5
Lack of exercise	38.1	54.0	7.2	0.7
Other	5.3	11.2	74.9	8.6

***Compliance***

Patients don't always comply with treatment. However, if, for example, antibiotics are not taken as prescribed they are likely not to be effective, and treatment may be unsuccessful. Do you think that patient who are known not to comply should pay some of the cost of treatment themselves?

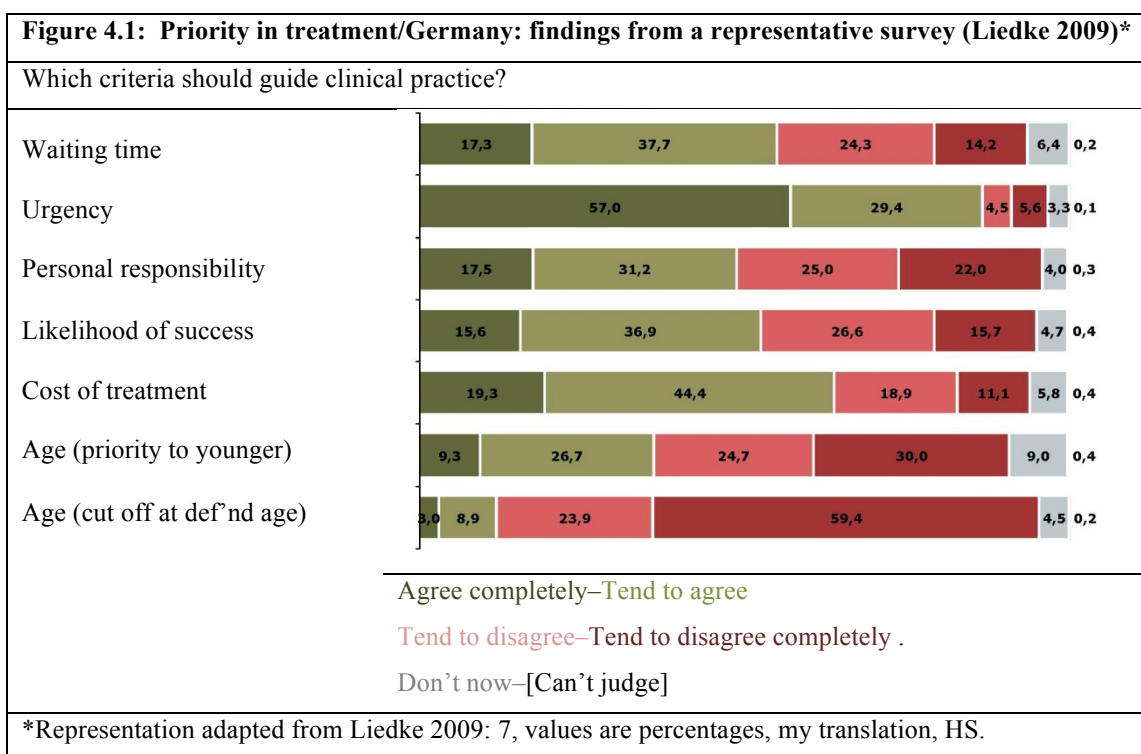
Yes	No	Don't know	Answer refused
72.4	23.0	4.2	0.3

\*Representation adapted from Diederich and Schreier 2010: 22–23, values are percentages, my translation, HS.

As Diederich and Schreier note in the discussion of the findings, there appears to be broad support for implementing some form of cost-shifting for a number of behaviours that may lead to health care needs, with the exception of ‘lack of exercise’, which 54% reject as a criterion, and ‘consuming unhealthy foods’. Regarding the latter, 45.9% are in favour, while the exact same number of people is opposed, with the percentage of people responding ‘don't know’ or ‘refuse to answer’ the highest, in comparison to the other items on the list (Diederich and Schreier 2010: 23-24). Non-compliance in treatment as a criterion for higher health care cost also receives much endorsement, scoring the third highest approval ranking at 72.2% (with extreme sports at 74.2%, and use of illicit drugs at 76.4%). Note, however, that respondents were not provided with figures for the level of co-payments, which, it might be argued, would be likely to affect their responses. It is also noteworthy that in earlier qualitative work using semi-structured interviews that were carried out in preparation of the survey, 9 of

45 respondents pointed out that the acceptability of higher co-payment depended on their level, even though 21 respondents agreed to the general principle that smokers should incur a higher burden, as they has caused their health care needs (Diederich and Schreier 2010: 899).

Posteriorisation, or assigning lower priority, can take different forms. One approach, as envisaged by Diederich and colleagues, focuses on financial disadvantage. Another question is what role personal responsibility might play in assigning priority in clinical practice, which was explored almost concurrently in research commissioned by the Allianz Deutschland AG in 2009 in the form of a telephone survey among randomly selected German adults ( $n=1,039$ ). In the survey, respondents were asked to rank seven criteria that might determine priority in treatment, as represented in Figure 4.1.



Given that 48.7% of respondents are sympathetic to giving people who bear some responsibility for their actions lower priority in treatment, but almost as many (47%) are opposed, Annika Liedke comments in her presentation of the findings that posteriorisation would not be straightforward, speculating that those opposed to using the criterion based their concerns on fairness grounds (Liedtke 2009: 7).



In a questionnaire based survey conducted in Australia in 2005, Erik Nord and colleagues sought to assess the extent to which there is support for drawing on the Quality Adjusted Life Year (QALY) approach in allocating health care resources. 2,000 questionnaires were distributed of which 551 were returned. One question concerned the role of smoking and asked:

Which of the following do you agree with?

1. If there is not enough money to treat everybody with heart disease or lung cancer, non-smokers should have some priority over smokers.
2. Smokers should have the same priority with respect to treatment for heart disease and lung cancer as everybody else.

In response, 59.5% believed that non-smokers should be prioritised, with the remainder opting against. The researchers point out that the bias was not explainable “because [respondents] thought outcomes tend to be better in non-smokers than in smokers [but instead] the great majority blamed smokers for self inflicted conditions” (Nord 2006: 434).

In the UK, Ann Bowling analysed a question on the role of personal responsibility in a survey on general rationing issues conducted in 2000 on a representative sample of UK residents, who participated in 2,005 face to face interviews. In response to the statement “People who contribute to their own illness, for example, through smoking, obesity, or excessive drinking, should have lower priority for their healthcare than others” the following responses were received: Strongly disagree (10%); disagree (33%), neither disagree nor agree (15%); agree (33%) strongly agree (9%); (Bowling 1996: 12). Here 42% were in favour of responsibility as a criterion for lower priority, while 43% were opposed, a result broadly similar to the findings Liedke reported for Germany, as noted above.

In a similar vein, earlier research by Herbert Matschinger and Matthias Angermeyer suggested that factors such as the urgency or severity of disease could rank higher than personal responsibility when it comes to funding priorities. The researchers analysed 5,025 interviews of respondents constituting a representative sample of the German population and asked them to select three out of nine conditions for which available resources should on no account be shortened. The vast majority (89%) selected cancer, almost half of the respondents selected HIV/AIDS (51%) and cardiovascular diseases (49%). This was followed by diabetes (33%) and Alzheimer’s

disease (28%); next was rheumatism (19%), schizophrenia (10%), depression (7%), and alcoholism (6%). While the study's clearest finding is that respondents differentiate between priority for the medically (in the narrow sense) ill as opposed to the mentally ill, the extent to which personal responsibility might play a role in health care needs is not as well aligned (compare, for example, the melanoma scenario explored by Diederich and Schreier above, and equally responsibility is attributed by many with regard to HIV/AIDS and cardiovascular diseases, making up the top three priorities in which no cuts should be made (Matschinger and Angermeyer 2004).

Three studies analysed on data from the 1998 *Eurobarometer*. Derek King and Alan Maynard drew on the UK segment, which was based on a representative sample of 1,055 respondents. Personal responsibility issues were explored in one of eight questions with relevance for rationing, and similar to the examples considered above, respondents were asked to rank "lifestyle" in relation to other factors regarding priority in treatment. King and Maynard presented the findings, but do not discuss them further, see Figure 4.5 (King and Maynard 1999). Reinhard Busse examined the *Eurobarometer* findings for Germany, which were in this case based on a representative sample of 2,000 respondents, see Table 4.3.

<b>Table 4.3: "Lifestyle" in relation to other factors regarding priority in treatment: findings from the 1998 Eurobarometer survey*</b>						
"Which factor that a doctor or other health professional might take into account when deciding which patients should be given priority for treatment do you consider to be the most important?"						
	Germany	UK	France	Italy	Netherlands	Sweden
Waiting time	32.4	36.4	21.3	32.3	39.7	45.0
Each case should be treated individually**	18.8	17.1	40.3	38.6	14.8	18.5
Family commitments	13.6	14.1	11.4	4.8	9.5	12.2
Treatment outcomes	12.7	14.0	9.4	11.9	16.0	9.0
Lifestyle	8.3	9.1	5.4	2.2	11.7	3.5
Age	4.1	6.9	8.0	5.5	1.9	6.4
Don't know	10.0	2.4	4.2	4.8	6.4	5.4
*Representation adapted from: (Busse 1999: 86; King and Maynard 1999: 46; Mossialos and King 1999: 100), values are percentages.						
** Spontaneous statement by respondents, not on initial list of options.						

Although, due to the different methods of ranking and different wording and substantive content of items, a comparison to the survey findings presented by Liedke above are not straightforward, there appears to be far less support for considering personal responsibility related factors in this (earlier) study. Contextualising these

findings in prior national survey work, and giving more meaning to what might meant by the notion of ‘giving priority’, Busse notes, regarding coverage by sickness funds:

In a 1993 Forsa survey, 55% of the 1,005 persons interviewed were of the opinion that sickness funds should pay for ‘everything’ while 41% thought that they should not cover certain diseases: smoking-related diseases 32%; alcohol-related diseases 28%; injuries through risky sports 26%; drug abuse 23%; abortion 11%; stress-induced diseases 3%; pregnancy 1%. Similarly, Polis’s 1995 survey in Northrhine-Westfalia showed that 23% thought that self-induced diseases should not be paid by the sickness funds. Seventy-five per cent said that raising sickness fund contributions could be avoided through increased efficiency in the health care system. In Forsa’s 1995 survey, 41% favoured the inclusion of health risks in the calculation of sickness fund benefits, mainly through bonuses for healthy lifestyle (29%) and less frequently through extra contributions for persons with risky behaviours (7%). (Busse 1999: 83)

It is noteworthy that despite a significant spread, these surveys indicate stronger support for implementing responsibility in practice than the *Eurobarometer* findings, with the 1995 Forsa study suggesting four times as much support for using ‘carrot’ approaches, as opposed to ‘sticks’. Elias Mossialos and Derek King examined the *Eurobarometer* findings across the six countries represented in Figure 4.4., but, as in King’s publication with Maynard, did not consider the “lifestyle” question in more detail in the description of the findings, nor in the discussion section, focussing instead on the remaining criteria. In part, this was a consequence of the paper’s main focus, in part it may be to do with an earlier discussion in the paper regarding the relevance of the “lifestyle” criterion. The authors note that in “the countries where attempts at priority setting have been made by government committees, however, lifestyle has generally been ruled out as a consideration determining access to services, though it may be taken into account in assessing outcomes” (Mossialos and King 1999: 90). As Chapter 2 here has shown, this practice has certainly changed since 1998. After a brief review of some of the survey literature in different European countries the authors also concluded that: “[o]verall, there appears to be little consensus on the relevance of lifestyle to priority setting decisions. In fact, most of the evidence suggests a sharp split in opinion between those who support the inclusion of lifestyle as a priority setting criterion and those who do not.” (Mossialos and King 1999: 92)

Such sharp differences of opinion may partly be the result of deeper implicit or explicit normative positions; in part, they may also reflect that the issues raised are highly complex, and that attitudes may change, after a period of deliberation. Paul

Dolan and colleagues sought to assess this hypothesis through research in which groups of people would discuss relevant issues, and any changes in the attitudes over time would be monitored. A total of 60 people met in ten groups of five to seven people on two occasions, separated by a fortnight. Participants were randomly chosen patients, recruited via two general practice lists in York. All discussions were moderated by the same two researchers, who mainly sought to ensure that everyone had an opportunity to be heard. A questionnaire was filled in by all participants in the first meeting, to record initial assessments, and another questionnaire was filled in at the second meeting, to record changes that were likely to be the results of discussion with others, or responses to a set of trade-off scenarios and other debate or information materials which the researchers presented. Table 4.4 shows the changes in attitudes.

**Table 4.4: Should some groups of patients have higher or lower priority for treatment than others? Findings on changes in attitudes of participants of group discussions in the UK (Dolan, Cookson, and Ferguson 1999)\***

Group features	Initial response assessment		Final response	
	Lower priority	Higher priority	Lower priority	Higher priority
Children	70 (42)	2(1)	2(1)	62 (37)
Illegal drug users	57 (34)	8(5)	43 (26)**	3(2)
Smokers	57 (34)	0	32(19)**	0
Heavy drinkers	55 (33)	3(2)	37 (19)**	2(1)
Disabled	0	48(29)	0	35(21)
Elderly	7(4)	47 (28)	5(3)*	27 (16)
Private health insurance	30 (18)	2(1)	33 (20)	2(1)
With children	2(1)	30 (18)	3(2)	20 (12)
Unhealthy diet	23 (14)	7(4)	17 (10)	5(3)
Rich	20 (12)	0	23(14)	0
Rarely exercise	17 (10)	0	20(12)	0
Poor	0	17(10)	0	10(6)
Low education	0	15(9)	2(1)	8(5)
Homosexual	13 (8)	0	10(6)	0
Important	13 (8)	0	5(3)	0
Women	0	7(4)	0	3(2)
Married	0	5(3)	2(1)	0
Contributed a lot	2(1)	3(2)	2(1)	2(1)
Unemployed	0	3(2)	0	3(2)
White	0	0	0	0
Men	0	0	0	3(2)

\*Representation adapted from: (Dolan, Cookson, and Ferguson 1999: 918. Values are percentages (numbers) of 60 respondents; responses of remaining respondents were that the same priority should be given to that group.  
\*\* P<0.01 compared with initial responses.

For the issues considered here, it is noteworthy that there is a clear shift in attitudes regarding the assessment of smokers, heavy drinkers, and illicit drug users. While on the initial assessment more than 55% wished to assign them lower priority,

on the second assessment this dropped to between 32 and 47%. Dolan and colleagues conclude from this that

the public's views about setting priorities in health care are systematically different when they have been given an opportunity to discuss the issues. If the considered opinions of the general public are required, surveys that do not allow respondents time or opportunity for reflection may be of doubtful value (Dolan, Cookson, and Ferguson 1999: 916).

The more fundamental critique of using survey data that the authors present will be considered again in the discussion section below. For now, it can be summarised that, although as already noted above, it is far from straightforward to aggregate findings from survey research across studies in a robust manner, it is clear that a range of different surveys carried out over more than a decade demonstrated considerable support for considering personal responsibility, in particular in relation to the somewhat general, and to some extent unspecific, question of whether people who drink excessively, exercise insufficiently, and so on, should be given 'lower priority' in the context of clinical practice, treatment, or cost-sharing. In all studies the concepts of 'causality'/'causal responsibility', 'voluntariness', 'opportunity of choice' arise as relevant in seeking explanations for the findings, although the data are generally insufficient to surmise what assumptions respondents made in their assessments.

#### 4.2.2.3 Responsibility and views of physicians

The attitudes of physicians towards patient responsibility have been studied far less extensively than those of the public and patients, and only three surveys were identified here. Piija Jallinoja and colleagues focussed less on health policy and fairness issues, but sought to address physicians' and nurses' views on patient and professional roles in the management of "lifestyle-related" diseases such as adult obesity, dyslipidemia, high blood pressure, type 2 diabetes, and smoking. Using a structured written questionnaire, the researchers surveyed 220 Finnish professionals in primary care (Jallinoja et al. 2007). Among other things they found that:

[a] majority of physicians (88%) and nurses (95%) agreed that patients themselves must accept the responsibility for lifestyle-related decisions. In respect of all the conditions presented, a majority of physicians and nurses considered that patients' unwillingness to change is always or nearly always a key barrier to treatment. Patients' insufficient knowledge of the risk of the condition was much more seldom regarded as a barrier; an opinion most pronounced in respect of adult obesity and smoking (Jallinoja et al. 2007; 246).

Later the authors noted that both physicians and nurses were faced with a dilemma regarding the role of patients' behaviours in the treatment of diseases such as obesity and smoking, as the patient's cooperation was regarded as central in disease management but at the same time often seen as a major potential barrier to treatment:

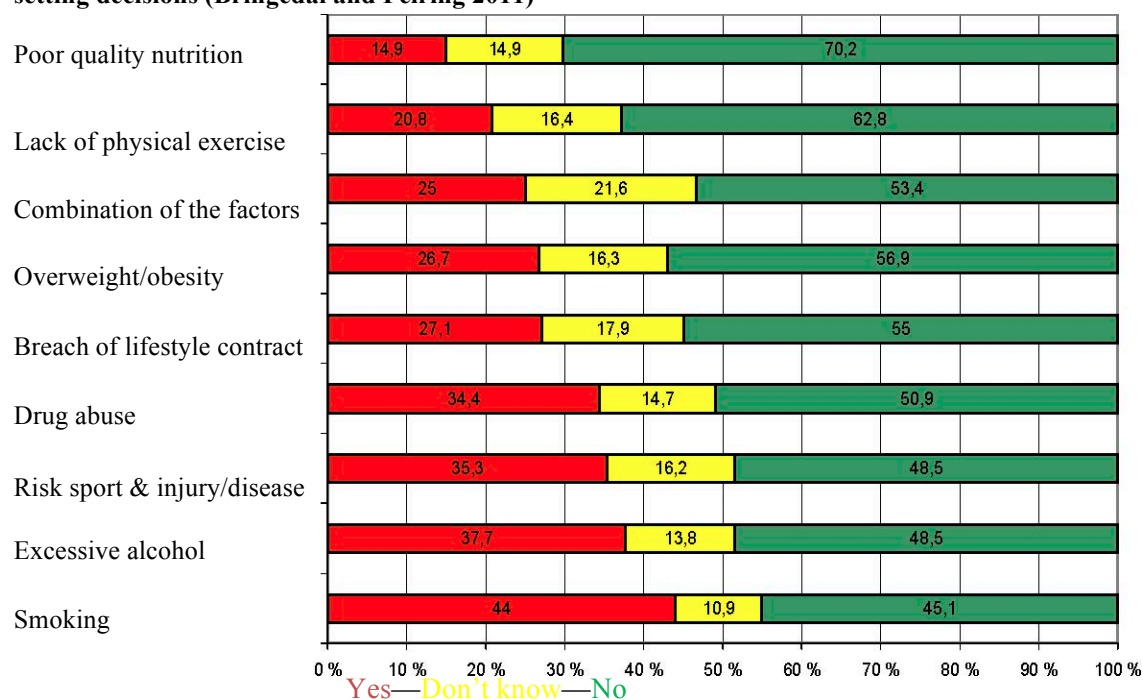
The primary care physicians and nurses studied here hold a view that while patients are responsible for their lifestyle change, for the majority they are not able to act in their best interests. The dilemma of this situation might be frustrating for professionals, and it might also lead some to neglect lifestyle counselling as useless and rely predominantly on pharmacotherapy in the treatment of lifestyle-related conditions (Jallinoja et al. 2007: 248).

Berit Bringedal and Eli Feiring focussed centrally on rationing-related issues.

Drawing on the 2008 Norwegian Medical Doctor Survey, which is composed of a representative sample of 1,650 Norwegian practicing medical doctors, data were collected using a cross-sectional questionnaire, with 1,072 responses being received. The authors sought to address three principal questions: (1) Do Norwegian medical doctors find personal responsibility relevant to priority setting decisions?; (2) Which dimensions of responsibility do the respondents find most relevant?; (3) Can different views between subgroups of doctors be traced to priority setting experience? Respondents were asked to assess a set of general propositions regarding the role of personal responsibility in priority setting, and to evaluate the importance of different responsibility-related factors that might be of relevance in priority setting decisions, see Table 4.5 and Figure 4.2.

	Partly/compl disagree	Neutral	Partly/compl agree
Healthcare priority should depend on the patient's personal responsibility for the disease	57,0 (602)	25,9 (273)	17,1 (181)
Access to expensive treatment should depend on the patient's personal responsibility for disease	55,6 (586)	25,3 (267)	19,1 (201)
Access to scarce organ transplants should depend on the patient's responsibility for the disease	49,3 (520)	23,8 (251)	26,9 (283)
Lower priority should be allotted to patients who violate a contract of changes in lifestyle	49,7 (523)	26,3 (277)	24,0 (252)
A patient who is responsible for the disease should pay additional co-payments	73,9 (780)	18,6 (196)	7,6 (80)
*Representation adapted from Bringedal and Feiring 2011, values are percentages, n in parentheses.			

**Figure 4.2: Norwegian physicians' views on responsibility-related factors of relevance in priority setting decisions (Bringedal and Feiring 2011)\***



\*Representation adapted from: Bringedal and Feiring 2011: 359, values are percentages.

In relation to the statements reproduced in Figure 4.2, Bringedal and Feiring highlighted that 43% choose the alternatives ‘partly/ completely agree/indifferent’ in response to the statement “Healthcare priority should depend on the patient’s personal responsibility for the disease”, while 44.4 % chose these alternatives to the statement “Access to expensive treatment should depend on the patient’s personal responsibility for the disease”. They emphasised that these assessments are in conflict with Norwegian legal provisions which state explicitly that only severity of disease, likelihood to benefit, and cost are to be considered. They also found that responsibility ascriptions vary with age and gender, with older doctors and females more reluctant to consider responsibility. There was no significant variation between GPs and other physicians (Bringedal and Feiring 2011).

That doctors have sympathy for considering personal responsibility, even if professional guidance suggests they should not, also became apparent in a UK survey on rationing issues carried out online by the Medical Hospital Doctor Magazine in 2008. 873 physicians participated in total, and 686 responded to a question that sought to assess whether there were conditions in which patients should be refused treatment (Medical Hospital Doctor Magazine 2008), see Table 4.6.

<b>Table 4.6: Attitudes of UK doctors towards refusing treatment (Medical Hospital Doctor Magazine 2008)*</b>		
“In which, if any, of the following scenarios do you believe the patient should be refused clinically indicated treatment on the NHS?”*		
	Favourable Responses (%)	Favourable Responses (count)
An intractable smoker who requires a bypass	48.0	329
An obese patient who requires a hip replacement	25.8	177
An alcoholic who refuses to stop drinking but who requires a liver transplant	93.7	643
A heroin addict who requires maintenance therapy	17.8	122
An injury resulting from a high-risk sport, such as boxing	10.5	72
An elderly patient who is likely to gain benefit from treatment but only for a short period (e.g. a statin for a 95-year-old after an MI)	27.8	191
	Answered question:	686
	Skipped question:	187

\* \*Representation adapted from: Medical Hospital Doctor Magazine 2008, multiple selections possible.

Unsurprisingly, these findings caused considerable media interest, prompting the British Medical Association (BMA) to publish a press release, in which the Chairman of the BMA’s Medical Ethics Committee, Dr Tony Calland stated: “Someone’s age or lifestyle choices should not impact on their eligibility for NHS treatment and the BMA would be against any such moves. The BMA is against blanket bans based on age or other arbitrary factors” (British Medical Association 2008).

While survey or interview work on physicians’ attitudes towards personal responsibility is in short supply, and does not concern the countries that are intended to be studied here, the data that do exist appear to suggest that physician’s views are not that dissimilar from those of the general population, but rather stand in a continuum. The example of the Finnish physicians shows that the concept of (non-normative) causal responsibility is of importance in every day clinical interactions, while the Norwegian and British surveys showed physicians do not necessarily shy away from making value judgements. As in the case of the surveys of the public and patients, this raises deeper questions about their assumptions regarding, in particular, the concepts of ‘voluntariness’, and ‘opportunity of choice’.

### **4.3 Discussion of findings and development of a new survey instrument**

The studies summarised in outline here provide a range of interesting insights. At the same time, they are also limited in significant ways, both for the purposes pursued in this thesis, as well as independently of it.



First, as noted, much research asks about conditions or behaviours that may justify giving people “lower priority” or, for example, demanding “higher co-payments”. Yet, none of the studies set out what level of co-payments exactly is envisaged. Apart from the Hospital Doctor Magazine’s survey which asks physicians to state under what conditions patients should be “refused” treatment, studies considering other forms of posteriorisation are opaque about how this would be achieved. Both readers and survey respondents must therefore be unclear about what precisely it should mean to receive less priority in organ allocation or clinical practice. Long et al. asked respondents to determine what levels would be appropriate for ‘carrots’, but the categories were very broad; the incentive programme used in the scenario was not framed in the way they are typically used in practice,<sup>14</sup> and the sample was a relatively small convenience sample. Lack of evidence about the acceptable magnitude of, particularly, penalties matters, as arguably, the results of, for example Diederich’s and Schreier’s interesting survey might look very different if numbers had been attached to the loose descriptor of “higher co-payments”: did the 65% of respondents who thought that solarium users should have higher co-payments have in mind one Euro, ten, 100 or 1,000? We don’t know. Yet, the discussions about responsibility appeals being coercive or unfair hinge to a very significant extent on the magnitude of the financial (or other) burden that people may be asked to bear. It therefore seems desirable to be precise about this aspect in the work developed here.

A further problem has to do with the fact that the focus of the research reviewed here is about examining the conditions under which people might be disadvantaged or penalised, rather than incentivised. As the previous chapters here have shown, to some extent, it is not always easy to discern the difference between ‘carrots’ and ‘sticks’, and often policies that are offered as ‘carrots’ turn out to be ‘sticks’. Yet, with the exception of Long et al. and Promberger et al., most of the work frames choices in such a way that respondents are asked to assess under what conditions ‘sticks’ might be appropriate. But, as the example of the BMA’s response to the Hospital Doctor Magazine’s survey showed, such policies are generally unlikely to be implemented,

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<sup>14</sup> The authors note: “The survey questions focused on rewards for change in behavior (losing weight), though most existing P4P programs reward absolute achievement (getting weight below some pre-set threshold). We did this because we feel that tying incentives to changes in behavior is more likely to increase the rate of healthy behaviors than if such programs focus on absolute achievement.” (Long, Helweg-Larsen, and Volpp 2008: 1651)

due to political and professional reservations. A similar reaction could be registered when Diederich and Schreier published the initial survey findings in the summer of 2010 in Germany. On the one hand, Marco Wanderwitz, MP, a backbencher of the conservative party, welcomed the findings and argued that they rightly underlined that people who voluntarily live in unhealthy ways would need to shoulder the financial consequences. At the same time, Prof Karl Lauterbach, MP, a health policy expert and ministerial adviser, simply chided the proposal of imposing higher cost as “bonkers”, with several newspapers suggesting that this was a typical proposal for the summer’s ‘silly season’ (Handelsblatt 2010).

Indeed, it would not be imaginable to implement higher co-payments (of whatever level) for the range of activities explored in the survey at this point in Germany. Yet, the aforementioned bonus programmes can easily have a similar penalising effect. Assessing attitudes on the acceptability of these initiatives, which are already in practice, would have been a useful complement to studies asking about the conditions under which of higher co-payments would be acceptable. Promberger et al.’s comparative examination of attitudes towards ‘carrots’ and ‘sticks’, and the finding that respondents in the US and UK samples prefer rewards over penalties is noteworthy, but it would also be interesting to know whether such attitudes vary with the size of the incentive—as noted, one major development in recent US reforms related to a significant increase in the levels of incentives. It therefore seems that the work proposed in this thesis can extend some of the general work already done and make it more specifically relevant for the actual policy context, exploring, in particular, some of the nuances in relation to the framing of ‘carrots’ and ‘sticks’.

This approach should also go some way towards addressing the concerns Dolan and colleagues have regarding the use of survey results. Of course, the conventional form of surveys means that the demand to “allow respondents time or opportunity for reflection” in order to ensure that results are not of “doubtful value” is likely to be overly demanding (Dolan, Cookson, and Ferguson 1999: 916). But in a constructive way the comment can be understood to emphasise that questions be phrased in a way that makes them as concrete as possible, avoiding highly abstract and general scenarios.

In line with this, a first draft instrument was developed, which was then refined further in a series of pre-tests for use in semi-structured interviews with primary care physicians and oncologists (Chapter 5), and in population level surveys (Chapter 6). The initial draft instrument is at Appendix 4A.<sup>15</sup> Below, a brief overview of its structure and the rationales for individual items is provided.

#### *The role of personal responsibility and other factors*

To begin with, a question is asked to assess how important respondents find the role of individual behaviour in relation to other relevant factors that can influence one's health, such as the environment, genetics, access to health care and so on. This has several purposes. First, to alert respondents to the possibility that the scope of individual behaviour may have limitations, and also to see where respondents 'are coming from', as views about the acceptability of rewards and penalties are likely to differ depending on one's general view of the role of individual behaviour. The question also helps to assess empirically whether the conceptual notion of health as co-production (Section 2.3.1, 3.4), that was highlighted in the previous Chapters 2 and 3, has currency among respondents. Since the extent of control that people have over their health was shown to be an important factor in evaluating the fairness of programmes, it will also be instructive to examine the extent to which there are differences among groups with differing income or health status regarding the role of personal behaviour.

#### *The car insurance analogy*

The analogy that people who are unhealthy behave like risky drivers was influential in the recent changes in US policy, but it is not clear to what extent it meets with approval by physicians or the public. The scenario is highly relevant for questions around solidarity, voluntariness, intrusion and opportunity of choice, and therefore central to several elements of the procedural justice framework set out in the previous chapter. The analogy also provides a crisp scenario that can help understand whether there are differences among German and American respondents.

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<sup>15</sup> Note that the instrument has changed considerably after pre-testing (as was to be expected). It might therefore be more instructive to review the instruments as used for the physician surveys (Appendix 5D and E) and population level surveys (as reproduced in Chapter 6).

*Weigh loss incentive*

A commonly used attainment-incentive is to provide a ‘carrot’ or ‘stick’ for meeting (or not meeting) specific Body Mass Index targets. Using a highly naturalistic scenario and realistic monetary levels of incentives, rather than exploring acceptability in the abstract, can further a better understanding of the acceptability of real-world applications of responsibility policies.

*Appropriate levels of ‘carrots’ and ‘sticks’ for weight loss*

To explore what levels would be acceptable in relation to a typical incentive scenario, respondents are invited to suggest amounts within the scope of the newly increased levels established under US health reform, for both a ‘carrot’ and (a) version(s)<sup>16</sup> of a ‘stick’ scenario.

*Motivation, behaviour change and deservingness in relation to weight loss*

In a range of different scenarios that partly mirror the ‘five groups problem’ (Section 3.5.3) it will be explored to what extent respondents find policies fair in which people: (1) obtain a reward without behaviour change, just because they happen to meet required targets, (a) with their personal motivation and lifestyle aligned with the programme’s goal, (b) with their personal motivation and lifestyle running counter to the programme’s goal; (2) obtain a reward for successful behaviour change, as a result of being motivated by the programme; (3) lose out on a reward as they genuinely tried, but failed to meet targets; (4) lose out on a reward because they object to the programme’s goal. These scenarios again relate to central issues around opportunity of choice and desert, and build, among other things, on the above-cited prior work by Long et al. and Gollust and Lynch.

*Economic status and weigh loss incentives*

The scenario above chiefly relates deservingness and acceptability of incentive rewards to personal effort. However the previous chapter also referred to survey data that suggests that healthier and economically better off people are more likely to benefit from incentive programmes (Section 3.5.3). The economic status of the primary beneficiaries can also matter for the acceptability of programmes and will

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<sup>16</sup> It was initially envisaged to use only two scenarios, but the population level surveys eventually included three different ones (see Section 6.2.2).

hence be explored in a separate scenario in which it is suggested that twice as many of the better off receive incentives, compared to the worst off.

#### *Colon cancer prevention policy*

The German cancer prevention policy is remarkable on a number of grounds and attracted much criticism due to its ambiguous framing that combines ‘carrot’ and ‘stick’ elements, and the potential to be coercive and penalising, as described in detail in Chapter 2. Yet, there is no data on population-level views. The instrument therefore includes an abstracted scenario, focussing on colon cancer prevention. Since the policy combines two elements (attending counselling and compliance in treatment), individual elements are then explored in separate scenarios. The first of these uses the initially envisaged plan to require undergoing screening (and not just counselling), to avoid a doubling of the co-payment threshold. The second explores whether the newly established, and largely unique, obligation to think about one’s health (in the context of incentivised counselling sessions) meets with approval or opposition.

#### *Framing of incentives*

The discussion in Chapters 2 and 3, and the prior work by Promberger et al. and Long et al. showed that attitudes towards ‘carrots’ and ‘sticks’ can vary, and that it cannot be taken for granted that ‘carrots’ will always be perceived as purely benign offers of assistance. For both the weight loss and the colon cancer prevention policy respondents will therefore be asked to state in what way they view the programmes (as rewards, penalties, or both at the same time).

#### *Impact on the doctor-patient relationship*

Since incentives are not merely transactions between individuals and a faceless health care system, but often mediated by health professionals with the potential to cause tension in the doctor-patient relationship, the instrument includes two scenarios relating to weight loss and colon cancer prevention that explore how likely patients are to request physicians to record an outcome in their favour so that they can secure an incentive; how likely physicians are to comply with such requests; and how complying physicians are viewed in terms of acting professionally.

#### **4.4 Conclusion**

While there is a substantial amount of survey literature on the role of personal responsibility, much of this is of a general or abstract nature, and only two of 21 relevant studies have examined the specific context of incentives. Themes that are of central relevance in the survey literature map closely onto the issues arising from Chapters 2 and 3 and concern, among other things, attitudes towards coercion, deservingness, effectiveness, and acceptability. While the principle of disadvantaging those who are viewed as having behaved in ways that lead to avoidable health risks is documented relatively extensively, nothing is known about the normatively relevant acceptable magnitude of penalties, and very little is known about the magnitude of acceptable rewards. The instrument developed here seeks to build on the existing literature and to help clarify central elements that are salient in the ethical discussion. By itself, this work does little to settle the question of how to proceed in implementing incentive policies. However, as one of several inputs, it can help establish a broader set of relevant reasons that feed into a procedural justice account (see Section 3.5).

## Chapter 5<sup>1</sup>

### Health responsibility: physicians' views

#### 5.1 Introduction and Aims

The approach of combining Norman Daniels' and James Sabin's Accountability for Reasonableness framework with Thomas Scanlon's Contractualism (Section 3.5), places great emphasis on the identification and due consideration of relevant reasons which different stakeholders may have, in particular, if they are cited in arguments seeking to reject a policy. One particularly important group of stakeholders is physicians. As Chapter 2 showed, physicians play a central role in implementing incentive programmes, typically have a keen interest in identifying measures that help patients to stay healthy, and are also likely to hold implicit or explicit views about what constitutes reasonable resource use within a health care system.

The consideration of physicians' views is then relevant not only on normative grounds, but also on practical ones, as physicians who object to particular elements of a policy may undermine its implementation. Conversely, proper alignment of policy goals and physician views can maximise benefits. The discussion in Chapter 2 of the responses of the professional interest groups of physicians in Germany and the US has shown that such alignment cannot be taken for granted, as there was strong opposition to several elements including the objectives of incentive programmes and a perceived policing role for physicians (Section 2.3.3 and 2.4.2).

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<sup>1</sup> I am very grateful to the following friends and colleagues for invaluable advice and assistance in developing the instrument and recruiting interviewees: Johann Ach, David Ash, Ronal Barg, Gene Bishop, Jochen Breinlinger-O'Reilly, Berit Bringedal, James Brooke-Turner, Alena Buyx, Shawneequa Callier, Hanno Charisius, Carmen Guerra, Rizwan Haq, Ingo Härtel, Ingo Höhr, Peter Hasselblatt, Paul Henning, Nilophar Lafrai, Tim Kennerly, Sabine Kies, Jan Köser, Julia Kreis, Srinivas Kuruganti, Stefan Lenz, Wolf-Dieter Ludwig, Georg Marckmann, Claus-Dieter Middel, Mathias Mrotzek, Jens Niehoff, Charles Orellana, Engin Osmanoglou, Birte Pantenburg, Elfteria Panagiotou, Lutz Rabe, Annette Rid, Markus Rudolphi, Bettina Schöne-Seiffert, Dorothea Schmidt, Lea Schmidt, Diana Seemann, Julian Strauss, Simon Tönsmeier, Sridhar Venkatapuram, Dan Wang, Joy Wang, and Andreas Vieth. Findings were also presented at the health service research Work in Progress seminar at the Perelman School of Medicine University of Pennsylvania, on 7 December 2011, and the discussion with participants has been most helpful for reviewing the analysis here. I am especially grateful to the physicians who generously agreed to give of their time, and provided most valuable views, but, for methodological reasons, must be unnamed here.

On a more conceptual level, Chapter 3 noted that it would be short-sighted to assume that analyses of incentive programmes only needed to focus on what they mean for users of a health care system: the impact on third parties, such as physicians, and in particular on the doctor-patient relationship, also needed to be considered. However, in both chapters, the level of analysis was by necessity of a somewhat general nature, either because it took the form of conceptual analysis, or of analysis of position statements that focused on the most important elements of the reforms. But the nuances of incentive programmes can be as important as their broad outlines, or overall goals. Moreover, as the previous chapter has shown, prior survey and interview work tells us little about a number of specific aspects that are raised by incentives, such as what amount of reward or penalty should be acceptable; whether 'carrots' or 'sticks' should be seen as more acceptable; and whether those involved in incentive programmes, including physicians, always 'see through' the implications of different ways of framing programmes.

This chapter seeks to complement current research by presenting findings from interviews with primary care physicians and oncologists in Germany and the US. There are, of course, several methods that can be used to provide a physician perspective, including nationally representative surveys of all types of physicians, surveys of specialised subgroups, carried out in a structured, semi-structured or unstructured way, or perhaps focus groups. These and further methods clearly all have different advantages and disadvantages. A qualitative research approach that allows an exploration of “the meanings, values and experiences of purposefully sampled individuals and groups in their 'natural' context” (Kitto, Chesters, and Grbich 2008: 243) by drawing on semi-structured interviews seemed both feasible and appropriate in this context. While this method will not enable measuring in quantitative terms the extent of agreement and disagreement regarding physicians' views on incentive policies, it can help shed more light on the reasons that may underlie some of the reported resistance and prepare the ground for further quantitative research. It is hence in this sense that the chapter intends to respond to the thesis' sub-research question 3:

In the views of members of the public and physicians in the US and Germany: which aspects of cancer care and obesity policies focussing on individual behaviour and contribution to efficient services are reasonable, and which ones are not?



After an outline of the methods, the interview findings are presented, and subsequently discussed, along with relevant limitations.

## **5.2 Methods**

This section describes the interview method; approach to sampling and recruitment; testing and development of the instrument; ethics review; data and methods of analysis, including the development of the code list, as well as use of computer-assisted qualitative data analysis software (NVIVO Version 8.03).

### *5.2.1 Interview method*

Data were gathered in 20 semi-structured interviews of approximately 30 minutes with five primary care physicians each in Berlin, Germany, and Philadelphia, USA, and the same number of oncologists in both cities. Interviews were conducted between March and September 2011. Interviewees were given the option of both a face-to-face and a telephone interview. Mixing these modes seemed acceptable as neither the topic nor individual questions raised significant mode-dependent issues that would have biased responses. All interviews were carried out by me.

### *5.2.2 Sample frame and actual sample*

The sampling was non-random and purposive. As Kelly Devers and Richard Frankel observe, purposive sampling is “designed to enhance understandings of selected individuals or groups’ experience(s) or for developing theories and concepts. Typically this goal is sought to be accomplished by selecting ‘information rich’ cases, that is individuals, groups, organizations, or behaviours that provide the greatest insight into the research question.” (Devers and Frankel 2000: 264). The authors also draw on Matthew Miles and Michael Huberman in observing that this strategy is particularly successful for the three groups of typical cases, deviant or extreme cases, and negative or disconfirming cases (“exceptions to the rule”, Miles and Huberman 1994: 34). While the latter two cases were not of interest to the study here, efforts were made to ensure that the sample approximated typical cases.

Accordingly, the sample frame inclusion criteria required that physicians were between 35 and 65 years old; had at least 5 years of qualified professional experience in primary care or oncology; and worked in a single or group practice or hospital in

metropolitan areas of Berlin and Philadelphia, cities with broadly comparable characteristics. The term ‘oncologists’ was understood to refer to physicians diagnosing and treating cancer, not merely carrying out the screening (which, of course, can often involve treatment too).<sup>2</sup>

I also aimed for roughly equal numbers of male and female interviewees. For each group of five physicians, I sought to recruit at least two who care for patients with predominantly low socio-economic status, two with high socio-economic status, and one with patients who had a medium status. Exclusion criteria were: first, physicians practicing wholly or partly alternative medicine, homeopathy or other forms of medicine that stand in some tension to the paradigm of evidence based medicine; second, individuals who had already formed an explicit opinion and were known for their views in the press or academic literature. The total target number of 20 may appear low, but is not uncommon for this type of research.<sup>3</sup> The first set of interviews was carried out with German primary care physicians, and the mode of recruitment was refined in light of the experiences, as set out at Appendix 5A which describes the method of recruiting physicians via professional organisations, snowball sampling, and profiling the socio-economic profile of residents in the respective practice areas. Table 5.1 provides more detail on the characteristics of interviewees who participated in the research.

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<sup>2</sup> The rationale was twofold. First, it was to ensure that physicians would be as familiar as possible with the epidemiology and treatment options of colon cancer, as well as the cost implications. Second, a controversial feature of the German policy relates to the role of physicians in reporting patients who refuse treatment, and it was intended to hear from oncologists who would face a realistic chance of finding themselves in such a situation.

<sup>3</sup> See, for example: Aira, Marja, Jussi Kauhanen, Pekka Larivaara, and Pertti Rautio. 2003. Factors influencing inquiry about patients’ alcohol consumption by primary health care physicians: qualitative semi-structured interview study. *Family Practice* 20 (3):270–275, (35 physicians); Fröjd, Camilla, Claudia Lampic, Gunnar Larsson, Gunnar Birgegård, and Louise von Essen. 2007. Patient attitudes, behaviours, and other factors considered by doctors when estimating cancer patients’ anxiety and desire for information. *Scandinavian Journal of Caring Sciences* 21 (4):523–529, (19 physicians); Guerra, Carmen, Samantha Jacobs, John Holmes, and Judy Shea. 2007. Are Physicians Discussing Prostate Cancer Screening with Their Patients and Why or Why Not? A Pilot Study. *Journal of General Internal Medicine* 22 (7):901–907, (18 physicians).