From:

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Health Promotion and Prevention Programmes in Practice
How Patients’ Health Practices are Rationalised, Reconceptualised and Reorganised


The shift to prevention and health promotion is an example of how policy makers aim to rationalise and organise both health systems and patients’ health practices. By applying a perspective from empirical science & technology studies (STS), based on qualitative research methods, this book presents a view behind the scenes and zooms into the micropolitics of prevention and health promotion. It analyses how patients are framed as being »at risk«, how preventative regimes shape medical practices, and what its practical consequences are in patients’ everyday lives. This makes the insights of this book relevant for prevention and health promotion practitioners, public health policy-makers and researchers.

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CONTENTS

Acknowledgements 7

Introduction: Health Promotion and Prevention Programmes in Practice 9
TOM MATHAR, YVONNE J.F.M JANSSEN

Prologue: Preventing Alzheimer’s Disease: Health, Ageing and Justice 29
TIAGO MOREIRA

Will the Entire Population be Overweight by 2230? Common Sense, Scientific Consensus and the "Obesity Epidemic" 53
ISABEL FLETCHER

Prevention as a Side Effect? Distributing Trial Participants in a Pharmaceutical Drug Trial 83
PETRA JONVALLEN

Configuring Professional Identity – a Way to Renegotiate Good Care 105
KATIA DUPRET SØNDERGAARD
Preferences versus Capabilities: How to Improve the (Future) Quality of Life for Women with Abled and Disabled Children 129
MARLI HUIJER

The Taming of Chance and the Actual Practice of Prevention; Rationalised Prevention and the Social 147
YVONNE J.F.M. JANSSEN

Body-Identity Trajectories of Preventive.Selves++ 171
TOM MATHAR

Epilogue: Translating Experience into Biomedical Assemblages. Observations on European Forms of (Imagined) Participatory Agency in Healthcare 195
STEFAN BECK

List of Contributors 223
Acknowledgements

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*Thomas Mathar and Yvonne J.F.M. Jansen*

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In the last ten years or so, prevention and health promotion have gained attention in the policy domain throughout European countries. The «National Service Framework for Coronary Disease: Winning the War on Heart Disease» from England’s Department of Health or a prevention law planned by German policy makers that would force health-insurance companies to invest more money in prevention are both examples of this trend. This emphasis on prevention can also be observed outside of Europe: the recently elected US president Barack Obama, for example, repeatedly stated that disease prevention and health promotion should be made a cornerstone of any healthcare reform.

This book begins by asking why such attention is currently focused on disease prevention and health promotion. For years public health experts have argued for more attention to prevention and health promotion as the public’s health is best served through prevention and health promotion. But for a long time this message has remained unheard. Why is it that initiatives aimed at avoiding the development of diseases or activities meant to prevent the emergence of certain symptoms are now taken up by policymakers? We contend that there are manifold
plausible explanations for this development and all reflect changes in societal thinking or an emerging shift in the overall discourse on public health in policy, media and everyday life. One of these explanations is that prevention and health promotion can be regarded as an economic necessity. Ballooning costs in many Western healthcare systems are often seen as caused by a specific demographic development: the number of elderly people in most Western societies is increasing and so is their rate of morbidity. The demand for health care in general, and particularly care specific to the elderly (de Hollander, Hoeymans et al. 2006), is therefore expected to grow. Similarly and related, the rise in the number of people with chronic illnesses is statistically significant and also understood to be a major financial burden on healthcare systems. The increased emphasis on prevention and health promotion, with their goals of achieving healthier lifestyles, can be seen as a consequence of the overall aim to keep healthcare systems affordable (Hunter 2003).

Another explanation of the trend towards prevention and health promotion is the explosion in epidemiological knowledge of certain diseases and chronic illnesses in the past decades (May 2009), which has gradually entered the policy arena. Public health, one of the disciplines that produces and operates with this kind of knowledge, according to Coughlin and others (Rychetnik, Frommer et al. 2002; Coughlin 2006) what we – as a society – do collectively to assure the conditions in which people can be healthy. As it is primarily concerned with the health of the entire population, rather than the health of individuals, its features are among others the collection and use of epidemiological data, population surveillance and other forms of empirical quantitative assessment (Childress, Faden et al. 2002). On the basis of statistical and epidemiological evidence, public health experts create prevention and health promotion programmes and public health policies that are directed at specific groups in society and aim to promote specific lifestyle activities among these groups (Childress, R.R. et al. 2002; Shim 2005; Coughlin 2006). Public health involves various strategies to encourage healthier behaviour amongst populations. These strategies range from bans (e.g. on smoking in public spaces in many European countries), changes in the availability of public goods (e.g. fluoridation of drinking water in the US), informa-
tion campaigns (e.g. on cholesterol and healthy eating habits in the Netherlands), to financial incentives (e.g. discounts on health insurance payments). Although a very invasive and restrictive public health measure, smoking bans are a popular example of the operation of epidemiological knowledge and public health policy. Smoking bans in workplaces and/or in other public spaces are enacted in order to protect people from effects of environmental tobacco smoke. This widely established policy follows epidemiological studies that reveal a strong correlation between passive smoking and lung cancer mortality: in other words, passive smokers have a higher risk of dying from lung cancer and this risk increases with an increasing exposure to environmental tobacco smoke. In this example, as well as in other prevention programmes, epidemiology’s and public health’s specific concept of risk is crucial: making claims on risk usually means drawing on a broad set of data and probabilities on that will define what illnesses will occur in society. It also involves making claims about the economic burden deriving from high rates of these illnesses (Carter 1995). Such an understanding of risk therefore allows for populations to be screened and diseases to be systematically detected in advance of their onset (Armstrong 1995; Howson 1998). In other words, information on health risks makes it possible to select ›at risk‹ populations with the aim to improve their health status and – at the same time – reduce the financial burden on society.

Currently, since cardiovascular diseases are considered to be important public health problems, a large number of prevention programmes target groups that are ›at risk‹ of suffering from these diseases, i.e. those affecting the heart or blood vessels such as atherosclerosis, angina pectoris, congestive heart failure, or coronary artery disease. Although there is still debate about the importance of particular risk factors and their thresholds, it is widely accepted that in order to prevent such diseases, some of their risk factors can be modified by healthy eating, physical exercise, and the avoidance of alcohol and smoking. Since cardiovascular disease prevention programmes have recently been expanded, and sometimes re-labelled, in order to tackle what is perceived by many as an ›epidemic‹ of obesity (James, Learch et al. 2001), four chapters of this book focus on these conditions.
A third and final explanation for the trend towards prevention and health promotion is the emergence of a new moral regime, which permeates current prevention and health promotion initiatives. Many sociologists studying prevention and health promotion have indicated that the most distinctive feature of today’s prevention and health promotion programmes is their emphasis on the facilitation of healthy lives (Bunton, Nettleton et al. 1995a; Burrows, Nettleton et al. 1995). In order to have individuals change their lifestyles, prevention and health promotion not only address individuals directly, they also encourage the creation and implementation of ‘healthy public policies’ on the basis of socio-economic structures (Burrows, Nettleton et al. 1995). As a result, these sociologists have argued that prevention and health promotion programmes reflect as well as foster changes in the patterning of solidarity and the distribution of responsibility. Thus, they implicitly carry a strong moral programme towards an individualisation of health care responsibility. Others have argued that a new discourse is unfolding in which the autonomous individual is taken out of the equation and health is understood foremost as the State’s responsibility. They argue that, despite all prevention efforts, individuals (i.e. the rediscovered lower classes) are not capable of changing their lives. Because of this, they claim, the State has to – by modifying their physical environments (e.g. stairs instead of escalators and childhood obesity prevention programmes) – direct individuals in such a way that good health is not a matter of choice (Niewöhner and Kontopodis forthcoming).

Even though these three explanations of the growing emphasis on prevention and health promotion have been presented as independent processes, they can also be regarded as interrelated. In his historical analysis on the relationship of politics and statistics, Desrosières (2002) has shown that scientific evidence is not only a tool for proof, but also a tool for governance, coordinating many social activities and legitimising specific political activities. In this sense, the aforementioned use of epidemiological and economic data for prevention and health promotion initiatives and public health policies not only indicate financial and health problems. They also indicate and motivate new values and moral judgements in society. The reader
will encounter this thesis explicitly and implicitly at many points in this book. Sometimes it is argued that a neoliberal moral system is at stake (Rose 1996), because a neoliberal concept of how social problems should be solved can be observed: many prevention programmes are not based on the assumption that diseases should be fought by collective responsibility, but by the activities and duties of individuals. The many prevention programmes aimed at altering the *individual’s lifestyle* fit with this thesis. In many prevention programmes, people are expected to actively manage their health with lifestyle modifications, self-surveillance and bodily restraint – these are then considered the morally right thing to do. They are expected to become what has been described elsewhere as *preventive selves* (Niewöhner 2007). If (good) health is to be a matter of self-control, it is implied that one is responsible for future illnesses, if one does not use the scientific health risk information provided to change one’s lifestyle (Lupton 1993b; Lupton 1993a; Lupton 1997; Bodenheimer, Lorig et al. 2002).

In conclusion, the trend towards prevention and health promotion observable in most Western societies can be interpreted as a change in the state-subject relationship. It can be interpreted as governments’ need to redistribute its responsibilities for the allocation of scarce resources in systems of social provision. However, with the perceived overextension of these responsibilities for the state and the subsequent rise in government expenditures, governments now tend to reallocate the responsibility for health and healthcare back to citizens with the aim to keep healthcare systems stable. This new state-subject relationship can be seen as a consequence of new *reflexive practices* (Collier and Ong 2005) and, thus, as a consequence of certain economic trends related to a demographic transitions, as a consequence of the explosion of epidemiological and public health knowledge of »chronic« diseases and as a consequence of the previously outlined new moral regime. Importantly, these trends are not separate from each other but interwoven and interrelated.
Studying practice

The ultimate aim of this book is to study health promotion and prevention programmes in practice. The aforementioned macro-social trends might explain a shift towards prevention and health promotion. They have been investigated in discourse and policy analyses; however, these trends are also manifested in specific patterns of practice on a micro-level. The scope of this edited volume consists in investigating these changing patterns of practice that are situated in specific contexts, discourses and actor-networks. It looks at the micro-level, at the specific contexts within which prevention is being done, framed or produced. By highlighting the two words »in practice« this book asks: how do certain prevention programmes work? How are they being conducted? It is not so much concerned with prevention as a rationale or as a culture but as something in action; it is concerned with doing prevention. In this sense, this book follows what has been called a ›practice turn‹ (Savigny, Schatzki et al. 2000):

>Although practice theory does not constitute a unified corpus, most of these scholars are joined in the belief that practical regimes constitute the horizon within which unreflexive reactions, actions, utterance, linguistic acts, behaviours, and routine conduct acquire meaning. Practice consists of all these elements but cannot be reduced to any of them. Practices and the complex nexuses of local and global interdependencies which they tend to form […] constitute therefore a phenomenon that needs to be studied in its own right.« (Nicolini 2007: 892)

By studying the actual practice of administering health promotion and prevention programmes to individual patients – the micro-level – this book aims to provide a different perspective than that of economists and public health experts. Doing prevention demonstrates how individuals are (re)configured as, say, ›patients at risk‹, as future-oriented selves or as test subjects in clinical trials. It further shows how health care professionals are reconfigured through the tensions between treatment ideals and their local enactment and how relevant categories such as obesity are never stable entities but rather fluid and shifting objects. In fact, by focussing on doing prevention, the book aims
to demonstrate the multiplicity of these programmes. It presents partialities, instabilities and situatedness. In this book, the in-depth analyses of prevention and health promotion initiatives therefore focus on the relational character of these initiatives.

It is precisely this focus on practice and the processual-relational perspective which makes this book a matter of science & technology studies (STS), or what this book series – VerKoerperungen/MatteRealities – terms empirical science studies. Empirical science studies is a relatively young field of research and has become institutionalised to some degree in Anglo-American countries. From its beginning in the 1970s, it has taken medicine as a field of investigation, although it has made different contributions than, for example, medical sociologists. Even though there is no clear distinction between the disciplines of empirical science studies, medical sociology and medical anthropology, there are some gradual differences that can be outlined: for example, medical sociologists are mostly concerned with the social dimensions around health and illness. They analyse how chronic diseases are being managed at home, what effect a disease can have on individual’s identities, how migrants interpret Western biomedical concepts, etc. By highlighting these aspects, medical sociologists and anthropologists have often criticised the medical system for being paternalistic or objectifying. They find fault with the powerful ›medical gaze‹ (Foucault 1973) that suppresses either lay beliefs or nurses’ perspectives, and have also criticised other interactional asymmetries and conflicts that may occur where science meets society. Very often, medical sociologists have – for many reasons – placed themselves in opposition to medicine without necessarily engaging with medicine.

In contrast, scholars from empirical science studies and medical anthropology, focussing on practice and interested in medicine, health and illness, have not necessarily been less critical of medicine; however, they have tried to overcome certain approaches of earlier scholars by taking the internal dynamics and logics of medicine in practice seriously. For this they engage in what they term symmetrical approaches. In the next section we discuss how the of a »symmetrical approach« has been fiercely debated by two different schools: the Strong
Programme and actor-network theory. However, both highlight the importance of taking seriously what scientists do, and how and why they do it. A current example for a symmetrical approach is Stefan Timmerman’s and Steven Haas’ argument for a »sociology of disease« that overcomes the approach of »sociologists of health and illness [who] have argued for an expansion of social factors in health but have ignored diseases that form the basis of much of the interventions« (Timmermans and Haas 2008: 671). Similarly, in his epilogue to this book, Stefan Beck lays out the importance of symmetrical approaches in a perspective he terms »relational anthropology«. Put simply, these approaches have in common that they aim to engage with health care professionals by taking what they believe to be relevant into account (e.g. medical facts such as biomarkers or metabolic systems).

The contributors of this book all met for the first time at the annual meeting of the European Association for the Study of Science and Technology in Rotterdam in August, 2008, entitled »Acting with science, technology and medicine«. For the organisers of this conference, the notion of »acting with« was crucial and its importance was explained in the call for papers of this conference:

»This meeting responds to some remarkable and interesting changes in the concerns of STS research. STS-approaches are no longer only relevant for understanding the production of science, technology and innovation; they also are relevant for understanding the co-production of science and technology with policy, democracy, law, and the organization of health care, among other major institutional matters. Similarly STS researchers have become increasingly involved with practices of technology development, policymaking, legal decision-making and governance in different fields, such as science and technology policy, environmental regulation, and health care. The balance between observation and participation seems to have changed in these consequential practices of »acting with«.

In the context of the »health promotion and prevention programmes in practice« session – and in the context of this book – that meant that an explicit aim was not to stand apart and evaluate a certain initiative from a distance; rather, this book tries to come closer to the medicine/epidemiology/economy
platform (Keating and Cambrosio 2003) that has emerged in recent times and is consequential in peoples’ everyday lives. The aim of this book is threefold:

*Which knowledge?* This question is not only concerned with historical shifts in the medical conceptualisations underlying certain health promotion and prevention programmes. It is concerned with the question of which actors’ social worlds, or »going concerns« (Hughes 1971) come together when creating knowledge about certain diseases. Again, the focus on the practice of *doing* knowledge production not only demonstrates discursive figures but also highlights which interactions between which regimes of practice are taking place.

*Which social practice?* Another focus of this book is directed towards the people for whom certain prevention programmes are designed. Here, the question is not only how people make sense of epidemiological data given to them, but also what the practical consequences of this data are, either in terms of peoples’ identities and self-understandings or their interactions with health professionals. Following Latour (Latour 1994) and other scholars from actor-network theory, this question is concerned with the mediation and translation of scientific knowledge and everyday practices.

*Which enactments?* A focus on enactments of prevention allows us to capture the diverse, ontologically different elements that come together in this field. Importantly, this very often means paying special attention to the materialities (i.e. technologies, artefacts and bodies) involved in both knowledge production and application. Studying enactments, as will be elaborated below, is an important perspective when studying the practice of administering health promotion and prevention programmes: it provides insights into who is actually *doing* prevention, as well as how different actors/actants determine and (re)configure other actors, routines, activities and identities respectively. Importantly, studying enactments also brings together knowledge production and everyday life as interwoven rather than understanding them as clearly separated realms.

The overall aim of this book, then, is to contribute *reflexive knowledge* to the field of prevention and health promotion in the way Ulrich Beck (1992) has suggested. By presenting empirical examples of actual practices of prevention and health promo-
tion, this book tries to present a *behind the scenes* view of and on prevention and health promotion rhetoric and practice that otherwise would have remained invisible. By explaining the invisible and unreflected practices of prevention and health promotion initiatives, this book provides insights that can inform the work of prevention and health promotion practitioners, public health policy-makers and prevention and health promotion researchers. With this book, a modest attempt is made to urge the field of prevention and health promotion to be (more) reflexive of developments in society and the form this takes in actual prevention and health promotion initiatives. It thus attempts not only to formulate a critique of prevention and health promotion, but wants to show the diverse reflexive practices interacting with it and reflect upon the consequences on the micro-level.

**Doing prevention: overview of the book**

The chapters in this book address the practice of prevention and health promotion empirically, albeit from different perspectives within empirical science studies.

The first chapter explores how obesity has been framed and reframed during the last six decades. Isabel Fletcher, who conducted this historical study by analysing policy documents, scientific papers, and technical reports released by the WHO, dedicates her attention to a phenomenon that has gradually become more problematic since World War II. Statistics show rising obesity rates in almost all Western countries; her title reflects this by citing the concern of an American scientist that the entire population might be obese by 2230. In fact, obesity is currently being regarded as one of the major risk-factors for cardiovascular disease, diabetes mellitus type 2, obstructive sleep apnea, and osteoarthritis (Poirier, Giles et al. 2006). Many health promotion and prevention programmes therefore aim at reducing obesity rates, and they do this especially by promoting a »healthier« lifestyle: one involving physical activity and balanced nutrition. In her chapter, Isabel Fletcher shows that not only in these programmes but in the category »obesity« itself there is a rationale, or what she calls – referring to Thomas Kuhn (1970)
a paradigm which has shifted over the past decades. For example, prevention programmes promoting a healthier lifestyle actually presume that too much weight can actually be remedied by individuals themselves. As she demonstrates, this paradigm has, however, been heavily questioned within the sciences that also acknowledge, say, societal factors related to obesity. As do many studies using a symmetrical approach suggested by scholars from the Strong Programme (Bloor 1976b), Fletcher shows that what counts as obesity is always the product of activities and practices of social actors who can never be said to be »modest witnesses« (Haraway 1997) of truth.

In recent shifts in science and technology studies, it is precisely this concept of symmetry that has been challenged by other sociologists. In what can be called »radical symmetry«, scholars working with actor-network theory (Callon 1986; Latour and Woolgar 1986) argue for a systematic acknowledgement of the non-human (materials, technologies, objects). By drawing on the achievements of the Strong Programme, actor-network theory’s enlargement into a »generalised symmetry« calls for, to put it abstractly, a symmetric analysis of semiotics and materiality. It is not only important to focus on the social construction of, say, scientific facts, but also the materials involved in this process. An important actor-network study, one that is also cited frequently in certain chapters of this book, is Annemarie Mol’s »the body multiple« (2002b) which is concerned with atherosclerosis, a chronic syndrome affecting arterial blood vessels. Mol looks at various observable practices and studies how atherosclerosis is treated at different sites in a certain hospital (e.g. by different medical experts) and which technologies are involved in this (x-rays, microscopes, etc.). By taking practices as the paramount unit of analysis and hereby considering what both actors and actants do, she lucidly demonstrates that in this hospital, multiple atherosclerosis’ coexist.

Studying such kinds of multiplicity is also at the heart of the chapters two and three. Petra Jonvallen is concerned with contract research organisations whose business is to recruit what are called »naive« and »newly debuted« participants for randomised controlled trials in which drugs on obesity and diabetes are tested. In her ethnographic study, however, Jonvallen is not analysing the multiple ontologies of obesity and diabetes.
Rather, she is studying the multiple categories of trial participants. This perspective enables her to reflect on the current tendency of clinical trials to shift from a research programme to a prevention programme on behalf of public health care practitioners. Her title »prevention as a side effect« captures this rather ironic, though not unproblematic trend. Importantly, besides discussing this empirical finding, Jonvallen enlarges Mol’s approach by reflecting on structural elements in fluid spaces, something Mol and many other studies in science and technology studies have not done. Jonvallen argues that this enlargement enables us to also reflect on structural transformations of healthcare systems and ask whether the trends observed are beneficial to the healthcare system’s beneficiaries, i.e. its patients.

Katia Dupret Søndergaard uses actor-network theory inspired theses and concepts when studying ›Open Dialogue‹, a treatment approach and prevention programme used in psychiatry primarily for patients with schizophrenia. In her chapter, this alternative to traditional, state-funded psychiatric approaches is not the object of a critique: ›Open Dialogue‹ reflects many social scientists’ critiques of medicine and psychiatry in that it applies strategies meant to avoid paternalism or an objectification of the patient, thereby establishing a patient-centred practice. It does not assume any hierarchies between the different actors involved in the treatment process. In this sense, ›Open Dialogue‹ can be understood as a post-modern treatment approach. However, by drawing on what Latour (1993) calls an a-modern approach, Dupret Søndergaard demonstrates that the application of the ideals of ›Open Dialogue‹ is quite difficult to achieve in practice. In seemingly banal situations, psychiatric staff try to engage in ›Open Dialogue‹ ideals and these ideals are challenged and transformed. In a thick description of three empirical episodes, explicitly taking non-human actants into account, she shows what post-modern criticism should acknowledge when designing prevention programmes and treatment approaches.

Chapter four by Marli Huijer also deals with the problem of choice and patient empowerment though from a different angle. Her focus is on the temporal presuppositions underlying the preventive character of prenatal genetic and chromosomal testing or, put differently, how time concepts become inscribed
in prevention programmes. Her starting point is the finding that in contemporary prevention programmes not only people’s health is taken into account but also their future quality of life. The protection of an individual’s future health is balanced against the impact this protection has on his or her current quality of life. Huijer postulates that it is difficult if not impossible for individual women to know what impact the care of a child with or without congenital defects can have on their future quality of life. The more philosophical issue is how to view women’s quality of life with a child in a temporal perspective. In line with Martha Nussbaum’s version of the capabilities approach, she argues that women’s future quality of life is better served by prevention and health promotion programmes that guarantee fair equality of opportunity to all newborns, whatever their abilities and needs, than by programmes that fulfil women’s present-day preferences for potential but as yet unknown futures.

While Huijer’s chapter is discussing her point from a philosophical point of view, Yvonne J.F.M. Jansen is giving an empirical example of how patients receive agency and how they co-constitute the shape of prevention programmes in practice. In chapter five, Jansen argues that prevention and health promotion programmes have a double obligation. On the one hand, she argues – referring to (Hacking 1990) – that prevention and health promotion have a rationalistic and deterministic character, that submits individuals to an increasing control and intervention upon their health and presumes the relation between health risk information and the actual health of individuals to be causal. On the other hand, by using concepts from the sociology of technology on the mutual shaping of technology and society for the analysis of her ethnographic material, she shows that the practice of prevention programmes is shaped by how health care professionals relate prevention regimes to individual patients, to their daily circumstances and how this is shaped by the extent of patients’ participation and conformation to such regimes. Jansen therefore argues that with lifestyles and health behaviours being the targets, contemporary prevention and health promotion are no longer solely about transferring the responsibility for good health to patients,
it is also about accepting ‘the social’ as basic ingredient of prevention and health promotion practices.

The importance of acknowledging patients’ perspectives is also emphasised in Tom Mathar’s chapter. Mathar studied patients with heart failure who are enrolled in a prevention programme using information- and communication technologies to monitor patients’ risk parameters. In his analysis, he also pays special attention to the non-human which, in his case, means the reflection of numbers and indicators that patients encounter when, for example, taking their blood-pressure. With his focus on patient-number/indicator interactions, he begins to synthesise some of the aforementioned concepts and theses by positioning himself as part of recent interactionist science and technology studies (Clarke and Star 2008). This means that he follows a line of reasoning which, on the one hand, reflects the epistemological roots of philosophic pragmatism and symbolic interactionism while, on the other, inserting some of the major theses and concepts of actor-network theory. Importantly, interactionist science and technology studies are less concerned with multiple materialities (such as the chapters of Jonvallen and Dupret Sondergaard) as with multiple perspectives (Mol 1999). This focus leads him to the construction of two types of patient profiles which he labels the preventive self and the »preventive.self++. He argues that it is especially the latter that are a challenge in current health policies since their practices are not congruent with the concept of patienthood that is inscribed in many prevention programmes.

While the first six chapters are all concerned with micro-perspectives and micro-politics, the prologue and epilogue to this book deal with broader questions clustering around health promotion and prevention programmes. The starting point of Tiago Moreira’s prologue is a reflection of the theses of philosopher Norman Daniels, who argued for a right to health care. He was specifically concerned with age discrimination and intergenerational justice and highlighted the importance of reflecting about the relationship between the ‘performance of justice’ and the ‘knowledge of ageing’. Moreira takes up these arguments. However, on the basis of his empirical data he shows that this relationship is differently enacted in various sets of arrangements. Using Mild Cognitive Impairment (MCI) as an
example – a diagnostic category that tries to capture a diffuse stage between cognitive ageing and dementia – he discusses how the concept of MCI configures times (the plural is crucial), and how these result in divergent ideals of justice. When presenting MCI first as a «risk factor» (for persons who might suffer from Alzheimer Disease), secondly as a «economic object» (i.e. as something that must be tackled for financial reasons), and thirdly as a «label» (i.e. a category that does not necessarily bring bad, but might bring dangerous consequences for those classified as cognitively impaired) he shows how the category of MCI is differently entangled within various attributes of current strategies to organise health care. Insofar, Moreira gives a concrete example of how the multiple, above-mentioned new reflexive practices present themselves in research, policy and management. Importantly, these different forms of knowing the process of ageing inherently transport ethical assumptions because they make claims on what «normal ageing» actually is. Moreira wonders if all these ethical regimes really do justice to the elderly and gives a striking example of what might be taken into consideration when organising alternative, «just» allocations of resources.

In his epilogue, Stefan Beck follows Clarke et al. in investigating patients’ perspectives on what can be called the process of «biomedicalisation» – i.e. the process in which medicalisation is increasingly accompanied by consumerism, developments in biotechnology, and managed care markets. Reflecting on empirical data gathered from an EU-wide research project, he argues that sufferers’ experience can make valuable contributions to current healthcare systems. Many health care systems do not incorporate patients’ experiences; working with individual activists or patient groups enables people working in healthcare to better meet the sick persons’ needs. Beck realises that this sort of reflective knowledge can be «budgeted» by decision-makers to, in his words, let volunteers «fill the gap» between medical knowledge and everyday life. However, these volunteers (as both individuals and collectives) engage in important relational work while translating the patients’ experience into the biomedical dispositif or assemblage. Not only do they challenge clear-cut distinctions between perception and knowledge, experience and expertise, cognition and interest and, by exten-
sion, the categorical division between the ontological zones of medicine and social sciences. Their work also contradicts the notion of information and knowledge underlying most prevention programmes. Beck concludes that just such a relational approach might allow what could be called reflexive prevention, health promotion and health policy.

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INTRODUCTION


