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Twee sterke vrouwen

koppige doorzetters

om naar op te kijken



# **Let's (not) talk about health and illness**

**A qualitative study into Belgian health-policy stakeholders  
through elite interviews and discourse analysis**

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## List of publications and manuscripts

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# **PART I: General introduction and background**

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## CHAPTER 1: Introduction

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Where health and illness were once considered as the domain of medical professionals, today's picture is more complex (Pereira Gray, White & Russell, 2016). Scott and colleagues (2000, p.1) argue that:

'We are confronted with much that is new: new technologies, new ways of delivering services, new mechanisms of paying for care, new types of healthcare organisations and cooperative and competitive relations between them, new regulatory systems (as well as deregulatory processes), new players in the sector, and new assumptions and beliefs governing healthcare'.

In this dissertation, I focus on this complex healthcare field and the various stakeholders involved. More specifically, I analyse what various stakeholders say about health and illness in their professional and official communication and I analyse how these definitions of health and illness are related to the interests and position of these actors within the healthcare field. In contrast to previous studies who mainly focus on one aspect (i.e. actor or field), I focus on actors as well as on the larger context of the healthcare field in which these actors operate. Actors are the various stakeholders that are nowadays involved within the healthcare field, such as pharmaceutical companies, patient organisations, and the news media (Conrad, 2005; Metzl & Herzig, 2007). The healthcare field refers to a social space that is structured around the network of relations and struggles between these stakeholders within the healthcare domain (Collyer, Willis, Franklin, Harley, & Short, 2015).

It is important to focus on both aspects since the stakeholders within the healthcare field have become increasingly diverse (Clarke, Shim, Mamo, Fosket, & Fishman, 2003) which has made the interactions between these stakeholders more difficult and

has complicated meaning construction within the healthcare field (Briggs & Hallin, 2016). The rise of patient organisations, for instance, has brought new forms of expertise to the healthcare field (Baggott & Jones, 2014a; Busfield, 2010; Moreira, 2015). Having better-informed patients with higher expectations has complicated the relationship between medical professionals and patients, as patients started to develop their own conceptions of health and illness and adopted experiential models of health (Clayman, Bylund, Chewning, & Makoul, 2016; Dew, Scott, & Kirkman, 2016; Fox & Ward, 2006). News media also increasingly report on health-related issues and rely on health professionals in order to do so, resulting in a complex process of co-production of health news (Briggs & Hallin, 2016; Declercq, 2018a). Consequently, meanings on health and illness are not produced and dominated by one single stakeholder. The healthcare field is occupied by various sources of health information that all have their own agenda. As a result, a wide and diverse range of discourses on health and illness are circulating within the healthcare field (Metaforum, 2015). Clarke and colleagues (2003) refer to this development as the heterogeneity of production, distribution, and access to (biomedical) knowledges. Therefore, if we really want to understand how these discourses have an impact on our knowledge of health and illness, and thus ultimately on our health itself, we have to develop a more comprehensive approach.

Researchers within medicalisation studies have already argued that the involvement of new drivers of medicalisation has redefined the medicalisation process (Bell, 2017; Bell & Figert, 2015; Busfield, 2017; Conrad, 2005). However, they have not been able to fully chart the diversity and multidimensionality of this process. Here Bourdieu's field theory (1983) offers a conceptual framework that allows researchers to chart the



interrelations between the various stakeholders involved in the healthcare field, which makes it possible to study how this relates to the discourses on health and illness of these stakeholders. Although field theory is not new (Bourdieu, 1983), it has only recently been applied to aspects of healthcare (e.g. Brown, Crawford, Nerlich & Koteyko, 2008; Collyer, 2018; Kurunmäki, 1999; Wagner, Polak & Świątkiewicz-Mośny, 2018). For instance, Collyer, Willis, and Lewis (2017) investigated how knowledge is used and acquired within the healthcare field. Another example that applies field theory to aspects of healthcare is the study of Brown and colleagues (2008). They analyse how nurses draw on discourses on the importance of infection control and hygiene to construct and maintain the boundaries of the healthcare field.

Drawing on a discourse-analytical approach, the main objective of this dissertation is twofold:

- ◆ I want to gain more insight into *how* various meanings of health and illness are constructed and negotiated by stakeholders within the healthcare field.
- ◆ I want to investigate *the impact* of these discourses on the healthcare field and knowledge production within this field.

These objectives are translated into specific research aims in Chapter 4 where they are analysed within the context of the Belgian social health insurance system. The involvement of various stakeholders within this system makes it an interesting case-study to investigate the fragmentation of the healthcare field and the diversity of discourses on health and illness. Before going into all of this, I start by outlining my **theoretical framework**. In Chapter 2, I discuss how meanings of health and illness come into place. In order to do so, I draw on previous research within medicalisation

studies (Figert, 2011), as at the heart of these studies is a focus on meanings of health and illness and the various stakeholders involved. The second part of my theoretical framework focuses on how these stakeholders are involved in the construction of discourses on health and illness. Here, I draw on Bourdieu's notion of a field and explain why it is useful to conceptualise healthcare as a field (Chapter 3). After discussing my theoretical framework, I describe the **research aims** of this dissertation (Chapter 4) and provide an extensive discussion of my **methodology** (Chapter 5). These research aims are translated into four **empirical chapters** (Chapters 6-9). First, Chapter 6 maps the various stakeholders involved in the Belgian social health insurance system. Second, after this general overview, I focus on two stakeholders, i.e. sickness fund agencies and the pharmaceutical industry, in order to be able to perform a more profound analysis of how these discourses on health and illness come into place (Chapter 7 and 8). Third, Chapter 9 deals with field relationality. As the social world consists of various fields, it is necessary to place the healthcare field within this larger context and analyse the intersection of the healthcare field with other fields, in this case the journalistic field. Finally, in my **conclusion**, I review the main findings, discuss the limitations of the study, formulate suggestions for further empirical research, and discuss the societal implications of this dissertation (Chapter 10).

## CHAPTER 2: The construction of discourses on health and illness

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This chapter provides an overview of the literature on medicalisation. Moreover, it discusses the evolutions within this research domain, and it discusses the construction and expansion of definitions of health and illness. The chapter illustrates how the medicalisation process has become increasingly complex and relational through the involvement of various stakeholders.

### 2.1. Once upon a time... a brief history of medicalisation

*'Medicalisation describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders' (Conrad, 1992, p. 209).*

#### *The emergence of medicalisation*

The concept of medicalisation emerged in the 1960's in the United States and the United Kingdom as a social critique on the expansion of medicine and its conceptual model (Davis, 2010; Nye, 2003). These scholars claimed that the boundaries between health and illness are social constructions, and that these boundaries are defined by medical professionals and medical discourse (Busfield, 2017; Conrad & Barker, 2010; Nye, 2003). This social critique can be divided into two traditions (Clarke & Shim, 2011; Crawford, 1980; Davis, 2010). First, the concept of medicalisation was used to critique the medical profession and its dominant position in society (Ballard & Elston, 2005; Figert, 2011). According to Freidson (1970, p. 251), medical professionals use their expertise to decide on 'what it is that shall be called illness'. Hence, the main focus of this first tradition was on institutionalized medical dominance, authority, and their (adverse) consequences. Ivan Illich (1976) – probably one of the most notable of these critics – referred to these adverse consequences as iatrogenic or

sick-making (see also Christiaens & van Teijlingen, 2009). Illich (1976) distinguishes between three types of iatrogenesis: clinical (i.e. complications and ineffective treatments), social (i.e. consequences of the 'sick role' and the depoliticising of social problems), and structural (i.e. loss of autonomy and dependence on medicine). Foucault's earlier work (1965; 1973) can also be placed within this first tradition. He focused on medical control, medical surveillance, and the power of medical professionals. Later on, he started to focus more on medical discourse and practices and how they regulate patient's lives (Davis, 2010).

The second tradition adopts a broader view on medicalisation. Building on Parsons' (1951) notion of the 'sick role' and labeling theory, medicalisation was used to critique the expansion of medicine's jurisdiction into other domains of life (Christiaens & van Teijlingen, 2009; Conrad, 1992; Davis, 2010). According to these scholars of the second tradition, the expansion of medicine results in defining previously nonmedical problems as deviant and in need of medical treatment, which does not necessarily mean the involvement of medical professionals (Ballard & Elston, 2005; Conrad & Schneider, 1980; Conrad, 1992; Szasz, 1960). The scholars of this second tradition assume that there will be a 'pathologicalisation of everything' (Conrad, 2013, p. 207; Zola, 1972, 1975). Zola (1972, p. 487) argues that 'medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institution of religion and law'. He perceives medicalisation as an insidious and infinitely expanding process that makes 'the labels "health" and "ill" relevant to an ever increasing part of human existence' (Zola, 1975, p. 83).

The work of Peter Conrad (e.g. 1975, 1992, 2005, 2007) can also be situated within this second tradition. His work has strongly influenced the work of medicalisation

scholars (Halfmann, 2012; Williams & Gabe, 2015). Conrad's (1992) definition of medicalisation is probably the most popular and most widely accepted definition (Bell & Figert, 2012). He states that:

'Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it' (Conrad, 1992, p. 211).

Conrad and Schneider (1980, p. 75-76) distinguish between three levels on which medicalisation can occur: the conceptual (i.e. use of medical vocabulary), the institutional (i.e. organisations adopt a medical approach), and the interactional level (i.e. medical professionals define a problem as a medical problem and/or offer a medical treatment). Conrad (2007) also describes the social consequences of medicalisation, which can be positive and negative. A benefit of medicalisation is that it allows for the recognition of certain diseases and may reduce individual blame and stigma (e.g. alcoholism or chronic fatigue syndrome). Medical treatments can also significantly improve the quality of life and life opportunities of individuals (Conrad, 2007). However, there are also several consequences of medicalisation that are rather troubling. First, there is the pathologicalisation of everything. Conrad (2007, p. 148) argues that 'the transformation of many human differences into pathologies diminishes our tolerance for and appreciation of the diversity of human life'. Second, medical treatment is increasingly seen as what is normal and expected, which results in a sort of moral imperative on how one should deal with these problems. Third, Conrad (2007) argues that medicalisation leads to the expansion of medical social control. Fourth, medicalisation can result in the individualisation of social problems. This means that instead of focusing on the social causes of certain

problems, the individual is treated and the social causes of these problems remain unresolved. Fifth and finally, medicalisation has resulted in the emergence of medical markets and commercialised medicine.

Following these two traditions, the concept gradually evolved, and more and more phenomena – ranging from social deviance to normal life experiences and lifestyle choices (Verweij, 1999) – were analysed within the framework of medicalisation.

### *Increased criticism*

The 1980's were a turning point for the medicalisation process; changes in the organisation of medicine and medical knowledge caused a shift in the forces driving medicalisation (Bell, 2017; Conrad, 2005, 2013). Although physicians can still be considered as the gatekeepers for medical treatments, medicalisation is increasingly driven by other stakeholders, such as pharmaceutical companies, patients, the media, and government institutions (Conrad, 2005; Metzl & Herzig, 2007). Thus, the agents driving medicalisation have become quite diverse and this has shifted the focus of medicalisation scholars, who started to analyse the active involvement of these various stakeholders in the medicalisation process (Ballard & Elston, 2005; Conrad, 2005; Bell & Figert, 2015; Dew, et al., 2016). Ballard and Elston (2005, p. 234) explain:

‘Medical sociologists have increasingly turned to the examination of the particular contexts and protagonist characteristics that are conducive (or not) to medicalisation, and of the different forms that medicalisation might take, rather than assuming it to be the inexorable outcome of medical dominance’.

Furthermore, more recently, the concept of medicalisation has been criticised and its validity has been questioned (Bell & Figert, 2015; Bordogna, 2014; Busfield, 2017;

Devisch & Van Hoyweghen, 2011; Rose, 2007). First, the nature of medicalisation has been criticised (Abraham, 2010; Davis, 2006; Clarke et al., 2003; Rose, 2007; Williams, Martin & Gabe, 2011a). Davis (2006) argues that the decoupling of medicalisation from the institution of medicine makes it difficult to determine what constitutes a medical term or treatment. He argues that, in order to analyse medicalisation, we need a certain notion of what constitutes legitimate medical boundaries, and this is impossible without the institution of medicine (Davis, 2006). Likewise, Bell (2017) argues that the medical institution, that is medicine's institutional dominance and prestige, is an essential part of medicalisation. According to her, it is 'the gas that fuels the engine' (Bell, 2017, p. 12). Although the engines of medicalisation may have changed, the process itself is still informed by the professional mechanisms of medicine (Bell, 2017). Hence, Davis (2006) and Bell (2017) urge to bring the institution of medicine back into research on medicalisation. Other scholars want to reconceptualise medicalisation (Poitras, 2012) or claim that scholars have to move beyond medicalisation (Abraham, 2010; Clarke et al., 2003; 2010; Moynihan & Henry, 2006; Rose, 2007; Williams et al., 2011a). The latter believe that the medicalisation thesis is no longer sufficient to explain recent trends in medicine and medical sociology.

Second, scholars have criticized Conrad's strong focus on the definitional aspect of medicalisation (Clarke & Shim, 2011; Halfmann, 2012). Conrad (2013, p. 197) states that 'the definitional issue is central to medicalisation; that is, how a problem is defined is key to what is done about it'. Several scholars argue that also practices and actors can be mechanisms of medicalisation (e.g. Clarke & Shim, 2011; Halfmann, 2012). For instance, Halfmann (2012) developed a typology in which he distinguishes

between various dimensions of medicalisation, i.e., discourses, practices, and actors. He emphasises that medicalisation is a process that can increase or decrease. Medicalisation increases or decreases when biomedical vocabularies, practices or actors become more or less salient in addressing social problems (Halfmann, 2012, p. 5-6). Demedicalisation, which is often defined as the opposite of medicalisation (Halfmann, 2012, p. 2), has also become more prominent in research on medicalisation. Lowenberg and Davis (1994, p. 594) argue that 'there is no unilateral movement in the direction of either medicalisation or demedicalisation'. Medicalisation and demedicalisation are different processes that can occur simultaneously (Lowenberg & Davis, 1994), and researchers are urged to focus on resistance and constraints to medicalisation (Ballard & Elston, 2005; Bell, 2016, 2017; Williams & Calnan, 1996; Williams & Gabe, 2015). Hence, scholars rooted in this second critique increasingly pay attention to the multidimensionality and continuous nature of the medicalisation process (Ballard & Elston, 2005; Bell, 2016, 2017; Halfmann, 2012).

Third, the external validity of medicalisation has been questioned. Most studies on medicalisation are North American in focus (Williams & Gabe, 2015), and they often use the United States (USA) as a single-case study (Bell & Figert, 2012; Conrad & Bergey, 2014; Olafsdottir, 2010). However, medicalisation varies across institutional settings and has become an increasingly global phenomenon (Buffel, Beckfield & Bracke, 2017; Conrad & Bergey, 2014; Olafsdottir, 2010). Olafsdottir (2010, p. 251) argues that 'medicalisation processes are embedded within institutional arrangements that shape how medicalisation happens and what mechanism are the main forces of medicalisation'. The USA is a unique case as it is the only advanced



industrialised society where healthcare is not universal to all citizens. Direct-to-consumer advertising, and private ownership and funding of health insurance have further contributed to the commodification of healthcare within the USA. Hence, by mainly focusing on the USA, and to a lesser extent the UK, medicalisation studies have ignored how medicalisation processes vary across different (institutional) settings (Bell & Figert, 2012; Conrad & Bergey, 2014; Olafsdottir, 2010). This dissertation therefore focuses on a different institutional setting, that is the Belgian social health insurance system. In Chapter 5, I provide an overview of the characteristics of this type of health insurance system and explain what makes Belgium an interesting case-study to investigate processes of medicalisation.

To conclude this section I want to highlight that, nowadays, scholars either move away from these early scholars (Bell & Figert, 2015; Halfmann, 2012), and perceive medicalisation as a more complex, contested, and relational process (Ballard & Elston, 2005; Bell, 2017; Busfield, 2017) that ‘shifts depending on the context’ (Bell, 2016, p. 44), or they turn to other concepts, such as biomedicalisation and pharmaceuticalisation. These concepts will be the focus of our next section.

## **2.2. And they lived happily ever after? New drivers, new concepts**

*‘Biomedicalisation is our term for the increasingly complex multi-sited, multidirectional processes of medicalisation that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine’ (Clarke et al., 2003, p. 162).*

Although medicalisation is increasingly perceived, and analysed, as a complex and contested process (Ballard & Elston, 2005), some scholars believe that the concept of

medicalisation does not suffice to capture recent dynamics, such as developments in genetics, technoscience, and the expanding pharmaceutical use (Bell & Figert, 2015). Scholars have developed many concepts that try to account for these dynamics, such as geneticisation, healthism, and disease mongering (Crawford, 1980; Lippman, 1991; Moynihan & Henry, 2006). In this section, I will only focus on the two concepts that are the most relevant for this dissertation and the most popular in general: biomedicalisation and pharmaceuticalisation.

### ***Biomedicalisation***

Technoscientific, socioeconomic, and cultural changes have complicated the medicalisation process and have made it more extensive. According to Clarke, Shim, Mamo, Fosket and Fishman (2010, p. 2), the concept of medicalisation does not suffice anymore to explain these recent changes as:

‘Biomedicine is today being transformed from the inside out through old and new social arrangements that implement biomedical, computer, and information sciences and technologies to intervene in health, illness, healing, the organisation of medical care, and how we think about and live life itself’.

Biomedicalisation better covers these transformations and is constituted through five processes (Clarke et al., 2003, 2010; Dew et al., 2016). First, due to the involvement of multinational companies in biomedical research, biomedicine is increasingly commodified and privatised. Second, there is an intensified focus on health, risks, and enhancements, which has resulted in the increased surveillance of individuals and populations and the commodification of health itself. Third, Clarke and colleagues (2010, p. 2) argue that biomedical practices become increasingly technoscientific as well, resulting in medical treatments and enhancements becoming

more reliant on science and technologies. Fourth, biomedicalisation is also constituted through transformations in the production, distribution, management, and consumption of medical knowledge, such as the availability of medical information on the Internet. The last process is the transformation of bodies and identities. Dew, Scott and Kirkman (2016, p. 103) argue that 'the body is no longer seen as static and unchanging; it is capable of being reconfigured and transformed'. Furthermore, new identities are constructed through technoscientific means. Clarke and colleagues (2003, p. 182) give the example of genetic testing. Through the application of these new technologies, individuals may become aware that they are genetic carriers of inherited diseases.

In conclusion, medicalisation emphasises exercising control over medical phenomena, such as diseases and bodily malfunctions. It captures the extension of medicine's jurisdiction. Biomedicalisation describes the extension of biomedicine through technoscience (Bordogna, 2014; Clarke & Shim, 2011). Hence, biomedicalisation differs from medicalisation as it emphasises transformations of medical phenomena, institutions, and bodies (Clarke et al., 2010, p. 2).

### *Pharmaceuticalisation*

Another concept that is strongly related to medicalisation is pharmaceuticalisation. With pharmaceuticalisation, scholars try to capture the expanding pharmaceutical use and the growing importance of the pharmaceutical industry, which does not necessarily entail medicalisation or biomedicalisation (Abraham, 2010; Bordogna, 2014; Williams et al., 2011a).

The concept was introduced by Nichter (1996), and further developed by Abraham (2009, 2010) and Williams, Martin, and Gabe (2011). Although Abraham (2011) and Williams and colleagues (2011a, 2011b) have slightly different views about the pharmaceuticalisation process, they formulated – in my opinion – rather similar definitions of pharmaceuticalisation. Abraham (2010, p. 604) defines pharmaceuticalisation as ‘the process by which social, behavioural or bodily conditions are treated or deemed to be in need of treatment with medical drugs by doctors or patients’. According to Williams and colleagues (2011a, p. 711), ‘pharmaceuticalisation denotes the translation or transformation of human conditions, capabilities, and capacities into opportunities for pharmaceutical intervention’.

Williams, Martin, and Gabe (2011a) identify six sociological dimensions of the pharmaceuticalisation of society. A first dimension is the expansion of pharmaceutical markets and the widespread use of pharmaceuticals to treat health problems. Second, the relationship between regulatory agencies (i.e. medicines agencies) and the pharmaceutical industry has changed. Regulatory agencies increasingly depend on the industry and are nowadays also more involved in the promotion of drug innovation. Hence, the relationship between regulatory agencies and the industry has become very close (Abraham, 2008). The Western regulatory system has also been expanded to other (non-Western) countries, which has opened up markets for pharmaceutical companies, and has resulted in the outsourcing of various aspects of the pharmaceutical development process (Williams et al., 2011a). Third, Williams and colleagues (2011a) argue that the media and popular culture also contribute to pharmaceuticalisation, as they celebrate but also criticise

pharmaceuticals. Furthermore, the Internet allows for easy access to pharmaceuticals resulting in a domestication of pharmaceutical consumption; pharmaceuticals are increasingly used to resolve problems of daily life (Fox & Ward, 2008). The fourth dimension is the role of consumerism. The increasingly active role of consumers and their growing expertise about health can fuel pharmaceuticalisation but can also be a form of resistance to pharmaceuticalisation (Abraham, 2010; Bell & Figert, 2012; Busfield, 2010; Williams et al., 2011a). The (non-medical) use of pharmaceuticals for enhancement purposes is the fifth dimension of pharmaceuticalisation. According to Williams and colleagues (2011a), pharmaceuticalisation in this case occurs in the absence of medicalisation as not all forms of enhancements have a medical purpose, e.g. the use of cognitive enhancement drugs by students to extend their work productivity. The last and sixth dimensions is 'pharmaceutical innovation and the creation of new future health scenarios' (Bordogna, 2014, p. 132). Promises about pharmaceutical innovation raise certain expectations about the future. These promises influence policy planning and shape paths for development, while ignoring alternatives, as pharmaceutical innovation and medicines are constructed as the best, and only, way of improving health and curing diseases (Williams et al., 2011a).

In conclusion, although medicalisation and pharmaceuticalisation sometimes overlap, they are distinct processes (Abraham, 2010; Bell & Figert, 2012; Williams et al., 2011a). Abraham (2010, p. 604) argues:

'While expansion of pharmaceutical use affects pharmaceuticalisation per se, medicalization theorists concern is solely about how this expansion reflects an increase in aspects of life previously outside the jurisdiction of medicine, being constructed as medical problems'.

In other words, although pharmaceuticalisation analyses the expansion of medical treatments (i.e. the use of pharmaceuticals), it can occur without medicalisation (Abraham, 2010; Williams et al., 2011a), since pharmaceuticals are also often used in a non-medical way for enhancement purposes or to treat established medical conditions, which does not always involve the transformation of a non-medical condition into a medical one (Abraham, 2010).

In this section, I have illustrated the differences, but also overlap, between medicalisation and biomedicalisation/pharmaceuticalisation. I agree with Bell and Figert (2015, p. 20) that we need to perceive these '-isations' as 'related and coevolving concepts and processes'. In the last section of this chapter, I will position my own research within the current debates on (bio)medicalisation and pharmaceuticalisation.

### **2.3. The end? Positioning this dissertation within current debates on (bio)(medi)(pharmaceuti)calisation**

*'We argue that alone each of the concepts captures distinct processes, that each is related to the others, and that each sometimes but not always overlaps with another. We suggest that instead of throwing out one or all of the -isations, we can move sideways and forge ahead by examining new ways of thinking' (Bell & Figert, 2015, p. 34).*

Although there have been discussions about the value of medicalisation in the 21<sup>st</sup> century (Busfield, 2017; Metzl & Herzig, 2007; Williams & Gabe, 2015), I have illustrated that medicalisation, biomedicalisation, and pharmaceuticalisation can be perceived as different, but related, concepts. These concepts each capture distinct processes, which sometimes overlap (Bell & Figert, 2015). In other words,

biomedicalisation or pharmaceuticalisation do not replace medicalisation or make medicalisation irrelevant for studying health and illness (Busfield, 2017). I agree with Figert<sup>1</sup> (2011, p. 294) who states that:

‘Both medicalisation and biomedicalisation are useful terms and we do not have to decide if one term is more useful or supersedes the other. If the concept of biomedicalisation is more useful as a heuristic and methodological concept than medicalisation, then we should use it where it applies and vice versa. Although both sides seem to be staking out oppositional turfs, I think that they are more similar than different and that medical sociology will benefit from increased development of both concepts under the larger umbrella term of medicalisation studies’.

What these three concepts have in common is that they analyse how some problems are constituted as objects of (bio)medical or pharmaceutical intervention and that they try to answer the question; ‘who has the power to define what constitutes health and illness?’ (Abraham, 2010; Clarke et al., 2003; Conrad, 1992). The current dissertation can be situated within this broader framework of medicalisation studies. I draw on this research tradition as it offers a conceptual framework to analyse discourses on health and illness and the various stakeholders involved. More specifically, it provides a framework to study *how* certain aspects of everyday life become defined and treated as medical problems, and *who* is driving this process (Ballard & Elston, 2005; Bell & Figert, 2015; Conrad, 1992). Medicalisation studies also provides an overview of how the healthcare domain and meanings of health and illness have evolved. Furthermore, it is concerned with the social consequences of

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<sup>1</sup> Although Figert (2011) does not mention pharmaceuticalisation, I believe this concept can also be placed under the larger umbrella term of medicalisation studies.

these discourses (Conrad, 2007), i.e. the impact these discourses have on society, which aligns with the discourse-analytical approach I will outline in Chapter 5.

Within medicalisation studies, I agree with scholars who construct medicalisation as a complex, contested, and relational process (Ballard & Elston, 2005; Bell, 2017; Busfield, 2017). I also follow researchers, such as Susan E. Bell and Anne E. Figert, who do not perceive the concepts of medicalisation, biomedicalisation, and pharmaceuticalisation as mutually exclusive (Bell & Figert, 2015). I believe that each of these concepts offers a framework that allows to grasp certain aspects of current debates on who contributes to the construction of discourses on health and illness, and how they do so. Therefore, within each chapter, I draw – sometimes implicitly – on one of these three processes, depending on the main research question of each chapter.

For instance, Chapter 6 focuses on medicalisation, as it analyses how certain problems come to be placed within medicine's jurisdiction. More specifically, this chapter studies how various health-policy stakeholders contribute to medicalisation and/or demedicalisation. In Chapter 7, I focus on ageing discourses. This chapter aligns with both medicalisation and biomedicalisation, although it does not explicitly mention both processes. First, it analyses how ageing becomes defined and treated as a medical problem. Second, the chapter also draws on biomedicalisation as it analyses how ageing bodies are seen as bodies that can be monitored, and the ageing process as something that can be managed and even avoided. Chapter 8 focuses on the pharmaceutical industry's discourse and how the industry constructs pharmaceuticals, pharmaceutical innovation, and the pharmaceutical industry as important, and necessary, assets to improve health and find solutions for diseases.



Although I do not explicitly mention pharmaceuticalisation, I believe this chapter draws on several aspects of pharmaceuticalisation, such as the sixth dimension within the framework developed by Williams and colleagues (2011a) (i.e. pharmaceutical innovation and the creation of new future health scenarios). Furthermore, it offers insights in how pharmaceutical companies construct discourses that praise and encourage pharmaceutical use. Finally, in Chapter 9, I draw on biomedicalisation. I study how the construction and distribution of medical knowledge has transformed and how this has changed the healthcare field. More specifically, I focus on the relationship between health-policy stakeholders and news media.

Finally, I try to respond to and go beyond the critiques on medicalisation. Most importantly, I want to go beyond a definitional approach to medicalisation. I agree with Halfmann (2011), who argues that also actors and practices can be mechanisms of medicalisation, and Figert (2011, p. 293) who argues that ‘if the days of physician control and dominance are over, how does medicalisation occur within the increasingly complex health care system? Who are all the actors/interested parties?’. Therefore, I do not only focus on the discourses of the various stakeholders involved but I also focus on the stakeholders themselves (i.e. their position and interests) and the larger context in which they operate. In order to do so, I complement these insights from medicalisation studies with concepts from field theory, which I will outline in the next chapter.



## CHAPTER 3: The healthcare field

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The previous chapter focused on how meanings of health and illness are constituted and on the stakeholders who are driving this process. In this chapter, I focus on how these stakeholders, through their interests and position, are involved in the construction of discourses on health and illness and I focus on the larger context in which these discourses are produced. More specifically, I draw on Bourdieu's (1983; 2000) concept of the field.

### 3.1. Bourdieu and field theory

*'A football field is a bounded site where a game is played. In order to play the game, players have set positions - when the football field is represented in visual form, it is as a square with internal divisions and an external boundary, with the set positions marked in predetermined places. The game has specific rules which novice players must learn, together with basic skills, as they begin to play. What players can do, and where they can go during the game, depends on their field position. The actual physical condition of the field (whether it is wet, dry, well grassed or full of potholes), also has an effect on what players can do and thus how the game can be played' (Thomson, 2008, p. 68).*

The above metaphor of a football field summarises the basic principles of Bourdieu's notion of a field. A field is 'a relatively autonomous domain of activity that responds to rules of functioning and institutions that are specific to it and which define the relations among the agents' (Hilgers & Mangez, 2015, p. 6). Bourdieu's concept of a field thus refers to a social space that is structured around a network of relations between social actors who have certain economic (e.g. money and material assets) and/or cultural (e.g. knowledge, reputation) resources at their disposal (Collyer et al.,

2015; Lewis et al., 2017). Each field is constructed and reproduced, through a struggle over the common good of the field and operates according to its own logic and rules (Albright, Hartman, & Widin, 2018; Bourdieu, 1993; Hilgers & Mangez, 2015). To go back to the football metaphor: 'fields are shaped differently according to the game that is played on them. They have their own rules, histories, star players, legends and lore' (Thomson, 2008, p. 69).

Within each field, actors take on a certain position. Bourdieu (1983) defines this process as *prises de position* or position-taking. He argues that 'each agent or each institution' has to be located 'in its relationship with all the others' (Bourdieu, 1993, p. 181). This position also depends on an actors' access to the resources of the field (Bourdieu & Wacquant, 1992). Actors who have access to the appropriate resources of the field are more capable to influence, and benefit from, the discourses that are produced within the field (Bourdieu, 1984; Lewis et al., 2017). As a consequence, powerful actors, that is actors who have access to the resources of the field, will be more successful at obtaining and maintaining their position within the field (Bourdieu, 1984; Bourdieu & Wacquant, 1992).

So, fields are characterised by a constant internal power struggle between the actors within the field who want to obtain resources and maintain or improve their position within the field (Bigo, 2011, Bourdieu, 2000; Hilgers & Mangez, 2015). Bourdieu and Wacquant (1992, p. 101) explain that:

'The strategies of agents depend on their position in the field, that is in the distribution of the specific capital(s), and on the perception that they have of the field depending on the point of view they take *on* the field as a view taken from a point *in* the field'.

This struggle centres around defining the doxa (Bourdieu, 2000), which refers to the rules of the game or the dominant ideas of the field (Collyer, 2018; Thomson, 2008). This doxa is a source of power for the actors within the field, since actors who are able to draw on this doxa will be better at obtaining and maintaining a favourable position within the field (Wagner et al., 2018). However, it is also a manifestation of power (Gaventa, 2003), since the struggle within the field centres around defining this doxa. Fields thus also encompass a certain hierarchy of ideas and practices (Collyer, Willis, & Lewis, 2017; Fligstein & Vandebroek, 2014). They consist of certain types of ideas and practices that are considered as good/preferred/valuable and others that are considered as bad/subordinate (Gaventa, 2003; Grenfell & James, 2004).

### **3.2. The rules of the healthcare game**

*'The field of healthcare, like all fields of social life, is a site of continuous games for power and control. Battles in this field are due to the diverse roles, and partially divergent objectives, of the various institutions and individuals involved in the functions of financing, production, and consumption of health services' (Kurunmäki, 1999, p. 96).*

The concept of the field has been applied to several domains, such as the journalistic field (Benson & Neveu, 2005; Eldridge, 2016), the literary field (Sapiro, 2015), or the field of sport practice (Kay & Laberge, 2002). It has only recently been applied to healthcare (e.g. Brown et al., 2008; Collyer, 2018; Kurunmäki, 1999; Wagner et al., 2018). For instance, Brown and colleagues (2008) analyse how medical discourses about infection control and cleanliness are used as a resource within the healthcare field.

Indeed, following Bourdieu's field theory, healthcare can be conceptualised as a field. First, the healthcare field is centred around a particular goal or stake (i.e. curing people and improving their health), which distinguishes the healthcare field from other fields (Bourdieu, 1993). Second, the biomedical model of illness defines the rules of the game and can be seen as the doxa of the healthcare field (Collyer, 2018; Thomson, 2008; Warde, 2004). The power struggle within the healthcare field thus centres around gaining control over this doxa, and defining what constitutes health and illness (Lewis et al., 2017). Third, within the healthcare field a specific form of capital, i.e. medical knowledge, is generated that is used by the actors within the field to gain legitimacy (Wagner et al., 2018). Consequently, the main holders of medical knowledge are the elites of the field (Hilgers & Mangez, 2015). Fourth, the field involves several key actors, such as physicians or pharmaceutical companies, and a structured set of, often historically formed, positions (Champagne & Marchetti, 2005; Collyer et al., 2017). For instance, within the Belgian social health insurance system, the relationship between physicians and sickness fund agencies was established, and institutionalised, by the 1963 Health Insurance Act (Corens, 2007). Finally, the healthcare field is characterised by a struggle between the various actors involved (Cheek, 2008; Collyer et al., 2017; Lewis et al., 2017). Collyer and colleagues (2017, p. 690) divide these actors into four groups based on the position they take on: 1) medical actors who occupy a dominant position and define health as the absence of pathology, 2) corporations that define health 'as a product for market exchange and profit', 3) 'the capitalist state where the medical definition of health and the need to support capitalist medicine sit somewhat uncomfortably alongside political goals to mediate the effects of the capitalist market on the health of the population', 4) a whole range of 'subordinate actors with a plethora of competing and diverse

position-takings, for example, patient rights, public health or complementary and alternative medicine' (Collyer et al., 2017, p. 690).

Some of the struggles within the healthcare field are discursive struggles (Wagner et al., 2018). The struggle on what constitutes health and illness thus plays an important role within the literature on the healthcare field, which is similar to the literature on medicalisation studies. What makes field theory interesting for the study of discourses on health and illness is that it highlights the importance of a stakeholder's position within the healthcare field, his position vis-à-vis other stakeholders, and his (access to) resources. Field theory thus allows to map the different stakeholders within the field and the relationships and power struggles between them. Gaventa (2003) and Navarro (2006) argue that field theory helps to understand how stakeholders are, or are not, able to be powerful within a field and thus to influence what constitutes health and illness. Field theory thus allows to place discourses on health and illness within the larger context of the healthcare field. This context is important as stakeholders do not operate in a social vacuum and the healthcare field itself also intersects with other fields, which will be the main focus of the next section.

### **3.3. Playing a different game: field relationality**

*'Each field, composed of specific rules, is to varying degrees, autonomous, though also simultaneously influenced by other overlapping and competing fields. Therefore, the players often occupy more than one social field simultaneously and are exposed to competing and contrasting logics of practice' (Albright et al., 2018, p. 42).*

The social world consists of various fields of which the healthcare field is only one field. Although fields are relatively autonomous, they do intersect and sometimes are entangled with other fields (Albright et al., 2018). Fields are thus not only shaped by internal struggles but also by external struggles with actors from outside the field whose input can change the dynamics of a field (Collyer et al., 2017; Fligstein & McAdam, 2012). Albright and colleagues (2018, p. 8) state that 'influxes of new players or agents in a field can be forces for transformation or conservation, depending on the situation in the field and the forces within and external to the field'. For instance, the rise of social movements (e.g. patient organisations) and a more active patient (Lupton, 2018) has brought new types of knowledge to the healthcare field. Clarke and colleagues (2003) argue that this has disrupted the division between lay and expert knowledge. In other words, these developments challenge the dominance of medical knowledge and the hegemony of the medical profession (Crinson, 2018; Wagner et al., 2018).

In the case of the healthcare field, it is important to look into the intersections of the healthcare field with others fields as these new actors and developments have challenged the traditional boundaries of the healthcare field, as illustrated by the example mentioned above. I draw on two examples to illustrate the intersection of the healthcare field with other fields.



### *Example 1: the pharmaceutical industry and the economic field*

The relationship between the pharmaceutical industry and the healthcare field exemplifies some of the complexities involved in contemporary healthcare (Bell & Figert, 2015). First, the involvement of pharmaceutical companies, who are commercial enterprises but also producers of products that are indispensable and often even life-saving (Busfield, 2006), has raised questions about the nature of health. Can health be treated as a commodity or is it a common good? (Pellegrino, 1999). These two goals, maximising profit and curing disease, are often perceived as contradictory (Nussbaum, 2009). Second, the rise of the pharmaceutical and biotechnological industry has brought ideas and principles of the economic field to the healthcare field (Clarke et al., 2003). For instance, there is a trend towards routinisation and standardisation of healthcare. Biomedical research has become increasingly privatised and commodified (Clarke et al., 2003), and there have been discussions about the storage and (commercial) use of patient data (Lowrance, 2003; Safran et al., 2007).

This example illustrates how the healthcare field intersects with other fields through the involvement of certain actors, in this case the pharmaceutical industry. Furthermore, the example demonstrates how the intersection between two fields raises new questions and causes new challenges for the healthcare field which eventually can change, and in fact in this case have changed (see also Clarke et al., 2003), some of the dynamics of the field.

### *Example 2: the journalistic field*

As a result of a more general societal interest in health, news media have become more interested in health and as a consequence interactions between health and media professionals have intensified (Briggs & Hallin, 2016; Clarke et al., 2003). Briggs and Hallin (2016) state that in this process health professionals have incorporated logics and practices from the journalistic field and vice versa. For instance, biomedical actors have established press offices and media institutions have hired journalists with a medical or scientific background to write about health issues. As a result of this entanglement, health news is increasingly co-produced (Briggs & Hallin, 2016). This entanglement challenges the traditional boundaries of the healthcare field and makes it more difficult to identify the boundaries between the two fields of healthcare and journalism. In other words, with their study, Briggs and Hallin (2016, p. 206) illustrate that the healthcare field is not only expanding its social influence (i.e. (bio)medicalisation), 'but also, as part of this process of expansion, becoming entangled with other fields – not only with media but with business, government, education, and more – and becoming increasingly complex internally'.

These examples illustrate that actors are involved in multiple fields, which makes it sometimes difficult to distinguish between fields and their actors (Fligstein & Vandebroek, 2014), and they highlight the importance of also looking into field relationality. To conclude this chapter, the next section discusses how the concept of the field is used within the current dissertation.

### 3.4. Using field theory as an analytical tool to study the healthcare field

*'What Bourdieu gives us is an option: a set of thinking tools to illuminate the social world'* (Grenfell & James, 2004, p. 518).

In this chapter, I have illustrated the value of using the concept of field to think about and analyse the increasingly diverse and contested healthcare domain. Following Collyer (2018), I believe that conceptualising healthcare as a field allows to acknowledge the agency of the stakeholders involved as well as the social structure in which they participate (Albright et al., 2018; Fligstein & Vandebroeck, 2014; Lewis et al., 2017). Collyer (2018, p. 121) states:

'By examining the struggles for legitimation and domination the very nature of the field itself is revealed, and by identifying the unique conditions of the field we can see how these modify the dispositions of the individuals and the positions they occupy'.

Furthermore, I illustrated that fields are dynamic and relational (Hilgers & Mangez, 2015). This aligns with my approach towards medicalisation as a dynamic, contested, and relational process. Field theory adds to this approach as it allows to investigate how stakeholders and the (institutional) setting in which they are embedded are involved in the construction of meanings of health and illness. I combine these conceptual frameworks of field theory and medicalisation studies with a discourse-analytical approach, which I will outline in Chapter 5.

In this dissertation, I thus use field theory as a conceptual framework to map the healthcare field and the various stakeholders involved. Chapter 6 sketches the positions these stakeholders occupy within the healthcare field and the relationships

between them. Chapter 7 and 8 focus on two specific stakeholders, i.e. sickness fund agencies and the pharmaceutical industry, and investigate how the discourses of these stakeholders are related to their position within the healthcare field. In Chapter 9, I focus on field relationality and investigate the relationship between the healthcare field and the journalistic field. Before turning to these empirical chapters, I will first discuss the research aims (Chapter 4) and the methodology (Chapter 5) of my dissertation.

## CHAPTER 4: Research aims and empirical papers

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### 4.1. Research aims

This dissertation aims to advance insights into the complexity of the contemporary field of healthcare. As I described in the previous chapters, the healthcare field has evolved from a space mainly occupied and dominated by the medical profession to an increasingly diverse and contested space in which new actors and new definitions of health and illness have entered, and, as a consequence, have (re)defined the healthcare field (Cheek, 2008; Metzl & Herzig, 2007; Pereira Gray et al., 2016). These (new) actors or – what I in the next chapter will define as – health-policy stakeholders and the social space they occupy are the main focus of this dissertation. More specifically, I analyse the discourses of these stakeholders and how these discourses are related to the interests and position of these stakeholders within the healthcare field.

In doing so, this dissertation has two research aims. First, health and illness are socially constructed concepts that are increasingly diverse and contested, due to the involvement of various stakeholders in the construction process (Cheek, 2008; Conrad & Barker, 2010; Lupton, 2003). I aim to gain a better understanding of how various meanings of health and illness are constructed, and negotiated, by these stakeholders. By not only focusing on the discourses of various stakeholders but also on their interests and position within the healthcare field, this dissertation tries to uncover some of the ‘layers of negotiation, compromise, and interests’ that are concealed behind these discourses on health and illness (Dew et al., p. 2). Here, I follow Conrad and Barker (2010) who argue that ‘by acknowledging that medical

knowledge about disease and illness is constructed by socially situated claim-makers and other interested parties, we can bring greater critical awareness to the policy-making process. After all, any policy response to a problem is determined by how the problem is defined or framed in the first place' (p. S74). Second, the aim is to not only advance insights in how these discourses on health and illness are socially constructed within an increasingly complex, differentiated, and contested healthcare landscape. By analysing these stakeholders and their position within the healthcare field, I also want to investigate the impact of these discourses on the healthcare field and knowledge production within this field.

These research aims are translated in four empirical chapters. First, however, it is important to define the three key concepts that are central to the research aims of this dissertation; *discourse*, *interest*, and *position*. In this dissertation, I define *discourse* as a specific way of structuring, thinking, speaking, and writing about reality that defines how individuals and institutions think about and behave in relation to certain phenomena, but that also restricts certain ways of thinking or behaving (Hall, 2001; Hodges, Kuper & Reeves, 2008; Lähdesmäki & Siltaoja, 2010). Applied to discourses on health and illness, this means that health-related discourses are specific ways of thinking, speaking, and writing about health and illness that define how society thinks about and deals with health and illness. For the concepts of *interest* and *position*, I once more draw on Bourdieu (1990; 1993; 1994) and his work on field theory. More specifically, with *position* I refer to the place a stakeholder occupies within (the network of relations of) the healthcare field (Collyer et al., 2017). For this dissertation, this means that I investigate a stakeholder's position within the Belgian social health insurance system. I draw on the concept of *interest* in order to refer to

practices that are aimed at securing the – for the stakeholder – most advantageous position within the healthcare field (Grenfell, 2008). Hence, these practices or interests are related to a stakeholder's position within the healthcare field.

#### **4.2. Situating the empirical papers**

In this section, the four empirical chapters of this dissertation are discussed. An overview of the empirical chapters and their research questions can be found in table 4.1. An overview of the exact contribution of the doctoral student to each empirical study can be found in Appendix 1.

Chapters 6 and 9 take on a more macro approach and focus on the healthcare field. Chapter 6 provides an overview of the various stakeholders within the healthcare field. This chapter investigates processes of medicalisation and demedicalisation within the healthcare field, and concentrates on the discourses, interests, and position of the stakeholders within the healthcare field. Thus, Chapter 6 focuses on the healthcare field and how various meanings of health and illness are constructed and constantly (re)negotiated by the stakeholders within this field. In Chapter 9, I analyse the relationship between the healthcare and the journalistic field. Chapter 9 covers the link between the healthcare field and other fields. In doing so, I try to gain insight into the relations between the healthcare field and other fields.

Chapters 7 and 8 take on a more meso approach and zoom in on the discourses of two specific stakeholders within the healthcare field; sickness fund agencies (Chapter 7) and the pharmaceutical industry (Chapter 8). In Chapter 7, I analyse sickness fund agencies' discourse on ageing and I investigate how this discourse is related to the various roles they take on within the healthcare field. Chapter 8 focuses on the

pharmaceutical industry and its reputational discourse. More specifically, it studies how the pharmaceutical industry's discourse is shaped by, what I define as, the *Bad Pharma* discourse, which threatens the industry's reputation and position within the healthcare field. So, these chapters try to understand how specific stakeholders construct and negotiate meanings of health and illness.

CHAPTER	RESEARCH QUESTIONS
<i>CHAPTER 6: Beyond Ubiquity: unravelling medicalisation within the frame of health insurance and health-policy making</i>	<ul style="list-style-type: none"> <li>▪ How are processes of medicalisation and demedicalisation constituted within the institutional context of the Belgian social health insurance system?</li> </ul>
<i>CHAPTER 7: The silver lining of greying: ageing discourses and positioning of ageing persons in the field of social health insurance</i>	<ul style="list-style-type: none"> <li>▪ How do sickness fund agencies position themselves within the societal debate on ageing?</li> <li>▪ How do sickness fund agencies discursively construct the ageing process?</li> <li>▪ How do they accordingly position ageing persons?</li> <li>▪ How are these discursive constructions linked to their organisational roles?</li> </ul>
<i>CHAPTER 8: In the Land of Pharma: a qualitative analysis of the reputational discourse of the pharmaceutical industry</i>	<ul style="list-style-type: none"> <li>▪ How does the pharmaceutical industry construct its reputational discourse?</li> <li>▪ What are the main discursive themes in the industry's reputational discourse?</li> <li>▪ How do larger societal discourses shape reputational discourses?</li> </ul>
<i>CHAPTER 9: (Dis)entangling medicine and media: a qualitative analysis of the relationship between the fields of healthcare and journalism</i>	<ul style="list-style-type: none"> <li>▪ What is the relationship between health-policy stakeholders and news media?</li> <li>▪ What position do health-policy stakeholders occupy within the healthcare field?</li> <li>▪ How do health-policy stakeholders discursively position news media with reference to the healthcare field? And what motivates them to do so?</li> </ul>

**Table 4.1.** Overview of empirical chapters and research questions



## CHAPTER 5: Methodology

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In the previous chapter, I explained that this dissertation tries to uncover the layers or intricacies that lie behind the discourses of health-policy stakeholders. Therefore, it seems useful to use a metaphor of an onion as my goal is to peel off several of the layers around them. This focus on discourses and their (hidden) meanings requires a qualitative approach. In this dissertation, I want to link these discourses to the specific characteristics of the stakeholders and the context in which they are produced, while quantitative approaches often lead to results that are time- and context-free (Johnson & Onwuegbuzie, 2004). Thus, a qualitative approach is most suited since the focus of this dissertation is on the social construction of meanings on health and illness.

As qualitative data are constructed through the interaction of the researcher with the research subject and are embedded in a historical and social context (Denzin, 2014; Kvale & Brinkmann, 2009), it is crucial to also uncover the layers of the methodology and the sampling decisions that led to these results. Rapley (2014, p. 49) states:

‘Given that the claims that qualitative researchers want to make are routinely based on working closely with relatively small numbers of people, interactions, situations or spaces, it is central that these are chosen for good analytic reasons. Above all, sampling should never be the product of ad hoc decisions or left solely to chance. It needs to be thoughtful and rigorous’.

In order to clarify the choices made during the sampling and data gathering process, I first have to provide some background information about the Belgian healthcare system. Therefore, this chapter starts with a brief overview of various health insurance systems, followed by more information about the intricacies of social

health insurance systems and a paragraph on the added value of using Belgium as a case-study. In the second part of the chapter, the methodological framework of the dissertation is presented. First, I discuss the sampling decisions that were made. Second, I provide an overview of the data gathering process and the different types of data that were gathered. Third, the data analysis and the framework, i.e. discourse analysis, that guided the analysis are discussed and illustrated. In the fourth part, the measures that were taken to ensure the quality of the data, research ethics, and some reflexive thoughts are presented.

### **5.1. Institutional context: the Belgian health insurance system as a case-study**

*'Social health insurance is not simply an insurance arrangement but rather a "way of life". In this view, social health insurance is a key part of a broader structure of social security and income support that sits at the heart of civil society. As such, social health insurance helps define how social order is established in society. It is part of the fabric of society, supported by a social consensus that is deeply rooted in the balance of society as a whole' (Saltman, Busse & Figueras, 2004, p. 5).*

#### ***Health insurance systems***

Although there exist many classifications of healthcare systems, Western healthcare systems are often grouped in three ideal types; national health insurance systems (NHI), private health insurance systems (PHI), and social health insurance systems (SHI) (Colombo & Tapay, 2004; Moran, 2000; Schieber, 1987; Thomson, Foubister & Mossialos, 2009; van der Zee & Kroneman, 2007; Wendt, Frisina & Rothgang, 2009). Notwithstanding internal variation within each healthcare model, which can often make it more difficult to classify countries, most countries can be classified in one of

these health insurance systems (Hassenteufel & Palier, 2007; Moran, 2000; Wendt et al., 2009; Wendt, 2014).

These health insurance systems differ in their financing, ownership, and provision of health services (Hassenteufel & Palier, 2007; Wendt, 2009). National health insurance systems are tax-funded and provide universal coverage. Health services are owned and organised by the state (Elola, Daponte & Navarro, 1995; Moran, 2000; van der Zee & Kroneman, 2007). The healthcare systems of the United Kingdom and Scandinavian countries are examples of national health insurance systems. Private health insurance systems, such as the United States, stand in contrast to this NHI system, because they are privately funded and owned, and, as a consequence, there is no universal coverage (Colombo & Tapay, 2004; Schieber, 1987). Finally, social health insurance systems can be seen as mixed systems that combine both public and private interests (Hassenteufel & Palier, 2007). Belgium and Germany are examples of SHI systems. As this dissertation analyses the discourses, interests, and positions of stakeholders within the context of the Belgian social health insurance system, the following section describes the core components of SHI systems and discusses the specific characteristics of the Belgian SHI system.

### *Social health insurance systems and the Belgian context*

Social health insurance (SHI) systems are corporatist-governed; they are managed by nongovernmental actors instead of the state (Saltman et al., 2004). They are funded by social contributions and also provide universal coverage (Elola et al., 1995; Hassenteufel & Palier, 2007; Normand & Busse, 2002). Germany, France, Switzerland and Belgium are examples of countries with a social health insurance system.

Saltman and colleagues (2004, p. 6) distinguish between seven core components or 'institutional mechanics' of SHI systems. First, contributions are risk-independent and transparent, which means that they are gathered separately from tax-revenues and are linked to the income of members and not to their health status. Second, health insurance is organised through not-for-profit private sickness fund agencies who collect these social contributions directly or receive them from a state-run fund. Third, principles of solidarity are applied to what concerns population coverage, funding, and the benefits package. Fourth, various stakeholders, such as medical associations and pharmaceutical companies, are included in and are seen as part of the SHI system. Fifth, SHI systems draw on a corporatist model of negotiations. Saltman and colleagues (2004, p. 8) explain that 'negotiations occur among peak organisations representing each health sub-sector involved'. Sixth, and related to the previous component, this corporatist model means that various stakeholders participate in governance decisions. Finally, patients are free to choose their healthcare providers and the sickness fund agency they want to become a member of (Saltman et al., 2004).

The Belgian SHI system has its roots in the late 19<sup>th</sup> century when voluntary and private mutual benefit funds were created by workers to protect themselves in case of disease and unemployment (Callens & Peers, 2015; Corens, 2007; Schepers, 1993). These mutual benefit funds gradually evolved and were officially recognised by the state in 1894 with the law on mutual benefit funds (Schepers, 1993). The current system was established after the Second World War (Corens, 2007; Schepers, 1993). The Social Security Act of 28 December 1944 made health insurance compulsory for all salaried employees (Callens & Peers, 2015, Corens, 2007). The Health Insurance

Act of 9 August 1963 extended this coverage to the whole Belgian population. Corens (2007, p. 16) explains that ‘the law extended coverage under the compulsory social health insurance within a private system of medical care based on the principles of independent medical practice, free choice of physician and hospital for the patient, and fee-for-service payment’. Important aspects of this Health Insurance Act were the initiation of a system of conventions and agreements, which regulates the financial and administrative relationship between sickness fund agencies and healthcare service providers, and the establishment of the National Institute for Sickness and Disability Insurance (NIHDI) (Corens, 2007; Gerkens et al., 2010). Sickness fund agencies and healthcare service providers thus directly negotiate about the fee schedule and the healthcare budget, while government institutions organise and facilitate these negotiations (Callens & Peers, 2015). At this point, it becomes clear that sickness fund agencies, healthcare service providers, and government institutions are the main constituents of the Belgian SHI system. Gradually their roles were further established and institutionalised; for instance, the 1990 Sickness Funds Act confirmed sickness fund agencies’ role as administrator of the compulsory health insurance system (Gerkens et al., 2010).

Over the past decades, several new government institutions were created or existing departments were enlarged. These new institutions and departments have to support health policy by, for instance, doing research or formulating guidelines, and/or they have to ensure the quality and safety of healthcare services and products (Corens, 2007; Gerkens et al., 2010). Along with these new institutions and departments, several consultation bodies were founded. This also introduced some new actors within the SHI system, such as the umbrella organisation representing the

pharmaceutical industry and the umbrella organisations representing several patient organisations. In other words, gradually, a wide range of stakeholders, often with competing interests, have become part of the health-policy making process within the Belgian SHI system.

### *Why Belgium?*

In this dissertation, I focus on the discourses of Belgian health-policy stakeholders and how these discourses are related to the interests and position of these stakeholders within the Belgian social health insurance system. Using Belgium as a case-study allows to add empirical insights from a new and different institutional context to research on medicalisation and field theory and increases the external validity of this body of research, as previous research has mainly focused on NHI and PHI systems (Collyer et al., 2015; Collyer et al., 2017; Conrad & Bergey, 2014; Olafsdottir, 2010). Second, the inclusion of both public and private actors within the SHI system allows to study the intersection of the healthcare field with others fields, as some of these private actors come from different fields. Third, the SHI system offers opportunities to study the healthcare field as the incorporation of various stakeholders means that it is structured around a network of relations. Additionally, due to its model of negotiations between the stakeholders involved, the SHI system also consists of struggles between these stakeholders. Fourth, and related to my previous argument, the institutionalisation of stakeholders within the SHI system makes it easier to observe these struggles as they are connected with and take place within these official consultation bodies. Fifth, the corporatist-model that characterises SHI systems automatically leads to a context in which meanings of health and illness are negotiated by various stakeholders.

## 5.2. Data & sampling

*'Stakeholder analyses are arguably more important than ever because of the increasingly interconnected nature of the world. Choose any public problem – economic development, poor educational performance, natural resources management, crime, AIDS, global warming, terrorism – and it is clear that “the problem” encompasses or affects numerous people, groups, and organisations. No one is fully in charge; no organisation “contains” the problem. Instead, many individuals, groups, and organisations are involved, or affected, or have some partial responsibility to act' (Bryson, 2004, p. 23).*

### *The research project*

The research presented in this dissertation is rooted in a larger transdisciplinary research project called '(de)constructing health news' that investigates the complex networks involved in the communication on (elderly-related) health issues and relates it to broader medical as well as sociological concerns. This dissertation aims at charting the different interconnected stakeholders involved in the healthcare field. The other research lines of this larger research project focus on the production of news stories about health, the news content, and the health-related information behaviour of young and senior elderly<sup>2</sup>.

### *Sampling decisions*

As this dissertation focuses on the position, interests, and discourses of various stakeholders, the data gathering and sampling process was based on the various steps of a stakeholder analysis (Buse, Mays & Walt, 2005). A stakeholder analysis generally consists of three activities: identifying the actors, assessing their resources

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<sup>2</sup> See also [www.healthmediasociety.net](http://www.healthmediasociety.net)

(knowledge, legitimacy, finances, relationships, etc.), and understanding their position and interests (Buse et al., 2005). In a first section, I describe how these stakeholders were identified. A second section describes the various steps that I took to gather more information on their resources, positions, and interests.

The previous section indicated that there are numerous stakeholders who are involved in the Belgian SHI system. In order to obtain a meaningful and manageable sample, three criteria were used. First, the focus is on health insurance and the corporatist model in which these decisions are made. This means that I focus on the stakeholders involved in the decision-making process (i.e. the policy level) and not on the actual provision of healthcare services. Second, I developed a list of categories in which these stakeholders can be classified. These categories are based on the stakeholders involved in the Belgian SHI system, as described in the previous section, but also on the categories that are used in the literature (e.g. Clarke et al., 2003; Conrad, 2005; 2007; Britten, 2008; Busfield, 2010). For example, Busfield (2010) distinguishes between the pharmaceutical industry, healthcare professionals, patients, the government, and medical insurance companies. Conrad (2005, 2007) focuses on similar stakeholders. He distinguishes between healthcare professionals, the pharmaceutical industry, healthcare consumers, and managed care organisations (i.e. insurance companies) as drivers of medicalisation. These examples illustrate that similar categories or groups of stakeholders (re)appear across the literature. For the purpose of this dissertation, I distinguish between six categories. In order to be included in the sample, a stakeholder needs to belong to one of these six categories:



- ◆ Government institutions
- ◆ Sickness Fund Agencies
- ◆ Associations of healthcare professionals
- ◆ Pharmaceutical industry
- ◆ Patient organisations
- ◆ Organisations of scientific medical experts

The first three categories were added because, as described above, they are the main constituents of the Belgian SHI systems. The pharmaceutical industry and patient organisations were added due to their increased involvement in the Belgian SHI system and because they are also mentioned in the literature as important (new) stakeholders (e.g. Busfield, 2010; Clarke et al., 2003). With its 35,000 employees, the pharmaceutical industry is the second largest industry in Belgium (Pharma.be, 2016). Moreover, pharmaceutical spending forms a large part of healthcare spending and is on the rise due to a steep increase in spending on high cost drugs (OECD, 2017). For these reasons, although the industry often only has an advisory function, it is able to weigh (heavily) on the health-policy process. For example, in 2015, they agreed on a pact for the future with the Minister of Public Health, which resulted in, among others, some tax cuts and the reimbursement of tests using biomarkers (Minister of Public Health, 2015). Patient organisations, and especially their umbrella organisations, are fairly new stakeholders within the Belgium SHI system. In 2015, these umbrella organisations were included in the Board of Directors of the Belgian Healthcare Knowledge Centre, which was an important step ahead for these organisations (De Block, 2015; Vlaams Patiëntenplatform, 2015). Finally, I also added

the category 'associations of medical experts'. The reason for their inclusion is twofold. First, there is an increased reliance on and institutionalisation of evidence-based guidelines within healthcare systems (Niessen, Grijseels & Rutten, 2004; Metaforum, 2015; Mykhalovskiy & Weir, 2004; Saltman et al., 2004). For example, in 2002 the Commission for Reimbursement of Medicines was founded which evaluates, based on the official guidelines for economic evaluations, the cost effectiveness of new medicines (Cleemput, Neyt, Van de Sande, & Thiry, 2012). Nevertheless, this approach is also increasingly contested (Greenhalgh, Howick & Maskrey, 2014; Metaforum, 2015). Second, in Belgium, these associations of medical experts often develop the guidelines that are used in clinical decision-making systems and, therefore, are important producers of discourses on evidence-based medicine.

A third sampling criterion relates to the definition of a health-policy stakeholder. It is necessary to define what a stakeholder is because this 'affects who and what counts' (Bryson, 2004, p. 23). In this dissertation, I defined a health-policy stakeholder as an organisation that has an interest in the SHI system or could have an active influence on the decision-making and implementation process. This definition is based on Freeman's (1984) original definition of a stakeholder and was adapted to the specific context of this research project. Furthermore, in order to be included in the sample, these stakeholders also had to be 'social actors' (Ramírez, 2001). An actor can be a stakeholder but he/she also needs to have the knowledge and capacity to actively participate within the SHI system. For example, individual patients are stakeholders because they have an interest in healthcare decisions. Yet, they were not included in my sample of stakeholders because they – as individuals – do not have the capacity

to act as social actors. Conversely, patient organisations were seen as stakeholders because they can act, and will be perceived by other stakeholders, as social actors (Ramírez, 2001).

Following these three criteria, a list was developed including possible health-policy stakeholders per category. However, in order to obtain a manageable sample (e.g. there are more than 100 patient organisations in Belgium) this list had to be reduced.

- ◆ *Government institutions.* There are several government institutions and departments involved in the Belgian SHI system. Some of these are involved in the practical organisation of the health insurance system, healthcare products and services, and others do research, develop guidelines, and support the health-policy making process. For the research that is part of this dissertation, I included two of each. All four institutions that were included in my sample incorporate various stakeholders in their consultation bodies.
- ◆ *Sickness fund agencies.* The 52 Belgian sickness fund agencies are at the national level grouped in five health insurance associations (HIAs) (Corens, 2007; Nonneman & Van Doorslaer, 1994; Schepers, 1993). Besides these HIAs, there is also a government agency (i.e. 'Hulpkas voor ziekte- en invaliditeitsuitkering or HZIV') that offers the legal health and disability insurance but no extra benefits or services, and a specific health insurance fund for employees of the Belgian National Railway Company (i.e. HR RailCare, 2018). Since the latter only targets a limited number of the population (i.e. employees of the National Railway Company) and the HZIV is officially not a sickness fund agency, I only focus on the five HIAs. More specifically, I selected two HIAs, the largest ideologically aligned HIA and the

largest not-ideologically aligned HIA. In Chapter 7, which is the only chapter that does not use interview data, I do not make a selection and focus on all five HIAs.

- ◆ *Associations of healthcare professionals.* The healthcare professionals are grouped within the SHI system in associations that represent the interests of specific groups of healthcare professionals. In this dissertation, I focus on physicians, who are, as healthcare providers, one of the main constituents of the SHI system. Furthermore, they are gatekeepers for medical treatments (Conrad, 2007), interact directly with patients, and remain important producers of discourses on health and illness. I selected the largest association of physicians, representing both medical specialists and general practitioners (RIZIV, 2014) and the largest association of Flemish general practitioners. I also focus on pharmacists, due to their involvement in the pharmaceutical-related activities of the SHI system. For example, the pharmacists are one of the stakeholders who finance the Belgian medicines agency through taxes and other contributions and reside in several of its consultation bodies. Furthermore, more recently, pharmacist have been ascribed a more active role in the care of patients. In 2014, patients were urged to give permission to share their pharmaceutical information (APB, 2014) and, in 2017, a campaign was launched to urge chronic patients to choose a family pharmacist (Minister of Public Health, 2017). Therefore, the association representing the majority of the Belgian pharmacists was also included in the sample.
- ◆ *Pharmaceutical industry.* With regard to the pharmaceutical industry, I selected an umbrella organisation which represents the interests of more than 130

pharmaceutical companies in Belgium, including the Belgian branches of the world's largest pharmaceutical companies. Besides this umbrella organisation, I selected one of these large companies. More specifically, I selected a large pharmaceutical company with Belgian roots that discovers, develops, and produces medicines and therapies. The company was included in the sample because it controls the entire pharmaceutical cycle. Furthermore, they are anchored within the global pharmaceutical landscape as they belong to a bigger American parent company. In Chapter 8, the data gathered from these two stakeholders were complemented with press releases from the four largest pharmaceutical companies in Belgium.

- ◆ *Patient organisations.* In Belgium, patient organisations are at the national level represented by two umbrella organisations (a French and Flemish one). Within the Belgian SHI system, these organisations are involved in various consultation bodies and are also part of the Board of Directors of the Belgian Healthcare Knowledge Centre since 2015. The largest umbrella organisation (i.e. the Flemish organisation which represents more than 110 patient organisations) was included in the sample. Moreover, because discourses on health and illness impact both patients as well as healthy individuals, I also included a consumer organisation who has a large health division and who is also included as a representative of patients/consumers in different consultation bodies of the SHI system. Finally, two patient organisations were included in our sample. These organisations were chosen because of the

specific conditions they focus on<sup>3</sup>, which are chronic conditions that have, due to the ageing of the population, a high prevalence and that are listed as some of the main causes of mortality (OECD, 2017). Furthermore, what makes these conditions interesting is that their medical treatment is contested (e.g. Redberg, 2016; Skolbekken, 2007).

- ◆ *Organisations of scientific medical experts.* Finally, two organisations of scientific medical experts were selected. The first organisation validates clinical guidelines, provides healthcare professionals with access to these guidelines, performs systematic reviews, and has developed a website providing the general public with evidence-based and reliable health information. The second organisation supports physicians and healthcare professionals by providing them with independent information about pharmaceuticals. They help physicians and healthcare professionals to implement evidence-based information.

In order to avoid the risk of excluding important stakeholders, this list was evaluated by two experts, who were familiar with the system. Finally, two test cases were added, a pharmaceutical company and a patient organisation, which were used to test the interview schedule. This resulted in a final theoretical sample of 19 organisations or stakeholders. In what follows, I provide more information about the data gathering process.

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<sup>3</sup> In order to guarantee the anonymity of the organisations in our sample, I cannot mention the names of these conditions.

## *Data gathering*

Step 1: Getting to know these organisations.

In order to obtain more information about these 19 organisations, the websites of these organisations were thoroughly scanned. An excel sheet containing several categories (see table 5.1) was used to systematically gather information. Relevant information and organisational documents, such as year reports or press releases, were also saved as pdf.

<b>Stakeholder</b>			
Name of the organisation		Description	
<b>Characteristics</b>			
Position: how are they involved in the production of health information?	Goals and interests	Relationships with other organisations	
<b>Distribution of information</b>			
Information channels (e.g. internet)	Medium (e.g. video)	Content	
<b>Discourse on health and illness</b>			
General	Definition of health and illness	Target population	Topics

**Table 5.1.** Overview of the categories of the excel sheet

Additionally, GoPress (i.e. Belgian press database) was used to search for recent news articles about each organisation. More specifically, I searched for news articles for the period 1<sup>st</sup> of January 2014 till the date of the search (i.e. February-March 2015). Hence, this first step provides a first introduction to the research context (Kvale & Brinkmann, 2009).

## Step 2: Elite interviews and developing the interview schedule.

As I wanted to study the discourses, interests, and position of Belgian health-policy stakeholders, I decided to not only gather organisational documents but also to interview the health-policy stakeholders in my sample in order to gain more insight into the motivations of these stakeholders. The second step therefore consisted of developing the interview schedule and preparing the interviews. Our sample of health-policy stakeholders consisted of 19 organisations. However, in order to gather information about these stakeholders, representatives had to be selected. I chose to work with elite interviews, which are interviews with individuals who 'occupy senior management and board level positions within organisations' (Harvey, 2011, p. 5). Hence, in this dissertation, elites are individuals who have a certain functional responsibility (Welch, Marschan-Piekkari, Penttinen & Tahvanainen, 2002). Following this definition, high-ranking management representatives and communication officers were selected. High-ranking management representatives, such as CEO's, are in charge of the daily management of the organisation and thus have to put into practice what the organisation stands for. Communication officers are in charge of the communication department and are the link between the organisation and the outside world. Furthermore, communication officers often act as spokespersons for their organisation and thus literally represent the organisation.

Subsequently, the interview schedule had to be developed. In this dissertation, semi-structured elite interviews were used. The interviews are semi-structured because I worked with a fixed set of topics that needed to be covered. By drawing on semi-structured interviews a systematic pattern was followed, which allowed to compare the different interviews, while at the same time this approach allowed to be flexible



and as a result to adapt to the specific situation of each interview (Kvale & Brinkmann, 2009). To make the representative feel at ease, the interview started with asking the representative to tell about his/her function within the organisation. After this introduction, questions were asked about the organisation and its goals, the relationship with other organisations, communication to and from other organisations, the organisation's view on health and illness, their communication policy, the content of their communication messages, and their relationship with the media. Nevertheless, this does not mean that other topics could not be raised as well during the interview. Finally, the managing director and the communication officer of each organisation were asked the same questions (i.e. the same interview schedule was used). However, there were some questions, such as 'are you involved in the content of these communication messages?', that were, as the communication officer is responsible for the content of the organisation's communication messages, only asked to the managing directors. The interview schedule can be found in Appendix 2 and consists of a list of fixed topics followed by suggestions for questions.

Finally, this interview schedule was tested. The CEO of a pharmaceutical company and the communication officer of a patient organisation were interviewed to test the interview schedule. These two test-interviews took place in March 2015. After these interviews, I evaluated the interview schedule and, since these test-interviews resulted in rich data, only some small changes were made. Because these test-interviews went well and only small changes in the interview schedule had to be made, the test-interviews were also included in the analysis.

### Step 3: Gaining access and conducting the interviews.

The third step in the data gathering process consisted of gaining access and conducting the elite interviews. Gaining access to elites can be a challenging task (Welch et al., 2002). In order to obtain access to the representatives of these 19 organisations various strategies were used. First, I prepared an e-mail which explained the research project's scope and in which I asked the representatives if they wanted to participate. As I expected that issues of confidentiality and anonymity would be very important for these representatives, I also attached the confidentiality agreement (see Appendix 3) to my e-mail. If, after two weeks, I did not receive a reply, the representatives were contacted by phone. Nevertheless, this e-mail often sufficed to convince the representatives to participate in the research project. Second, to some representatives I was introduced by Thierry Christiaens and Marc Bogaert, who, as members of the Belgian Centre for Pharmacotherapeutic information (BCFI), had direct access to these representatives. Third, it was often difficult to obtain the contact information of the managing director. Therefore, I started with interviewing the communication officer. Subsequently, at the end of the interview, the communication officer was asked if it would be possible to interview the managing director and if they could provide me with their contact information. This was a strategy that also worked very well.

These strategies made it possible to gain access to 18 of the 19 organisations in our sample. The 19<sup>th</sup> organisation, the umbrella organisation representing several patient organisations, unfortunately, refused to participate in the study. Additionally, it was not always possible to interview two representatives per organisation, as some organisations did not have a communication officer. There were also three interviews

were the key representative asked to involve a second person due to his/her specific expertise. This resulted in three double interviews. Finally, one patient organisation insisted that both the managing director and the communication officer were interviewed at the same time. Table 5.2 provides an overview of the total number of interviews (including the test-interviews) that were conducted between March and October 2015 and which lasted between 40 and 110 minutes.

<b>Type of organisation</b>	<b>Number of organisations</b>	<b>Number of interviews</b>
<b>Pharmaceutical industry</b>	3	5
<b>Government institutions</b>	4	8
<b>Sickness Fund Agencies</b>	2	6
<b>Patient organisations</b>	4	4
<b>Organisations of scientific medical experts</b>	2	2
<b>Associations of healthcare professionals</b>	3	5
<b>TOTAL</b>	<b>18</b>	<b>30</b>

**Table 5.2.** Overview of the organisations and number of interviews (including the test-interviews)

The interviews themselves always followed the same pattern; I started with providing the respondent with information about the research project's scope and privacy procedure, after which the respondent signed the confidentiality agreement (see Appendix 3), followed by the interview itself. At the end of the interview, respondents could ask the interviewer questions about the interview and/or the research project. Each interview was recorded and I tried to transcribe the interview as soon as possible afterwards.

The entire interview process was characterised by constantly going back and forth between step 2 and step 3 (Kvale & Brinkmann, 2009). This means that after each interview, the interview guide was evaluated and, if necessary, adapted. For instance, during the first interviews I asked the representatives what their organisation’s definition of health and illness was. However, I quickly learned that this question was too broad and too difficult for them and that they often gave a personal definition. Therefore, I changed this question to ‘If you communicate about health, which topics do you communicate about?’, which was a question that worked really well.

Step 4: Gathering additional data.

Finally, for two empirical chapters (i.e. Chapter 7 and 8) additional data were gathered. Table 5.3 provides an overview of these additional data.

<b>Stakeholder</b>	<b>Type of data</b>	<b>N</b>
<b>Sickness Fund Agencies</b>	Press release	26
	Website article	222
<b>Pharmaceutical Industry</b>	Press release	28
	Policy document	2
	Corporate communication document (annual CS report & booklet)	2
	Recording of meeting	4

**Table 5.3.** Overview of the additional data

*Press releases and website articles of sickness fund agencies.*

Chapter 7 draws on 248 website articles and press releases that concern ageing and ageing persons of the five health insurance associations (HIAs). Both press releases and website articles were gathered in May 2017 from the websites of these five HIAs.

First, press releases published in 2015 and 2016 were gathered. All HIAs, except of the HIA of the Neutral sickness fund agencies, publish their press releases online. In order to obtain the press releases from the HIA of the Neutral sickness fund agencies, their press liaison was contacted, who informed us that their HIA did not publish press releases. Subsequently, this sample of 106 press releases was read after which only the ones discussing ageing and ageing persons were kept. This resulted in a final sample of 26 press releases.

Second, the websites of the five HIAs were analysed. The Socialist, Liberal, and Christian HIAs have one general website for all the sickness fund agencies who are part of the HIA. Hence, for these three HIAs I used information from the general websites. Compared to the former, the Neutral and Independent HIA's have an individual website for each sickness fund agency that belongs to the HIA. Therefore, I decided to analyse these individual websites. More specifically, I selected all the websites of the Neutral (two websites) and Independent (two websites) sickness fund agencies active in the Dutch-speaking region (i.e. Flanders) of Belgium. I read every page and subpage of these seven websites, searching for information about ageing and ageing persons. Relevant pages were saved as pdf files, which resulted in a final sample of 222 website articles.

*Press releases, policy documents, and ethnographic data of pharmaceutical companies.*

In Chapter 8, I only use the interviews with the representatives of the pharmaceutical industry, which I supplemented with press releases, policy documents and ethnographic data. First, I collected all the press releases released by the four largest pharmaceutical companies in Belgium and their trade association in 2015. The Belgian websites of these companies were checked for press releases. When there were no press releases available, the Belgian press liaisons were contacted, who referred me to the international websites of these companies. These international press releases were often only meant for shareholders or specific populations (e.g. United States citizens). I then decided to only use press releases targeting a Belgian audience, written in Belgium's official languages (Dutch/French/German), resulting in a sample of 28 press releases. Second, during step 1 (getting to know the organisations), organisational documentation was gathered. During this step, I became aware of a relevant policy document; a pact between the Ministry of Public Health and the pharmaceutical industry. For the purpose of Chapter 8, I gathered the full-length version and the brochure of this pact. Third, I used data gathered by a colleague from the larger research project; Jana Declercq. She conducted ethnographic fieldwork at a large international pharmaceutical company for 15 non-consecutive days between May and July 2015, during which she gathered interviews, audio-recorded meetings and informal conversations, and collected field notes, documents on site, and extracts from the website (see also Declercq, 2018a; Declercq & Jacobs, 2018). As we were working on a similar topic (i.e. the discourse of the pharmaceutical industry), we decided to collaborate, which allowed me to use the data she gathered. More specifically, I selected the information that dealt with public

affairs and external communication of the company; an annual corporate social responsibility (CSR) report, a booklet titled 'facts & figures', and the audio-recordings of four meetings on external communication.

### **5.3. Framework guiding the analysis: discourse analysis**

*'Discourse analysis is not so much a recipe as a perspective from which to approach a text'*  
(Willig, 2014, p. 344).

Although my sampling and data collection draw on procedures that are similar to some of the basic procedures used in Grounded Theory (Evans, 2013; Strauss & Corbin, 1990), such as the interrelation between data collection and analysis, the ideas and principles that have guided my analysis derive from discourse analysis (Starks & Trinidad, 2007). Discourse analysis focuses 'on how language and discursive practices construct the social world in which human beings live' (Kvale & Brinkmann, 2009, p. 14). Discourse analysts thus try to understand the process of discourse construction and its social consequences (Lupton, 1992). This specific focus on language makes discourse analysis a suitable framework from which to approach my data (Burck, 2005), as I am interested in how health-policy stakeholders use language to construct and enact their interests and position.

There are many forms of discourse analysis which all have their specific theoretical and methodological premises (Bischoping & Gazso, 2016; Hodges et al., 2008; Schiffrin, Tannen & Hamilton, 2001; Willig, 2014). In order to emphasise the multidisciplinary and diversity of discourse analysis, Traynor (2013, p. 283) even wrote 'what are discourse analysis?'. However, even though there are theoretical and methodological differences between these approaches, there are several general

assumptions that underpin most of them (Burr, 1995; Jørgensen & Philips, 2002). These assumptions are based on social constructionism, as, according to Jørgensen and Philips (2002, p. 4), discourses analysis is 'one of the most widely used approaches within social constructionism'. A first assumption concerns how knowledge of the social world is treated (Jørgensen & Philips, 2002). Discourse analysts argue that our knowledge of the social world is not an objective truth but the result of the way in which we think, speak, and write about the social world. In other words, it is a product of discourse (Burr, 1995). Second, discourse analysts do not perceive these knowledges as fixed. Knowledges are historically and contextually situated, and, as a consequence, can change over time. Third, knowledges are constantly (re)constructed through social interactions. Fourth, the social construction of knowledge has social consequences (Jørgensen & Philips, 2002). More specifically, discourses define how we think about and behave in relation to certain phenomena and also restrict certain ways of thinking or behaving (Hall, 2001; Hodges et al., 2008; Lähdesmäki & Siltaoja, 2010). This also means that different discourses lead to different social actions (Baxter, 2010).

In this dissertation, I start from these assumptions and focus on the sociological use of language (Baxter, 2010; Hodges et al., 2008). Understanding how stakeholders define a problem is important as it 'affects how (or even if) society responds to the problem, and how the experiences of individuals are influenced by the definition and response to their problem' (Conrad & Barker, 2010, p. S76). Furthermore, Albright and colleagues (2018, p. 14) argue that it is interesting to study the language of stakeholders within a field as it shows 'how the field as a whole is constructed by the various moves players make through texts'.

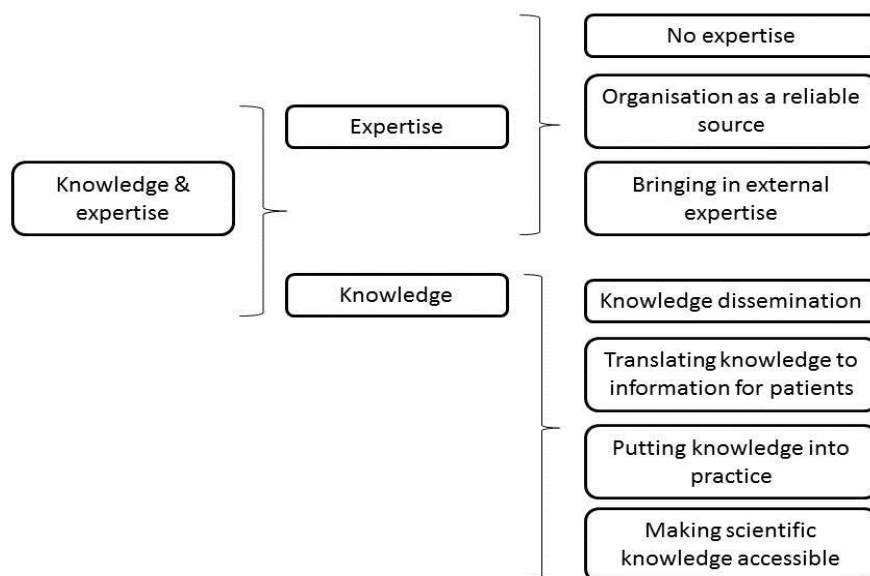


In contrast to some approaches to discourse analysis, such as Critical Discourse Analysis (CDA) or Foucauldian Discourse Analysis, I do not explicitly align myself with a particular theorist or movement (Bischoping & Gazso, 2016; Traynor, 2013). I use discourse analysis and its assumptions as a way to approach and analyse my data and I combine this perspective with theoretical insights and concepts from medicalisation studies and field theory. Supplementing a discourse analytical approach with other analytical theories on the specific research topic at hand is a common and valued approach within research that draws on discourse analysis (Jørgensen & Philips, 2002). Furthermore, I agree with Willig (2014) that discourse analysis is more a perspective from which to approach a text than an actual recipe on how to analyse these texts. Therefore, in order to facilitate the analysis, I often used the ideas and tools of two qualitative techniques<sup>4</sup>, which allowed me to structure and analyse the data in a more systematic way. More specifically, in Chapter 8, I draw on thematic analysis, which is 'a method for identifying, analysing, and reporting patterns (themes) within data' (Braun & Clarke, 2006, p. 6). In Chapter 7, I use positioning theory, which is a way to study how organisations discursively represent a) themselves as an organisation, b) their services, products, customers, and c) their positions on certain topics in formal communication, in order to encourage and sometimes even persuade their audiences (James, 2014). Chapters 6 and 9 do not explicitly draw on these two techniques. However, the observant reader might identify some traces of both techniques, as they have offered me a lot of inspiration and tools during the coding process.

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<sup>4</sup>The current chapter does not provide details on these techniques, as Chapters 7 and 8 provide an extensive description of them.

The actual coding process itself was characterised by various stages of coding and constant comparison. Starks and Trinidad (2007, p. 1375) explain that both Discourse analysis, Phenomenology, and Grounded Theory follow a similar general process of interpretation, starting with assigning codes to parts of the text, examining these codes for patterns, and grouping the data around central themes. As I was interested in the sociological use of language, I focused on recurrent patterns and broader themes within the discourse of health-policy stakeholders instead of individual utterances and words (Hodges et al., 2008). Figure 5.1 provides a visual example of how I integrated recurring themes that emerged from my data into broader themes. In this example, subthemes referring to issues of expertise and knowledge were embedded in two larger overarching themes. As both subthemes of ‘expertise’ and ‘knowledge’ were related and dealing with similar issues, they were eventually grouped in one large overarching theme ‘knowledge & expertise’.



**Figure 5.1.** Coding tree

#### **5.4. Quality of the data, research ethics, and reflexive thoughts**

*'Statistical analysis follows formulas and rules while, at the core, qualitative analysis is a creative process, depending on the insights and conceptual capabilities of the analyst' (Patton, 1999, p. 1190).*

##### ***Ensuring the quality of the data***

Although qualitative research has gained ground, its quality, rigorousness of its methods, and credibility are often questioned (Denzin & Giardina, 2008). Therefore, it is important to be transparent about the decision-making process and the techniques and methods that were used to gather and analyse the data (Patton, 1999), and to incorporate some quality checks into the research process (Tracy, 2010). The previous sections already provided details about the various steps and decisions that were made at the start of the research project. The current section discusses the quality checks that were incorporated into the various stages of the research process.

First, full-recording of the interviews and verbatim transcription of each interview by myself allowed to stay as close as possible to the interviews, as also the tone of the voice and pauses or hesitations were preserved (Giske & Artinian, 2007; Halcomb & Davidson, 2006). Furthermore, (re)listening to the interviews allowed me to evaluate the interviews, and thus to be reflexive about my own role and actions as an interviewer. An important advantage of verbatim transcription by the researcher herself is that it can also be seen as a form of data analysis (Wellard & Kenna, 2001). It allows to become familiar with the nuances of the research context and the researcher can take back some first impressions to the next interview. Hence, this approach enhances the quality of the data as it contributes to the process of

constantly going back and forth between data analysis and data gathering (i.e. constant comparison). Second, Nvivo 11 was used to assist in data management and to support the coding process. Using Computer Aided Qualitative Data Analysis Software (CAQDAS) helped to incorporate systematicity and consistency into the coding process. Third, 'thick description' was used. Denzin (1989, p. 83) describes thick description as:

'A thick description ... does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another' (Denzin, 1989, p. 83).

In other words, thick description means that the researcher provides the reader with details about the context in which the data are embedded (Tracy, 2010). Therefore, I tried to use large parts of texts to illustrate the results, instead of only selecting small parts. In the accompanying text, I also provided a lot of details and background information, which allows the reader to gain more insight into the context in which these discourses are produced.

A final, quality measure was the use of different types of triangulation. Triangulation is the use of 'two or more sources of data, theoretical frameworks, types of data collected, or researchers' (Tracy, 2010, p. 843) with the purpose of accounting for the bias and limitations that are linked to a specific method, framework, or type of data (Patton, 1999). This is important for a study, such as the current one, that deals with representatives that are rather experienced in answering questions and in which it is necessary to be able to distinguish between personal and organisational views (Berry, 2002). First, analyst triangulation was applied. Some of the data were analysed

independently by two researchers (i.e. the doctoral student and the second author of the specific study) and/or parts of the data were gathered by another researcher than the doctoral student (see also Appendix 1). Second, method triangulation was applied. More specifically, the interview data were complemented with organisational documentation. Third, by using information from various organisations and several representatives within an organisation, I also made use of source triangulation. Finally, with regard to theoretical triangulation, different theoretical perspectives were used (Patton, 1999). More specifically, I often drew on insights and perspectives from other disciplines, such as economics (e.g. literature on reputation in Chapter 8) and communication studies (e.g. journalism studies in Chapter 9), which allows to gain a broader as well as a deeper insight into the research topic. These different types of triangulation thus contribute to the inclusion of various perspectives into the research project and, as a consequence, enhance the quality of the data.

When talking about the quality and credibility of qualitative research, the credibility of the researcher is also an important element, because the researcher is at the heart of any qualitative inquiry (Patton, 1999; Tracy, 2010). In the next section, I reflect on my role as a researcher.

### *Researcher reflexivity*

Researcher reflexivity refers to a process of self-reference (Davies, 2008). It means turning back upon oneself and investigating one's impact on the research process (May & Perry, 2014; Steiner, 1991). Therefore, in this section, I turn back upon myself and investigate how some of my personal characteristics might have influenced the data.

First, when I started this research project, I had some experience with interviewing. Nevertheless, this experience was limited to the interviews I conducted for my master's thesis. Being that interviewing is not a method but a craft one has to learn (Kvale & Brinkmann, 2009), I had the feeling I still had a lot to learn. This means that the whole process of conducting interviews, transcribing, and analysing them was also a learning process. I gradually gained more confidence, improved my skills and, thus, became a more experienced interviewer. This definitely had an impact on the interviews. During the first interviews, I sounded very nervous when I asked a question. The questions I asked were also sometimes too broad and I used a lot of 'ok' and 'uhm'. For example, I asked the representatives what their organisation's definition of health and illness was, but I quickly learned that this question was too broad and too difficult for them and that they often gave a personal definition. So after a while I learned to be more specific and I started asking them 'If you communicate about health, which topics do you communicate about?'. The last interviews are thus more to the point and I think I dared to challenge the representatives more, which led to more nuanced and/or detailed answers from the representatives.

I also took some precautions in order to compensate for my limited experience in interviewing and to learn from possible mistakes. For instance, during the first test-interview, I was accompanied by an experienced post-doctoral researcher who, afterwards, evaluated my performance. I also compelled myself to, after each interview, make some notes and reflect on how the interview went. I also started with interviewing the organisations I was more familiar with or representatives who

I thought would be more responsive, and planned the more unfamiliar and/or more challenging ones at the end of my round of interviews.

Second, since I did not have a medical background and was, especially in the beginning, not familiar with all the intricacies of the Belgian social health insurance system, I was often perceived as an outsider. However, this is not necessarily problematic (Gair, 2012). I often felt this was beneficial. It allowed me to position myself as ignorant and ask questions about things that were self-evident. Furthermore, I think that it made me a neutral and less threatening actor within a field full of competing interests (Walt et al., 2008). If I would have had, for instance, a medical degree, patient organisations or sickness fund agencies could have positioned me as 'one of them' (i.e. one of the physicians).

Finally, there is the issue of power dynamics in elite settings (Declercq & Ayala, 2017; Kvale & Brinkmann, 2009; Smith, 2006). Traditionally, elite interviews are distinguished from non-elite interviews due to the impact this elite status might have on the data gathering and data construction process (Berry, 2002). However, more recently, researchers have argued that the powerful status of elites does not automatically mean that they manipulate the data construction or that they overpower the researcher (Declercq & Ayala, 2017; Smith, 2006). When I started the interviews, I knew that interviewing elites could be challenging, as they are used to being in control and telling other people what to do, and that I, during the interview, had to be aware of this issue. For instance, during one interview, I felt that the public relations officer, who was also a part-time university professor, really tried to get in charge of the interview. At one point, he started to ask me some questions:

Interviewer: Ok, so now I want to ask you some questions about health and illness. I've noticed that some people find this a difficult part of the interview, but let's try.

Representative: Ok, so you mean the people you have interviewed?

Interviewer: Yes.

Representative: Actually, who did you already interview?

Interviewer: I will answer your questions later. Can you give me examples of health-related problems that are important for your organisation?

Although I knew how to deal with a situation like that, it was challenging to interview someone who tends to ask a lot of questions, as it tends to disrupt the relationship between interviewer and interviewee. Nevertheless, during most interviews, these power dynamics did not explicitly surface. Most representatives did not position themselves as powerful and some of them even seemed nervous. Furthermore, the fact that I gathered a lot of information about each organisation during step 1 also allowed me to stay in control, as this allowed me to ask questions about things that the representatives, (un)intentionally, forgot to mention:

Interviewer: All those things indirectly target the general public, are there things you do that directly target them?

Representative: Not really, uhm patients are not really our direct uhm task

[Goes on explaining how they indirectly target the general public]

Interviewer: Don't you have a website, I think it's called [name of the website], that is targeted towards the general public?

Representative: Oh yes that's right, that is targeted to the public.



### *Ethical issues*

In this final section, I address some ethical issues, which are based on the statement of ethical practice of the British Sociological Association (BSA) (2017) and the code of ethics of the American Sociological Association (ASA) (1998; 2018).

*Consent, anonymity, and confidentiality.* First, as described above, when I contacted the potential representatives to invite them to participate in the research project, I provided them with an initial description of the focus of my study and I already offered them insight into the confidentiality agreement (see Appendix 3). At the start of the interview, the research project was more thoroughly explained and I gave the representative time to read the confidentiality agreement and ask questions about it. Afterwards, the agreement was signed and the representative received a copy of this document.

This confidentiality agreement also guaranteed the anonymity of the representative and their organisation. When I use the interview data, I, therefore, only mention the function of the representative and the stakeholder category of the organisation. The press releases and website articles used in Chapter 7 were not anonymised as these are data that are publicly available. In Chapter 8, I use both publicly available data (i.e. press releases and policy documents) and data from interviews and ethnographic fieldwork. Although these press releases and policy documents are public information, this chapter does not mention the names of the organisations as this jeopardises the anonymity of the organisations that participated in the interviews and ethnographic fieldwork.

*Duty of care.* The researcher also has a duty to take care of the respondents when they find it (emotionally) difficult to talk about certain topics. Although personal topics were not discussed, if respondents would have found it difficult to talk about certain topics, I would have suggested to stop the interview or talk about another topic. Some topics, such as conflicts of interests, were, for certain organisations, rather sensitive topics. Here, I reassured the representatives that this information would be treated with caution and that I would not literally quote them. Some respondents were already prepared to deal with sensitive issues and, during the interview, mentioned that 'what they were going to say next' was off the record.

*Data storage and access.* The raw interview data, interview transcripts, and the organisational documents are stored on the password protected computer of the doctoral student and on a secure server to which only the doctoral student, the student's main supervisor, and the server administrator of Ghent University have access. As this research project is part of a larger transdisciplinary research project, which was also explained to the representatives before the interview and in the confidentiality agreement, the transcribed and anonymised interviews are also stored on a secure server to which only the doctoral student, the other members of the projects' research team, and the server administrator of Ghent University have access. Unauthorised people cannot access the data. After the PhD is completed, the main promotor will remain responsible for the data and can grant access to the anonymised data for specific research purposes and this only five years after the PhD is completed.

*Distribution and publication of research.* As a researcher, one also has the duty to disseminate research findings to the participants of the study and to a broader non-

academic audience. The research findings were shared with the representatives from my sample during a stakeholder event in November 2017. The findings of Chapter 7 will also be shared with the Socialist HIA during a meeting in October 2018. Additionally, parts of the results have already been reported in non-academic articles. More specifically, together with Jana Declercq, an article was written for *Gids op Maatschappelijk Gebied*<sup>5</sup> and preliminary results were published in a small article on *Versvak*<sup>6</sup>, which is a website specialised in science communication. I plan to write, and disseminate, two other non-academic articles based on Chapters 7 and 8 of this dissertation.

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<sup>5</sup> Declercq, J., & Van den Bogaert, S. (2017). De informatiejungle van het gezondheidsnieuws in Vlaanderen, *De Gids op Maatschappelijk Gebied*, 108(9), 40-47.

<sup>6</sup> Van den Bogaert, S., & Jitomirskaya, V. (2015). Gezondheidsinformatie, waar komt dat vandaan? Available at [www.versvak.nl/gezondheid](http://www.versvak.nl/gezondheid)



## **PART II: Empirical studies and conclusion**

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## CHAPTER 6: Beyond ubiquity: unravelling medicalisation within the frame of health insurance and health-policy making

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Besides being extensively studied by health sociologists, medicalisation has also become a term that frequently appears in mainstream discourses on health and illness. Recently, scholars started to acknowledge a greater complexity within medicalisation. This chapter is situated within this research tradition and draws on three recurring critiques on the validity of medicalisation; critique on the construct validity, internal, and external validity. By examining the interests and network of health-policy stakeholders, this chapter attempts to unravel different mechanisms of medicalisation and demedicalisation within a social health insurance system. The empirical data for this chapter derive from 30 elite interviews with key informants from 18 organisations in Belgium. Key representatives of these organisations provided us with in-depth information about their political intentions and interests. This chapter provides empirical evidence that both medicalisation and demedicalisation are different processes that can occur simultaneously. Furthermore, in order to facilitate studies on medicalisation in an institutional context, this chapter proposes some indicators for medicalisation and demedicalisation.

## 6.1. Introduction

Over the past decades, numerous studies on medicalisation have been published. Early attempts of conceptualising medicalisation emphasised the expansion of medical jurisdiction and the definitional aspect. 'By medicalisation we mean defining behaviour as a medical problem or illness and mandating or licensing the medical profession to provide some sort of treatment for it' (Conrad, 1975, p. 12). These studies assume that there will be a 'pathologicalisation of everything' (Conrad, 2013, p. 207; Zola, 1972). More recent studies have taught us that 'rather than a fixed, universal process, medicalisation is fluid, relational, and shifts depending on the context' (Bell, 2016, p. 44).

Drawing on the results of a large qualitative study in Belgium, this chapter adds to this literature by presenting further insights into the medicalisation process. This article calls on three recurring critiques on the validity of medicalisation and uses the Belgian social health insurance system as a case-study, which is characterised by the inclusion of nongovernmental actors within the decision-making process. In this corporatist model, these various actors collaborate but also compete with each other. Decisions on what belongs to the medical sphere — and what does not belong — are, thus, constantly (re)negotiated. Hence, in this context, medicalisation is a fluid process instead of a fixed process. Starting from this fluid nature of medicalisation, we explore how processes of medicalisation and demedicalisation are constituted in this institutional context.



## 6.2. A brief history of medicalisation

Medicalisation is often defined as; ‘the process by which previously nonmedical problems become defined and treated as medical problems, usually as diseases or disorders’ (Conrad, 1992, p. 211). In early formulations of medicalisation, the concept was linked to medical dominance and the extension of medicine’s jurisdiction (Ballard & Elston, 2005), and was rooted in criticism on the medical takeover of everyday life (Illich, 1976; Zola, 1972). From the 1980s onwards, changes in the organisation of medicine and medical knowledge caused a shift in the drivers of medicalisation (Conrad, 2005). Ballard and Elston (2005, p. 234) argue that:

‘Medical sociologists have increasingly turned to the examination of the particular contexts and protagonist characteristics that are conducive (or not) to medicalisation, and of the different forms that medicalisation might take, rather than assuming it to be the inexorable outcome of medical dominance’.

Consequently, scholars view medicalisation as ‘a more complex, ambiguous, and contested process’ (Ballard & Elston, 2005, p. 230), and focus now on variations within medicalisation (Bell, 2016; Halfmann, 2012). Other publications have emphasized the importance of demedicalisation (Lowenberg & Davis, 1994; Halfmann, 2012), which is often defined as the obverse of medicalisation (Halfmann, 2012, p. 2). Lowenberg and Davis (1994, p. 594) argue that ‘there is no unilateral movement in the direction of *either* medicalisation or demedicalisation’. They emphasise that both processes can occur simultaneously and, consequently, encourage researchers to focus on resistance and constraints to medicalisation (Lowenberg & Davis, 1994; Halfmann, 2012).

Furthermore, different researchers have criticised the validity of medicalisation as a concept (Busfield, 2017). First, the very nature of medicalisation has been questioned. Davis (2006) has criticized the severing of the connection between medicalisation and medicine. He argues that the decoupling of medicalisation from the institution of medicine has created a situation in which 'we have no way to determine what constitutes a 'medical' term or framework' (Davis, 2006, p. 53). Others have claimed that the medicalisation thesis is no longer sufficient to explain new trends in medicine and medical sociology (Abraham, 2010; Clarke & Shim, 2011; Williams et al., 2011a). Clarke and Shim (2011, p. 173), therefore, conceptualised biomedicalisation as 'the transformation of medical phenomena by technoscientific means'. Another related concept is pharmaceuticalisation, which Abraham (2010) as well as Williams and colleagues (2011a) have conceptualised. Pharmaceuticalisation can be defined as 'the transformation of human conditions, capabilities and capacities into opportunities for pharmaceutical intervention' (Williams et al., 2011a, p. 711). Second, scholars have criticised the strong focus on the definitional aspect. More recently, the attention for practices and actors as mechanisms of medicalisation has increased (Clarke & Shime, 2011; Halfmann, 2012). Halfmann (2012), for example, developed a typology in which he distinguishes between three levels and dimensions of medicalisation and demedicalisation. According to him, medicalisation increases when biomedical vocabularies, practices or actors become more prevalent in addressing social problems (Halfmann, 2012, p. 6). Third, the external validity of medicalisation has been criticised. Most theories of medicalisation use the United States (USA) as a single-case study (Conrad & Bergey, 2014; Olafsdottir, 2010). This has led to an incomplete understanding of the medicalisation process as, according to Olafsdottir (2010, p. 241), 'the US has a unique relationship between the market, the

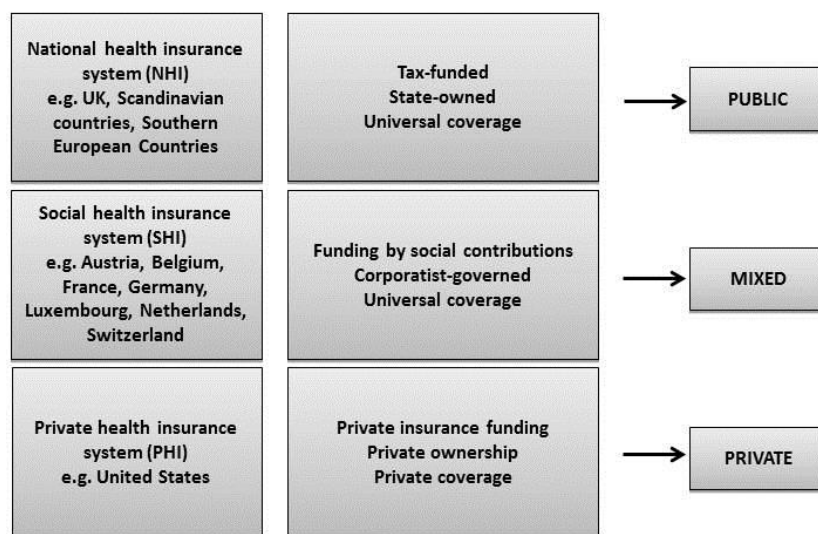
state and medicine'. Being the only advanced, industrialised society where healthcare is not universal to all citizens, medicine in the USA has become a commodity. Other practices, such as direct-to-consumer advertising, private ownership and funding of health insurance, further contribute to the commodification of healthcare (Busfield, 2010; Moran, 2000). In fact, Olafsdottir (2010, p. 251) argues that: 'medicalisation processes are embedded within institutional arrangements that shape how medicalisation happens and what mechanism are the main forces of medicalisation'. Consequently, medicalisation varies across institutional settings (Buffel et al., 2017; Conrad & Bergey, 2014; Olafsdottir, 2010).

This chapter addresses these critiques and contributes to the literature that focuses on the complexity of medicalisation. First, by focusing on the healthcare system, we bring the institution of medicine back into medicalisation. Second, by focusing on the interests and interplay between health-policy stakeholders, we go beyond a definitional approach towards medicalisation. That is to say, we perceive medicalisation as a multidimensional concept and analytic tool that allows us to investigate the expansion of medicine beyond its boundaries (Busfield, 2017). For the purpose of this study, we will focus mainly on two dimensions of medicalisation: practices and actors (Halfmann, 2012). Third, by using Belgium as a case-study, we add to the literature that analyses medicalisation in different institutional settings. More specifically, we will focus on the institutional context of a social health insurance system.

### **6.3. Social health insurance systems**

Within Western Europe we can distinguish two types of healthcare systems: national health insurance systems (NHI) and social health insurance systems (SHI) (Thomson

et al., 2009; van der Zee & Kroneman, 2007). The Organisation for Economic Co-operation and Development (OECD) adds a third type to this classification: the private health insurance model (PHI) (Schieber, 1987; Colombo & Tapay, 2004), which only exists in the USA (Giaimo & Manow, 1999; Olafsdottir, 2010; Colombo & Tapay, 2004). Figure 6.1. illustrates the differences in financing, ownership and provision of health services between these systems (Hassenteufel & Palier, 2007; Wendt et al., 2009). Although, it is often difficult to classify countries because of the internal variation within each healthcare model (Moran, 2000; Wendt et al., 2009) most countries can be situated in at least one of these systems (Hassenteufel & Palier, 2007; Wendt, 2014).



**Figure 6.1.** Overview of the three healthcare systems in Europe and the United States.

Figure 6.1 indicates that SHI systems are funded by social insurance contributions and managed by nongovernmental actors (e.g. sickness funds, physicians) (Wendt et al., 2009). In order to understand the SHI type of system, and the complexity it

implies, it is necessary to revisit its seven core components (Saltman et al., 2004, p. 6). A first core component is a scheme of risk-independent, transparent contributions, tied to the affiliated users' income and collected separately from other state revenues. Secondly, health insurance is organised through non-profit private sickness fund agencies, which collect health insurance contributions or receive them from a state-run fund. Third, citizens are free to choose their healthcare providers as well as the sickness fund agencies they affiliate to. Fourth, the SHI operates upon a principle of solidarity in what concerns the coverage, funding, and benefit packages.

The three remaining traits of the system are important for our analysis. A fifth trait is the inclusion of different actors that are all considered as constituent parts of the organisational structure. Sixth, SHI systems consist of a corporatist model of negotiations. The seventh, and last, core component also relates to the inclusion of different actors within the SHI system. As Saltman and colleagues (2004, p. 8) explain:

'SHI systems typically incorporate participation in governance decisions by a wide range of different actors. The most visible manifestation is the traditional process of self-regulation by which sickness funds and providers negotiate directly with each other over payment schedules, quality of care, patient volumes and other contract matters'.

At this point, it becomes clear that the SHI system is unique in that both private and public interests are combined in the public policy-making process through a network of stakeholders (Hassenteufel & Palier, 2007), which is key in the focus of this article. In order to fully grasp these various interests and potential conflicts between stakeholders, a qualitative approach is necessary. Considering that these intentions

and interests are often hidden to the naked eyes of researchers and other actors within the system, this process is difficult to fully comprehend by merely observing behaviours. Therefore, this study uses elite interviews. The term 'elite interviewing' is used to describe interviews with 'those who occupy senior management and board level positions within organisations' (Harvey, 2011, p.5).

#### **6.4. Methods**

##### *Selection of stakeholders*

This study is part of a larger research project that deals with health-policy stakeholders in Belgium. For purposes of this study, a stakeholder is defined as an organisation that has an interest in the SHI system or could have an active influence on the decision-making and implementation processes (Bryson, 2004). This definition is related to what Ramírez (2001) calls 'social actors'. Someone can be a stakeholder, but he/she also has to have the knowledge and capacity to act as a social actor. For example, individual patients are stakeholders because they have an interest in healthcare decisions. Yet, they are not included in our sample of stakeholders because they as individuals do not have the capacity to act as social actors. Conversely, patient organisations are seen as stakeholders because they have both the knowledge and capacity to actively participate within the SHI system. Moreover, other stakeholders will perceive them as social actors.

In order to construct a meaningful sample, we organised the stakeholders in six categories (see table 6.1) that are based on the types of organisations as described in the literature (Britten, 2008; Busfield, 2010) and the types of organisations included in the organisational structure of the Belgian SHI system. Subsequently, to overcome

the risk of accidentally omitting important parties, these categories were scrutinised by two experts, who were familiar with the system. The final sampling model included 19 stakeholders operating across the Belgian SHI system.

### *Selection of key figures*

Once the stakeholders were defined, elite interviews were conducted with key informants within each organisation. The first key figures we selected were high-ranking management representatives (e.g. Chief Executive Officer and managers), as their position provides them with a general overview of the respective organisation and its goals. Since this study was concerned with health politics and communication, the communication officers were also recruited as interviewees. Interviewing two key figures per organisation allowed to distinguish between the official organisational rhetoric and personal views, and it offered a quality check (Berry, 2002). It enabled comparing the information provided by one person or organisation with the information by another person or organisation (Patton, 1999).

Table 6.1 gives an overview of the number of organisations and interviews, which were undertaken between March and October 2015. Although the sampling model considered 19 organisations, one stakeholder declined to take part in the research. Note that, in case of small size organisations, only someone at the management level was interviewed. Finally, in four cases a double interview took place because the key informant either asked to involve a second informant or insisted that the director and the communication officer were interviewed at the same moment.

Type of organisation	Number of organisations	Number of interviews
Pharmaceutical industry	3	5
Government institutions	4	8
Sickness Fund Agencies	2	6
Patient organisations	4	4
Organisations of scientific medical experts	2	2
Associations of healthcare professionals	3	5
<b>TOTAL</b>	<b>18</b>	<b>30</b>

**Table 6.1.** Overview of organisations and interviews.

### *Data gathering and analysis*

A semi-structured guide with open-ended questions was used to gather in-depth information about the interests and relations between these stakeholders. Each respondent was given an explanation about the research project's scope and privacy procedure and then signed a confidentiality agreement allowing us to record the interviews. Several strategies were used to ensure the quality of the data and results, such as full recording and transcription of the interviews (Aberbach & Rockman, 2002), and CAQDAS techniques to ease data management. Organisational documentation, press releases and policy documents were gathered as well. The analysis itself consisted of different stages of coding and constant comparison.

### **6.5. Findings**

Our results indicate that the various interests of these stakeholders and the complex interplay between them lead towards both medicalisation and demedicalisation processes. To better understand this complex interplay between stakeholders and



their interests, the following subsections provide an in-depth analysis of each stakeholder.

### *Sickness Funds*

The following quote of one of the representatives of the sickness funds summarises the main interests of sickness fund agencies:

‘We’re a social insurance company. We’re a social movement and we’re a social entrepreneur, and everything we do is related to one of those 3 domains’ (Sickness Fund Agency 1).

First, sickness fund agencies are *social insurance companies*. The Belgian SHI system was conceived when in 1894 the law on mutual benefit funds was enacted (Corens, 2007; Schepers, 1993). Starting from 1900, these sickness fund agencies were grouped at the national level in six Health Insurance Associations (HIAs), which are private, non-profit organisations entrusted with a central role in the SHI system (Nonneman & van Doorslaer, 1994). These HIAs gradually became more important and were in a constant struggle with the medical profession (Schepers, 1993). The Health Insurance Act of 1963 extended the coverage of the compulsory health insurance and introduced a system of conventions and agreements (Callens & Peers, 2015; Corens, 2007). Furthermore, the compulsory health insurance market is closed to new entrants, granting HIAs a monopoly position within the system (Nonneman & van Doorslaer, 1994).

Before 1994, sickness fund agencies were not held financially responsible for their expenses, meaning that for them cost containment was less important. Starting from 1994, a system of financial responsibility was introduced (Callens & Peers, 2015).

Sickness fund agencies became more focused on keeping the healthcare budget within certain limits. This has become a part of their identity, and their discourses reflect this identity:

‘We don’t have campaigns that encourage the use of medicines. On the contrary, I can give you two, even three, examples of campaigns against the overconsumption of medicines’ (Sickness Fund Agency 1).

This quote reflects one of the main themes within their discourse, namely the overconsumption of medicines and other treatments. Other recurring themes were self-care and the use of generic medicines. Moreover, the law on financial responsibility uses the efforts made with regard to health education, promotion, and the use of less expensive treatments as one of the bench-marks to evaluate the financial management of sickness funds (Callens & Peers, 2015). Our interviewees provided us with various insights into these efforts. For example, one sickness fund agency developed an online tool that helps losing weight and gives dietary advice. Furthermore, in our interviews and in a recent position paper (Brenez, 2015), the battle against overconsumption and fraud was described as an important challenge for the future:

‘For example, physicians and hospitals who charge the same treatment twice. Physicians who perform a treatment that they aren’t allowed to perform. Unnecessary testing of urine or blood by hospitals’ (Sickness Fund Agency 1).

As a consequence, their identity, discourse, and practices are focused on lifestyle solutions for (medical) problems instead of biomedical practices, and encourage demedicalisation of certain problems (Halfmann, 2012).

Second, sickness fund agencies are *social movements*. Historically, sickness fund agencies were associated with the labour movement and they developed along political and religious lines (Nonneman & van Doorslaer, 1994). One representative explains:

‘They developed on the stairs of churches or in “*volkshuizen*” [social meeting places for working people]’ (Sickness Fund Agency 1).

This historical background still influences their goals and priorities. For example, the Independent sickness fund agency is the result of a merger between small mutual benefit funds for professionals. Nowadays, this focus on professionals is still reflected in their magazine for health professionals. Moreover, these different ideological backgrounds lead to differences in the benefits packages offered by the sickness funds. For example, recently the Socialist sickness fund agency announced that they would reimburse the non-refundable part of medical expenses, so that GP consultations would become free of charge (Solidaris, 2016). According to the Socialist sickness fund agency, this reimbursement leads towards increased access to care and more solidarity within the healthcare system. Other sickness fund agencies disagree with this practice, as it encourages medical treatment. According to them, the non-refundable part is necessary to raise awareness of its costs.

These differences in benefits packages are also related to the third function of sickness fund agencies; their *social entrepreneur* function. Besides having a monopoly position within the compulsory system, sickness fund agencies also offer additional insurance and benefits, such as sauna sessions. These additional benefits are driven by a competition between sickness fund agencies for new members (Nonneman & van Doorslaer, 1994), a logic that is amplified by the competition within the private,

supplementary, health insurance market, in which sickness fund agencies also participate. This competition is driven by two goals: more members means more revenue, and competition for ideological dominance and political power (Nonneman & van Doorslaer, 1944). The representatives in our sample often referred to each other as *'con-collega's'*, meaning that they are colleagues but also competitors. They are colleagues in the sense that they often work together and negotiate as one group. Nevertheless, they are also competitors, and this competition often results in medicalising practices. One of the representatives gave the example of alternative medicine, which is not reimbursed within the compulsory system (Corens, 2007). Notwithstanding their important role within the compulsory system, most sickness fund agencies offer some reimbursement for alternative medicine. The representative explained that, *'although they —as a sickness fund agency — know that alternative treatments do not work, lay people use these alternative treatments'*. Consequently, they reimburse some treatments. More specifically, the ones that are prescribed by physicians, in order to protect patients from *'charlatans'* and potentially harmful treatments. Undoubtedly, this is the official discourse. Most of these treatments are reimbursed in order to attract new members, and to compete with each other.

### ***Patient organisations***

From our historical overview of the development of sickness fund agencies, it becomes clear that they originally were conceived as the defenders of patients (Schepers, 1993). In 1999 and 2000, two umbrella organisations each representing around 100 patient organisations were founded (Belgian Official Journal, 1999, 2000). These umbrella organisations gradually became more prevalent within the SHI system, and there is a tendency towards including them in different consultation

bodies. In March 2015, the Belgian Minister of Public Health announced that these organisations would be included in the Board of Directors of the Belgian Healthcare Knowledge Centre (KCE). Moreover, she announced that patients needed a voice within the health-policy making process, because they were '*an essential actor*' within the organisation of healthcare (De Block, 2015). This announcement suggests that the Minister questions the role of sickness fund agencies as defenders of the patient. In fact, some of our interviewees also questioned their role, and indicated that they preferred working together with patient organisations because they are independent from any political background. The following interview excerpt of one of the sickness fund agencies summarises the main differences between these organisations:

'That's something that isn't yet clear. What is the role of the patient organisation and what is the role of the sickness funds? As I mentioned, patient organisations will focus on the interests of the sick. We [sickness fund agencies] have to defend all our affiliated members and look to the future, to the challenges that lie ahead. What are the needs? Which budgets do we need? And how are we going to organise those budgets?' (Sickness Fund Agency 2).

Patient organisations focus on '*the sick*', while sickness fund agencies have to defend all their members, irrespective of their health status. These patient organisations are what Halfmann (2012) calls biomedical actors – advocating for a specific disease is key to their identity. Furthermore, our interviews and a recent study indicate that most patient organisations are continuously struggling to find sufficient (financial) resources (Denis & Mergaert, 2009). As a consequence, patient organisations often depend on financing by the government or the pharmaceutical industry, and they are constantly balancing between maintaining their independence and surviving. This financial dependence further strengthens their focus on biomedicine and their

identity as biomedical actors (Denis & Mergaert, 2009). Consequently, one could argue that, because of their specific background, the rise of patient organisations as more prevalent and powerful biomedical actors increases medicalisation within the Belgian system.

However, as they are fairly new, these umbrella organisations are not yet anchored in the system. They are still, as the previous interview excerpt showed, struggling with their identity. As they represent various patient organisations, they have to find a balance between the different goals and interests of all their member organisations. The following interview excerpt of one of their members illustrates this difficult balance between the interests of individual patient organisations, who focus on one disease, and the development of a general framework that suits all these individual organisations:

‘Our focus is on [name of disease]. It’s good to think about a general framework, that there’s an organisation that represents everyone. But in the end, we will always focus on [name of disease]. That’s our focus. And as an umbrella organisation, you have to find a good balance’ (Patient organisation 4).

This has resulted in a strong focus of these umbrella organisations on patient rights, empowerment, and the organisation of the healthcare system in general, instead of advocacy for certain diseases or therapies. When asked what these organisations do, one of their member organisations answered:

‘Making sure that patients are represented within the healthcare policy-process. They also focus on a number of social issues, such as patient rights and insurances. When it comes to a specific disease, they always refer to the

individual patient organisations. They have a very strict code about that' (Patient organisation 4).

We can argue that by mainly focusing on the position of patients within the SHI system these umbrella organisations demedicalise because they try to decrease the power of the medical profession and increase the power of patients. This corresponds with the fact that, notwithstanding their differences, the representatives of the sickness fund agencies and patient organisations in our sample also refer to each other as allies. They explain that they often work together, and try to be a united cartel against the industry and associations of healthcare professionals. This suggests that these organisations identify themselves as counterforces against medicine. For example, a coalition of sickness fund agencies and patient organisations recently launched a petition against the pricing policy of pharmaceutical companies (Test-Aankoop, 2016a). Undoubtedly, in this context, these stakeholders challenge the power of biomedical actors, therefore encouraging demedicalisation.

### *Pharmaceutical industry*

Another important stakeholder within the Belgian SHI system is the pharmaceutical industry, who are at the institutional level represented by an umbrella organisation. In the previous subsections, we have unravelled different conflicting interests and practices both within and between organisations that lead to both processes of medicalisation and demedicalisation. Our interviews reveal a slightly different pattern for the pharmaceutical industry. They do not experience the same internal challenges as our previous stakeholders, but do get challenged by other stakeholders.

Our interviewees often referred to the same issues. For example, on an institutional level, their main concern is for patients to get access to their products by getting them approved and reimbursed, which is clearly reflected in their discourse and practices.

‘Our main goals as [name of the company] are... of course... making sure that patients get access to our medicines. We develop new medicines that have to be registered and then it’s our goal to make sure that they’re available for patients’ (Pharmaceutical industry 3).

Market approval and reimbursement are important tools for getting new – often very expensive – innovative medicines to patients. When talking about market access, our interviewees often referred to Belgium as an important ‘*Pharma country*’. The pharmaceutical industry is indeed a significant economic player. In 2015, they invested 2.6M€ in research and development (R&D) on pharmaceuticals, making Belgium one of the leading R&D countries in Europe (OECD, 2015). Furthermore, they are the third largest exporter of pharmaceuticals in Europe (EFPIA, 2016), and with an added value of €181,500 per employee they are the second most important industry in Belgium (Pharma.be, 2015). Since they only have an advisory function within the different consultation bodies, this economic position is often used to influence policy-decisions. The Itinera Institute even described them as one of the most powerful players within the SHI system (Daue & Crainich, 2008). Undoubtedly, this is a result of their significant economic position, which has also resulted in a pact with the Ministry (Minister of Public Health, 2015). Increased access to new innovations and the reimbursement of tests using biomarkers were important results of this pact (Minister of Public Health, 2015). Both decisions increase the use of biomedical technologies in the administration of health and illness. As a



consequence, this focus on new biomedical treatments and their economic position make them a prevalent and powerful biomedical actor within the Belgian SHI system, therefore increasing medicalisation.

Notwithstanding this position, the pharmaceutical industry is just one of the many stakeholders within the Belgian corporatist-model and they — due to their advisory function— have to look for other ways to influence policy-decisions. Our interviewees often referred to the need to collaborate with other stakeholders. One of the representatives described this logic as follows:

‘There are different projects in which we work together with them [the pharmacists]. We believe in collaboration. Nowadays, there are less organisations who follow an individual path. For us, dialogue and collaboration are two important goals. I believe it’s the only way to develop good initiatives’ (Pharmaceutical industry 2).

The representatives referred to regular meetings with the association of pharmacists and collaborations together with sickness funds. The following quote from an association of healthcare professionals explains the goal of these meetings:

‘We frequently talk to [umbrella organisation of the pharmaceutical industry]. We also have regular meetings with other industries in order to exchanges views on the evolution of medicines’ (Association of health professionals 1).

Furthermore, medical representatives still play an important role within the medical education of physicians as well. And recently, a website revealing the financial transfers between the pharmaceutical industry and healthcare professionals was founded. In 2015, 138.5M€ were spent on research, conference and lecture fees. Of this sum, 7.5M€ were used to reimburse healthcare professionals for their services

(Eckert & Cools, 2016). Consequently, serious investments are made to maintain relationships with other stakeholders.

However, this multi-stakeholder model also means that other stakeholders can act as counterforces against the industry. For example, in 1998, an independent organisation of medical representatives was founded (Farmaka, 2016). Other stakeholders publicly challenge the pharmaceutical industry. For example, in March 2016, a patient organisation published a report in which 7250 medicines were evaluated. This report questioned the use and safety of 13% of the evaluated medicines (Test-Aankoop, 2016b). As a consequence, these stakeholders challenge the power of the pharmaceutical industry and discourage the use of pharmaceuticals, therefore encouraging demedicalisation.

### *Associations of healthcare professionals*

In Belgium, physicians are grouped in medical associations (Schepers & Casparie, 1997). The first medical associations date back as early as 1840 (Schepers, 1993). Since 1998, elections are held to decide on the number of representatives of each union in the Medicomut (the negotiations between physicians and sickness fund agencies). These unions represent different groups of physicians and models of medical practice (Schepers & Casparie, 1997), which has consequences for their identity, practices and discourses. First, these unions have to decide on their own identity. Do they represent only medical specialists or general practitioners or both? Do they represent Dutch-speaking or French-speaking Belgian physicians? Do they defend liberal medicine (autonomy and dominance for physicians) or are they more moderate? Clearly, there are large differences between these unions. For example, one of the oldest unions represents mostly medical specialists, both French-speaking

and Dutch-speaking, and is rather conservative in its approach. Its representative frequently repeated: *'we are a union for physicians'*, which means that all their activities are focused on keeping or extending the freedom — and dominance — of physicians and of the medical profession. They stress the importance of the physician-patient relation:

'The individual, the patient has to be looked after and the GP or the physician is his lawyer' (Association of healthcare professionals, 2).

The union that represents mostly Flemish general practitioners has a more progressive, moderate, approach. They believe that:

'Uhm we want to promote the GP but in a broader context. So, the GP as one of the many caregivers of a patient. We want to promote every aspect of their profession. We specifically chose to not use the word defending, because we want to support the future, and a new view on care' (Association of healthcare professionals, 3).

These differences also lead to different practices. For example, the first union, due to its emphasis on physician's autonomy, strongly advocated against the introduction of a third-party payment scheme, as it would allegedly threaten that autonomy (BVAS, 2015). Consequently, they have a strong biomedical identity and encourage medicalisation. The second union, on the other hand, did not oppose the idea of a third-party payment scheme, but opposed the way the scheme would be implemented. Therefore, they came with an alternative implementation plan (AADM, 2015). This shows that they are less focused on medical dominance, have a weaker biomedical identity, and can contribute to demedicalisation.

Furthermore, as elections are held to decide on the number of representatives in the *Medicomut*, these organisations also compete with each other. The following interview excerpt indicates the importance of being elected:

‘If we aren’t elected, we consult other stakeholders then the physicians to obtain information. We believe in a holistic approach. We don’t want to be conservative. The [name of other union] is also more progressive, but the [name of union] is very conservative. They will withhold information. That’s the way it works’ (Association of healthcare professionals, 3).

Consequently, the union that obtains the majority of the votes can heavily influence the direction of the health-policy process. In 2014, the more conservative union obtained 55% of the votes, whereas the progressive— and first time participant — union obtained 21% of the votes (RIZIV, 2014). In 1998, however, the conservative union obtained 67% of the votes (RIZIV, 2014). Hence, the new progressive union may become a counterforce against the dominance of the conservative union, and could decrease medicalisation.

Finally, as explained earlier, both sickness fund agencies and associations of healthcare professionals are anchored in the SHI system, and decisions are made through a system of conventions and agreements. Even though both groups often compete with each other, they are also allies in lobbying for a larger budget. A larger budget involves more means for sickness fund agencies, because the total healthcare budget is divided between the different sickness fund agencies, and it means a better fee schedule for providers (Callens & Peers, 2015). Consequently, this identity as supporters of a larger budget increases medicalisation.

However, every two years sickness fund agencies and associations of physicians have to agree on the fee schedule (Callens & Peers, 2015). During these negotiations sickness fund agencies and associations of physicians are opponents. The following interview excerpt illustrates this duality:

‘The associations of healthcare professionals are partners, who’re also — just like sickness fund agencies — anchored in the system. They defend their members. This means that you have the physicians who advocate for quality of care and fair, sometimes undue, fees. Sickness fund agencies also defend quality of care, but want reasonable fees. They negotiate with healthcare professionals to obtain higher quality and reasonable fees. Sickness fund agencies have to keep the healthcare budget in mind’ (Sickness Fund Agency 1).

Hence, in this case, associations of healthcare professionals medicalise because they, by raising the fees and extending the number of treatments, want to extend the autonomy and dominance of physicians. However, due to the multi-stakeholder model, their power is limited. They have to come to an agreement with sickness fund agencies, who will resist higher fees and —as described in the first subsection — encourage demedicalisation. These tensions between physicians and sickness fund agencies create stability within the SHI system, but also impede drastic healthcare reforms (Cantillon, 2008).

### *The government and Minister of Public Health*

The Belgian SHI system is a part of the broader Belgian welfare state. Belgium is classified as a conservative or Bismarckian welfare regime, where the role of the market is marginalised and benefits depend on employment status (Esping-Andersen, 1990. Eikemo & Bambra, 2008). This welfare regime is characterised by

'neocorporatism' (Cantillon, 2008). Decisions are made by negotiations between different stakeholders but the government does not play a passive role. The government organises these negotiations, facilitates, and regulates this corporatist process, limiting the autonomy of these stakeholders (Cantillon, 2008). The following interview excerpt illustrates the role of the state:

'The minister is, as you know, responsible for the social security. The social security consists of different departments. One of those departments is the NIHDI [National Institute for Health and Disability Insurance]. The NIHDI distributes the money. It goes to the sickness fund agencies and these are public law bodies managed by unions. The Minister holds the guardianship. In other words, the Minister has a veto concerning the decisions of the social partners (e.g. sickness fund agencies and healthcare providers)...' (Sickness Fund Agency 1).

Clearly, the agreements made by the other stakeholders need the final approval of the Minister of Public Health. Moreover, it was the Minister who decided to include patient organisations in the Board of Directors of the KCE. The figure of the Minister as a veto player is, thus, important. Tsebelis (2000, p. 442) describes veto players as 'individual or collective decision-makers whose agreement is required for the change of the status quo'.

Over the past decades, healthcare expenditures have grown significantly. In 2012, health spending accounted for 10.2% of the Belgian GDP, while in 1997 this was only 7.6% (Cantillon, 2008; OECD, 2015). Consequently, rational spending and budget cuts have become important matters and have led to more interventions by the state. For example, in October 2015, the stakeholders within the NIHDI rejected the budget proposal of the Minister because the budget cuts were too deep. She ignored their

advice and convinced the government to approve the proposal. This example indicates that role of the Minister as a veto player has important consequences. Here, this discourse on limiting the healthcare spending encourages demedicalisation.

The political and professional background of the Minister also plays a role. For example, the previous Minister – a lawyer, representing the Socialist Party – created opportunities for homeopathy, increasing the medicalisation of alternative medicine, while the current Minister – a physician, representing the Liberal Party – only accepts Evidence-Based treatments (De Morgen, 2013; Vankrunkelsven, 2014), demedicalising alternative medicine. Clearly, politics play a role within the medicalisation process. Through the minister certain political ideologies become more or less prevalent. This more active role of the Minister is related to the evolution towards a more active welfare state, that focuses on more active investment policies instead of passive protections policies (Cantillon, 2008). The law on financial responsibility of sickness fund agencies is one of the results of this more active welfare state. Another characteristic is the focus on empowerment and individual responsibility, which – as we explained in the first subsection – encourages demedicalisation. Consequently, the health-policy process is not neutral. Welfare state characteristics and political ideologies influence decisions, leading towards both processes of medicalisation and demedicalisation. For example, current neoliberal policies focus on cost containment and individual responsibility that are realised by an increase in state intervention, which encourages demedicalisation. However, these policies also increase the involvement of market-forces in health-policy making (e.g. the pact between the Minister and the industry), which encourages medicalisation.

### *Mechanisms of medicalisation and demedicalisation*

Following these findings, we are able to distinguish some mechanisms of medicalisation and demedicalisation. Table 6.2 gives an overview of these indicators.

<b>Medicalisation</b>	<b>Demedicalisation</b>
<ul style="list-style-type: none"><li>• High competition between health insurance companies and/or sickness fund agencies</li><li>• Number of disease-specific patient organisations involved in decision-making process</li><li>• Financial transfers between pharmaceutical industry and health-policy stakeholders (e.g. patient organisations, associations of healthcare professionals)</li><li>• Share in GDP<sup>7</sup> of pharmaceutical industry</li><li>• Involving market forces in health-policy making</li></ul>	<ul style="list-style-type: none"><li>• Campaigns of health-policy stakeholders focusing on self-care, overconsumption of medicines or use of generic medicines</li><li>• Involvement of umbrella organisations grouping various patient organisations and diseases in decision-making process</li><li>• High competition between associations of healthcare professionals</li><li>• Increased state interventions related to cost containment</li></ul>

**Table 6.2.** Indicators of medicalisation and demedicalisation.

These mechanisms go beyond the specific context of the Belgian case and can serve as indicators for medicalisation and demedicalisation in an institutional context. For example, the USA has a PHI system and health insurance is organised through private insurance companies. As sickness fund agencies, these insurance companies operate within a health insurance market and they compete with each other for

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<sup>7</sup> Gross domestic product (GDP)



members. The United Kingdom has a NHI system, which is a state led system. During the Thatcher regime, cost containment and efficiency, which are principles that encourage demedicalisation, were key principles leading government decisions. Hence, state intervention was strengthened but also some market-forces, whose involvement encourage medicalisation, were introduced (Giaino & Manow, 1999). These simple examples suggest that these indicators of medicalisation and demedicalisation can be applied to various institutional settings. Nevertheless, comparative research is needed in order to compare these indicators systematically across different institutional settings, and to expand this list of indicators as well.

## **6.6. Conclusion**

Recent studies have emphasised the contested and fluid nature of medicalisation. Starting from this premise, we used elite interviews to gain in-depth insight into the political intentions and behaviours of various health-policy stakeholders within the institutional context of the Belgian SHI system. The main goal of this study was to analyse how processes of medicalisation and demedicalisation are constituted within this specific institutional context. This SHI system brings various public and private interests together which results in a constant struggle over what belongs to the medical sphere (and what does not) and, therefore, offers the possibility to observe the fluid nature of medicalisation. Moreover, this case-study allowed us to distinguish between some mechanisms of medicalisation and demedicalisation on an institutional level.

As we have shown, medicalisation and demedicalisation are two different processes that can —and in fact do in our setting — occur simultaneously. This is an important observation that needed more empirical support. Despite drawing on elite interviews

alone, ours is a relevant contribution in this line. Moreover, we have addressed three recurring critiques on the validity of medicalisation. First, by focusing on practices and actors, this article goes beyond a definitional approach towards medicalisation. Our study adds to the literature that provides empirical evidence for the multidimensionality of medicalisation. Second, by focusing on the context of the Belgian healthcare system, we brought the institution of medicine back in our analysis and we add to the literature that goes beyond the USA as a single-case study. Not only have we analysed medicalisation in another institutional setting, we have used this setting to develop indicators of medicalisation and demedicalisation that go beyond the context of the SHI system, and can be used by other researchers as indicators for medicalisation or demedicalisation. For example, various countries have emphasised the need to involve patients in health-policy making. Researchers who want to gain more insight into medicalisation or demedicalisation by patient organisations can use their funding and type of organisation as indicators. However, this list of indicators is not comprehensive and needs to be validated by comparative quantitative research. Furthermore, although other scholars have offered valuable insight in this field (Buffel et al., 2017; Olafsdottir, 2010), more comparative research on medicalisation in various institutional settings is necessary.

## CHAPTER 7: The silver lining of greying: ageing discourses and positioning of ageing persons in the field of social health insurance

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Contemporary ageing discourses and policies perceive being active as the key to a good later life and thereby focus on individual responsibility and self-care. Drawing on website articles and press releases of Belgian sickness fund agencies, this chapter analyses the ageing discourses and positioning of ageing persons of these organisations. A discourse analysis was performed using positioning theory to analyse how sickness fund agencies discursively construct the ageing process and position ageing persons, and to investigate how these positioning acts are related to sickness fund agencies' roles as social insurer, social movement, social entrepreneur, and private insurer.

Our results reveal three storylines on ageing; ageing as a medical problem, ageing as a new stage in life and ageing as a natural life process. These storylines are applied to construct ageing and position ageing persons in different ways. Depending on their role, sickness fund agencies take on a different position drawing on these different storylines. We also show how these storylines reproduce the moral framework on how to age well and thereby disempower ageing persons. Our results underline the importance of multidimensional perspectives on ageing.

## 7.1. Introduction

The ageing of the population has resulted in discussions on how to age well. Ageing discourses contain socially constructed assumptions about ageing and structure how society thinks, speaks, writes about, and deals with ageing (Kotter-Grühn, 2014; Lassen & Moreira, 2014; Rudman, 2006b). It is important to understand this continuous process of discourse construction because these ideas have material impacts on how ageing persons are treated, valued, and supported (Allen & Wiles, 2013).

Ageing discourses increasingly focus on staying active and avoiding ageing altogether (Zaidi & Howse, 2017). Conrad (2007, p. 25) states:

‘we live in an ageist society in which the ageing process is resisted and often feared. Instead of accepting the natural progression of the life course, we medicalise old age in an attempt to control it’.

Ageing discourses and the governing of the ageing body also increasingly involve a variety of stakeholders (Holstein & Minkler, 2007; Lassen & Moreira, 2014). Through their discourses and related practices, they contribute to a moral framework on how to age well (Rudman, 2015) that consists of an evaluation of people’s life course in which ageing and disability are perceived as personal failures (Cardona, 2008). The current chapter focusses on Belgium as a case-study and explores how sickness fund agencies (SFAs) shape discourses on ageing and ageing persons. Drawing on a large sample of website articles and press releases of SFAs, we investigate how SFAs position themselves within the societal debate on ageing. More specifically, we analyse how SFAs discursively construct the ageing process, how they accordingly

position ageing persons, and how these discursive constructions are linked to their organisational roles.

The Belgian social health insurance system (SHI) is funded by social contributions and health insurance is organised through non-profit private SFAs, who are, together with physicians, the main constituents and decision-makers within this system. SFAs divide their activities in four roles (Van den Bogaert, Ayala & Bracke, 2017). First, SFAs fulfil an institutional role. As social insurers, they are entrusted with executing the benefit package of the compulsory national health insurance (Nonneman & van Doorslaer, 1994). SFAs also have to provide their members with information on the health insurance program and are increasingly in charge of health promotion. Furthermore, SFAs do not only act as intermediaries between governmental bodies and health insurance consumers. SFAs are also social movements originally conceived as the defenders of patients (Schepers, 1993). Historically, SFAs were aligned with labour movements organised along different political and religious lines (Nonneman & van Doorslaer, 1994). Third, they are social entrepreneurs. SFAs offer various benefits, such as gifts for young parents and their children, and extra services, such as gardening and cleaning services, to their members (Hancké & Vermeeren, 2000). Finally, SFAs are also private insurers. They participate, and compete in, the market for complementary health insurance (Corens, 2007). These various roles make it interesting to focus on SFAs because such analysis not only offers insight into the construction of ageing discourses but also into how these discourses are put into practice.

## 7.2. Ageing discourses

Notions of ageing and old age have drastically changed (Moreira & Palladino, 2009; Stevenson & Higgs, 2011). Where ageing and old age were once seen as static and natural parts of the life course, ageing is increasingly perceived as a process that is malleable and even avoidable (Jones & Higgs, 2010; Kaufman, Shim & Russ, 2004; Lassen & Moreira, 2014; Marshall & Katz, 2012).

Ageing evolved from a natural and unproblematic process towards a medical problem. More specifically, medical developments have changed societal understandings of the nature of later life and the accompanying creation of medical diagnostic categories has turned normal aspects of the aging process into medical problems (Kaufman et al., 2004). As ageing became defined as a medical problem, medical interventions in later life have become normal (Kaufman, 2015). This medicalised view on ageing focuses on dependency and decline, and positions ageing persons as passive subjects of medical interventions (Jones & Higgs, 2010). Gradually, new innovations within biomedicine have caused a shift from a focus on cure towards a focus on life enhancement and growing older without ageing (Kaufman et al., 2004; Marshall & Katz, 2012). Jones and Higgs (2010) argue that this has resulted in a culture of fitness, which is constructed as the norm on how one 'ought' to age.

Within the social sciences, ageing is also seen as dynamic and changeable, and many frameworks and perspectives have been used to study ageing (Kaufman et al., 2004; Victor, 2005). In this chapter, we focus on positive ageing as these discourses entextualise the above mentioned ideas on normative ageing. Positive ageing discourses are rooted in the activity perspective, which challenges the idea that older

people disengage from society, and can be seen as a reaction against ageist stereotypes (Estes, Biggs & Philipson, 2003; Foster & Walker, 2015; Zaidi & Howse, 2017). According to Katz (2001, p. 27), positive ageing discourses 'depict activity, autonomy, mobility, choice, and wellbeing in defiance of traditionally gloomy stereotypes of decline, decrepitude, and dependency'. Hence, ageing persons are ascribed a more active position. Examples of positive ageing discourses are the frameworks of successful and active ageing (Foster & Walker, 2015).

Rudman (2006a, p. 189) describes four characteristics of positive ageing discourses. First, ageing is dissociated from disease. It is argued that the physical and mental problems often associated with ageing are not the direct result of the ageing process in itself, but from diseases or lifestyle choices, and that they can, therefore, be avoided. Jones and Higgs (2010, p. 1516) argue that:

'ageing has become connected to an increasing emphasis on self-care which is aimed at delaying or denying bodily decline and where the image of dependency is banished to the margins'.

Second, later life is divided into two stages; third age and fourth age (Rudman, 2006a; Gilleard & Higgs, 2010). The third age is constructed as a phase of relatively good health, independence, and agency. Ageing people in this category are constructed as vital and enjoying life and the process of ageing itself is constructed as something that needs to be avoided (Gilleard & Higgs, 2010; Rudman, 2006a; Stevenson & Higgs, 2011). This focus on avoiding ageing, seeing ageing as something negative, contradicts the idea that these discourses are referred to as 'positive' ageing discourses. The fourth age is seen as a phase of dependency in which people are strongly affected by the ageing process and the physical limitations that accompany

this process (Stevenson & Higgs, 2011). Third, being active is framed as 'key to obtaining health, youthfulness, and happiness in later life' (Rudman, 2006a: p. 189). Finally, this responsibility for being active and obtaining health is transferred from the public sector to the individual. Positive ageing discourses construct a moral framework in which ageing persons have a 'duty to age well' (Rudman, 2006b, p. 197).

Although these discourses have sharpened policy attention for the role of social aspects of the ageing process (Zaidi & Howse, 2017), positive ageing discourses still sketch a rather negative picture of the ageing process and of ageing persons, especially the oldest-old (Nosraty, Jylhä, Raittila & Lumme-Sandt, 2015). Consequently, various scholars have questioned some of the aspects of positive ageing (Angus & Reeve, 2006; Martinson & Berridge, 2015; Stephens, 2017). First, although positive ageing discourses construct images of active, healthy, and independent ageing persons, they also contribute to ageism, which is 'the discrimination against individuals based on their age' (Angus & Reeve, 2006: p. 138). More specifically, by constructing ageing as something undesirable, ageist stereotypes are reproduced. Marshall and Katz (2012) define this as 'post-ageist ageism'. This fear of ageing results in negative stereotypes, stigmatization, and discrimination of ageing persons (Angus & Reeve, 2006; Ng, Allore, Trentalange, Monin & Levy, 2015; Martinson & Berridge, 2015), which can have a negative influence on their physical and mental wellbeing (Levy, 2009; Demakakos, Gjonca, & Nazroo, 2007). Furthermore, although positive ageing discourses try to disassociate ageing from disease, they do contribute to the medicalisation of ageing by focusing on the absence of disease, managing and monitoring risks, and by framing ageing as



a problem that can be avoided (Cardona, 2008; Kaufman et al., 2004). Second, the distinction between 'good' and 'bad' ageing combined with an emphasis on individual responsibility result in a moral framework that blames individuals who do not live up to this standard (Cardona, 2008; Rozanova, 2010; van Dyk, Lessenich, Denninger & Richter, 2013). Gilleard and Higgs (2013, p. 373) argue that:

'even attempts to demonstrate the very normality of health and wellbeing in later life paradoxically lead to asserting the categorisation of later life into "good" versus "bad", "successful" versus "unsuccessful", "healthy" versus "diseased" and "active" versus "inactive"'.

Third, positive ageing discourses do not take the diversity of the group of ageing persons into account. They neglect ageing persons who do not have the financial resources, educational background, or physical health to age well (Rudman, 2006a; Lamb, 2014; Martinson & Berridge, 2015; Rozanova, 2010; Stephens, 2017). Fourth, the criteria on how to age well formulated by positive ageing discourses often do not align with the perspectives and priorities of ageing persons (Martinson & Berridge, 2015; Van Dyk et al., 2013). For example, Hvas and Gannik (2008) use the case of menopause to illustrate how women draw on various discourses to talk about ageing and health. A last critique concerns the strong focus on individual responsibility of these discourses (Rudman, 2006b) and their link to neoliberalism (e.g. Oster et al., 2016; Rudman, 2015; Stephens, 2017). Neoliberal policies focus on cost containment and market solutions, thereby shifting the responsibility of health from the public sector to families and individuals (Jolanki, 2009; Rudman, 2006b). As a consequence, later life circumstances are constructed as the culmination of individual decision-making (Stephens, 2017).

### **7.3. Ageing discourses and the role of sickness fund agencies**

Ageing discourses emerged alongside the development of welfare regimes (Estes et al., 2003). Within these regimes, responses to ageing were historically institutionalised within retirement systems and were linked to intergenerational solidarity (Estes & Philipson, 2002; Lassen & Moreira, 2014; Mann, 2007). As a consequence, ageing became associated with social rights and ageing persons were constructed as passive and dependent receivers of social care (Walker & Maltby, 2012). Due to economic and political pressures on governments and global transformations, policy-makers have started to reform these systems thereby redefining post-war understandings of ageing (Estes et al., 2003; Mann, 2007). Welfare systems were increasingly seen as a financial risk and ageing policies focus on individual responsibility, activity, and private initiatives (Estes et al., 2003; Rechel et al., 2013; Walker & Maltby, 2012). Hence, gradually, ageing persons were ascribed a more active role.

Some of these reforms are the result of EU initiatives, such as the Europe 2020 strategy (see Rechel et al., 2013), resulting in similar ageing discourses across European countries (Walker & Maltby, 2012). Furthermore, Lassen and Moreira (2014) illustrate that the EU and the World Health Organization (WHO) both draw on the active ageing discourse but use different strategies to implement these ideas. In Belgium, this evolution from a focus on dependency and ageing as something static towards activity and ageing as malleable has also taken place (Hofäcker, 2015; Van Malderen, Mets, De Vriendt & Gorus, 2013). We illustrate this by focusing on sickness fund agencies (SFAs) and their activities.

In 2016, the Belgian Minister of Public Health and the SFAs signed a pact to modernise and adapt the SFAs to current challenges and evolutions within the healthcare sector (Ministry of Health and Social Welfare, 2016). An important aspect of the pact is the evolution of SFAs towards health funds that help their members to stay (or become) healthy, rather than just helping the sick. The pact thus describes a shift towards an individual responsibility for health. More specifically, SFAs should empower their members and help them to take care of themselves.

#### **7.4. Methods**

##### *Sample*

This study is part of a larger interdisciplinary research project that focuses on the stakeholders involved in the production of elderly-related health news discourses, such as health-policy stakeholders, news media, and the general public in Flanders (the Dutch-speaking region of Belgium). The current study focuses on the group of people aged 50 and older, as this group of (pre-)retirees are often linked to the third age (Gilleard & Higgs, 2002).

For the purpose of this case-study, we gathered press releases and websites articles of SFAs that concern ageing and ageing persons. SFAs are at the national level grouped in five Health Insurance Associations (HIAs) (Nonneman & van Doorslaer, 1994). With a membership rate of 41,79% of the Belgian population, the Christian HIA is the largest SFA. They are followed by the Socialist HIA (28,87%), the Independent HIA (19,46%), the Liberal HIA (5,04%) and the Neutral HIA (4,83%) (RIZIV, 2017). The sample (see table 7.1) is limited to press releases and website articles targeting the

main stakeholders (as described above) of the overarching research project of this study.

*Press releases* published in 2015 and 2016 were gathered from the websites of the HIAs, as all HIAs publish their press releases online, except for the Neutral HIA who informed us that they did not publish press releases. This resulted in a sample of 106 press releases. Subsequently, all press releases were read and only those that discussed ageing and ageing persons were included in our final sample.

Additionally, we scrutinised the *websites* of the five HIAs for information about ageing and ageing persons. The Socialist, Liberal, and Christian HIAs have one general website for all the sickness fund agencies that are part of their HIA. Hence, for these three HIAs we extracted information from the general websites. The Neutral and Independent HIAs, on the contrary, have a separate website for each sickness fund agency that belongs to the HIA. Therefore, we decided to analyse the individual websites. More specifically, we selected all the websites of the Neutral (two websites) and Independent (two websites) SFAs active in the Dutch-speaking region of Belgium. In total, all pages of these seven websites were checked for information about ageing and ageing persons and relevant pages were saved as pdf files.

Sickness Fund Agency	Press releases	Website articles
Christian	8	55
Socialist	10	63
Liberal	6	36
Independent	2	52
Neutral	0	16
<b>TOTAL</b>	<b>26</b>	<b>222</b>

**Table 7.1.** Final sample

### *Analysis*

Positioning theory was elaborated by James (2014) as a way to study how organisations intentionally represent a) themselves as an organisation, b) their services, products, customers and c) their positions on certain topics (such as ageing) in formal communication, in order to encourage and sometimes even persuade their audiences (e.g. SFA members, policy-makers) to think similarly and act accordingly. We employed positioning theory as the analytical framework for our discourse analysis, which allowed us to systematically analyse how sickness fund agencies as organisations represent or position themselves and others – in this case ageing persons (Allan & Wiles, 2013; Harré, Moghaddam, Cairnie, Rothbart & Sabat, 2009; James, 2014). More specifically, we used the different analytical devices that are central to positioning theory to structure our coding process (i.e. positions, storylines, rights and duties).

Positioning is the discursive process of intentionally assigning attributes or characteristics (i.e. to take on or assign a position) to oneself as an organisation or to others, such as ageing persons, with the intent to achieve specific communicative outcomes (Hughes, Breault, Hicks & Schindel, 2017; James, 2014). This position is

supported by a carefully chosen storyline (Slocum & Van Langenhove, 2003) and is defined by a cluster of rights and duties that offer options for organisational action (James, 2014). The different roles of SFAs described above, all come with such sets of specific rights and duties, which influence how SFAs can position themselves as an organisation within the societal debate on ageing.

Our sample was coded independently by two researchers using NVivo 11. Our analysis consisted of various stages of coding and constant comparison. The initial focus was on how different SFAs define ageing and accordingly position ageing persons, as well as on the respective roles from which the different fragments were written. Excerpts were further scrutinised for recurrent linguistic devices and vocabulary that exemplify different positions and storylines, such as contrasts, repetitions of words, metaphors, analogies, and schematic representations. We then further analysed the rights and duties associated with different positions regarding ageing and how these coincided or diverged from organisations' official roles. Results were validated by both researchers in an iterative process until analytical consensus was reached. In a final stage, the most illustrative excerpts were translated into English, which are used below to clarify our results.

## 7.5. Findings

Our analysis revealed three different storylines on which SFAs draw to communicate about ageing. Table 7.2. provides an overview of these storylines and their appearance in our sample.

Storyline	Press releases	Website articles
Ageing as a medical problem	25	193
Ageing as a new stage in life	1	20
Ageing as a natural life process	0	9

**Table 7.2.** Overview storylines divided per type of document.

In what follows, we will provide an in-depth analysis of each storyline. For each storyline, we will analyse how ageing is constructed, how ageing persons are positioned, and how these discursive constructions are linked to the different roles of the SFAs.

### Storyline 1: Ageing as medical problem

In the largest number of articles ageing is constructed as a medical problem. Ageing is portrayed as an undesirable process of natural decline and disease, as the following excerpt illustrates:

‘Over the years, everyone becomes physically and mentally weaker, slower, and more vulnerable’ (Website article – Independent SFA).

In a first set of articles ageing persons are positioned as passive and in need of being taken care of. Ageing persons are positioned as already – or becoming – ‘frail, vulnerable, weak, helpless, infirm, ill’. These messages are targeted towards policy-makers. Depending on the rights and duties associated with the different roles of SFAs, the specific content of these messages differs. Articles written from a social insurer’ perspective focus on the healthcare budget. SFAs advocate for certain policy measures, such as accessibility to affordable healthcare. Furthermore, they warn policy-makers for the consequences of the greying of the population:

‘Flanders is greying rapidly. The number of old and very old persons will rise rapidly, which will lead to a larger demand for eldercare and, thus, also rising healthcare costs’ (Website article – Socialist SFA).

The greying of the population is linked to multimorbidity, increasing numbers of chronically ill, rising healthcare costs, and the need for more eldercare services. Moreover, the following excerpt illustrates how ageing persons are positioned as a possible threat for the current healthcare system:

‘The population is greying. The number of people who are chronically ill is rising. Treating patients increasingly takes place outside the hospital. If we want to have a strong health care system for the future, we have to take these challenges into account’ (Press release - Christian SFA).

Interestingly, by focusing on policy makers and urging them to deal with the greying of the population, SFAs also downplay their own role as social insurer in this decision-making process. Furthermore, in these examples, the duties associated with SFAs’ roles of social insurer and social movement interact. SFAs are, as social insurers, part of the health-policy decision-making process. Within SHI systems,



health-policy decisions are the result of negotiations between the various stakeholders involved. In these different consultation bodies, SFAs negotiate and compete with each other as well as with other stakeholders, while they also have to interact with the Minister of Public Health. Therefore, to be able to criticise healthcare policy-decisions, SFAs must distance themselves from their social insurer role. SFAs thus rely on their social movement role to explicitly position themselves as 'defenders of their members'. Nevertheless, instead of empowering their members, the following excerpt illustrates that ageing persons are positioned as powerless, which gives these excerpts a rather paternalistic tone:

'Due to a lack of social cohesion, elderly in our society become isolated too often. You do not solve loneliness with a little pill. It's better to make time for the elderly, to be there [for them], to cherish and love [them], rather than to prescribe antidepressants. Organisations, such as Samana and Okra, have understood this well and fully engage in this. Let us follow that good example, during these Christmas Days. A visit and a chat can do miracles' (Press release – Christian SFA).

What these social insurer and social movement messages have in common is that ageing persons are positioned as different from the mainstream population. This process of 'othering'<sup>8</sup> results in the construction of ageing as a threatening and undesirable state of being and in the construction of ageist stereotypes. For example, the excerpt of the Christian SFA depicts ageing persons as lonely and isolated.

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<sup>8</sup> Othering = 'a process that identifies those that are thought to be different from oneself or the mainstream, and that can reinforce and reproduce positions of domination and subordination' (Johnson et al., 2009, p. 253).

In this first set of articles ageing is constructed as a process that is unavoidable and cannot be changed. In a second set of articles, a slightly different view on ageing is noticeable. Although ageing is constructed as a medical problem and as a process of decline, it is also constructed as a process that is malleable and that can be delayed or even avoided.

In these messages, SFAs distinguish between two groups of ageing persons. The first group of ageing persons are positioned as frail and already experiencing age-related problems, and are urged to take care of themselves in order to remain independent and to live at home as long as possible. Fall prevention is one of the most popular messages targeted towards this group, as illustrated in the following excerpt:

‘One in three people aged 65 or older falls at least once a year. This can have severe consequences. Imbalance problems and muscle power are some of the important causes of a fall. You can avoid this through frequent exercise’ (Website article – Socialist SFA).

Hence, as the following excerpt illustrates, ageing is constructed as something that can be delayed if one stays mentally and physically fit, which differs from the previous gloomy image of inevitable decline.

‘In order to prevent health problems the Christian SFA and the compulsory health insurance program give you various reimbursements and benefits, such as a reimbursement for the flu vaccine or a reimbursement for dietary advice. But there is also our happiness coach who helps you to keep mentally fit, and our weight loss coach, who helps you to build a healthy lifestyle’ (Website article – Christian SFA).

In these website articles, SFAs often take up their roles of social movement and social entrepreneur. SFAs not only inform their members about how to stay autonomous but also offer additional services and benefits, as illustrated in the following example:

‘When you grow older or when you are ill or disabled, there are often many practical issues. Our occupational therapists help you to increase your quality-of-life. They give you free expert advice so that you can function as independently as possible’ (Website article – Independent SFA).

Hence, ageing persons are not exclusively positioned as SFA’ members but also as users of eldercare services. This example illustrates that SFAs often act as social movements in order to achieve the duties associated with their other roles.

This idea of ageing as a process that can be anticipated and avoided is more apparent in articles written from a private insurer and social movement perspective. In these articles, SFAs focus on a second group of ageing persons; the ones who are not old yet. These messages emphasise risk and individual responsibility.

In the articles written from a private insurer perspective, SFAs position themselves as commercial enterprises that have to compete with other insurance companies on the private health insurance market. Ageing persons are positioned as high risk customers and are, therefore, warned to prepare themselves and proactively buy certain types of insurance.

‘Retirement leads to a loss of income. Furthermore, it is almost certain that when you grow older, your medical expenses will rise. [...] The older you are, the higher the risk you will have to go to a hospital. That’s why it’s a good idea to obtain a hospital insurance’ (Website article – Christian SFA).

The above excerpt illustrates a central aspect of these messages; the idea of proactively managing the risks associated with later life.

In the articles written from a social movement perspective, SFAs describe various diseases and symptoms one can be confronted with when ageing. *'The older you are, the more chance you have to...'* is a frequently used sentence. Surprisingly, in our sample, some contested age-related conditions, such as osteoporosis, are problematised and are addressed by drawing on the first storyline. These conditions are perceived as objects of medical intervention because they are believed to be manageable and avoidable.

In these articles, SFAs take on a more passive role and focus on ageing persons' responsibility for their own health. More specifically, ageing persons are urged to take up specific preventive health measures to slow down or even avoid the ageing of the body, such as regular medical check-ups, a healthy lifestyle, or self-care for age-related disorders:

'When you grow older, a lot of things change, also concerning your body and health. You want to stay healthy and active as long as possible. That's why it is a good idea to evaluate your alcohol consumption' (Website article – Liberal SFA).

What this second group of articles has in common is that they both draw on aspects of positive ageing. More specifically, they construct a framework of how ageing persons need to deal with the ageing body. Both people who are already experiencing some problems as persons who are not 'old' yet have to stay active in order to avoid, or slow down, the ageing process. Consequently, by focusing on

activity and independence, ageing is constructed as something undesirable and thus SFAs contribute to post-ageist ageism (Marshall & Katz, 2012).

### Storyline 2: Ageing as a new stage in life

However, ideas of positive ageing appear most prominently in the second storyline. These messages targeting ageing persons use a more optimistic, positive outlook on ageing and were usually titled '*what to do when ageing*' or '*what to do when retiring*'.

'We don't often think about it but then suddenly it's your last day at the office. Tomorrow you're retired. What is next? We offer you 5 tips to help you prepare for this new stage in life' (Website article – Independent SFA).

The above excerpt illustrates how ageing is depicted as a step towards a new stage in life. In this storyline, ageing persons are ascribed an active role and are urged to enjoy and keep participating in society:

'Your children become independent, maybe you work part-time. If you are older than fifty you possibly have more time, especially when you retire. It is important to stay active and stay in touch with other people' (Website article – Christian SFA).

These messages emphasise positive activities and behaviour, such as enjoying life, an active social life, keeping an active mind, and going on trips, and thus highlight the proverbial silver lining of ageing. The following excerpt illustrates the tone of these messages:

'When you grow older, several aspects of your daily life change. Your children move out, you become a grandparent, you retire, your body changes and you lose friends and loved ones. We like to help you to feel good about yourself

despite these many changes. Take care of your social network. [...]. Live a balanced life. Being generous to others creates a sense of meaning, a feeling of happiness and a higher life satisfaction. Besides giving to others, it is also important to take care of yourself. Going for a walk or reading a book in the sun can give you positive energy. In order to enjoy life, it is important to give and take or to find a balance between remaining active and relaxing' (Website article – Neutral SFA).

Hence, this new stage in life is constructed as a period of independence and vitality. These references to activity and enjoying later life illustrate the idea of the third age as a post-retirement period in which ageing persons actively enjoy their lives (Stevenson & Higgs, 2011).

In this storyline, SFAs position themselves as coaches who motivate their members to fully enjoy this later stage in life. The articles written from a social insurer perspective provide ageing persons with practical information about their pension and assist them with the transition to this new period.

'When you reach the legal retirement age, you don't have to do anything. Only when you retire early, you have to apply for your pension with the local authorities. When you retire, the government automatically informs your SFA' (Website article – Liberal SFA).

SFAs, as social movements, draw on this storyline to inform their members about ways to stay active and give meaning to this new stage in life. The following excerpt illustrates that SFAs also position themselves as the defender of the rights of this group of active ageing persons:

'OKRA [name of the organisation] is the largest association for ageing persons in Flanders, which organises various activities for an active retirement and promotes the interests of people aged 55 and older' (Website article – Christian SFA).

This idea of third agers as a group of active and vital consumers of (leisure) activities and workshops, is most apparent in the messages in which SFAs act from the perspective of social entrepreneurs:

'If you are over 50, you probably have more free time, especially when you retire. It is important that you stay active and stay in touch with other people. We have some suggestions.

- Become a volunteer. Guiding vacations, visiting people, calling or chatting, at CM volunteers make a difference. You will find an activity that suits you.
- Participate in workshops. You are never too old to learn. That is why CM organizes several workshop on health and wellbeing.
- Be active and go out. Being active, keeps you young. That is why CM reimburses sport activities. Various CM-organisations organise vacations for young and old, ill and healthy people.
- Mobility plays an important role when one wants to remain active and interactive (Website article – Christian SFA).

In this storyline, there are no references to dependency or old age. Ageing persons who are dependent or experience bodily decline (i.e. the fourth age) are absent from these messages. Hence, this storyline offers an example of post-ageist ageism (Marshall & Katz, 2012). Furthermore, SFAs construct an image of ageing as

something that can be managed and, as the above excerpt illustrates (i.e. '*being active, keeps young*'), avoided. SFAs construct a framework of how ageing persons have to behave. Finally, these references to positive ageing illustrate that both the first and second storyline draw on elements of positive ageing discourses, which results in similar elements appearing in both storylines, such as a framework on how ageing persons should behave.

### Storyline 3: Ageing as a natural life process

Lastly, a small number of website articles depicts ageing as a natural and unproblematic part of the life course. Similar to the first storyline, these articles perceive ageing as a process of natural decline. However, in contrast to the first storyline, ageing and age-related conditions are constructed as unproblematic. SFAs draw on the third storyline to address conditions that are more difficult to avoid through preventive measures. Contested conditions, such as osteoporosis, are addressed using the first storyline.

In these articles, SFAs take on their role as social movement. This is not surprising as this is the only role in which SFAs do not deliver any type of healthcare service. As social movements, SFAs defend and inform their members, which is a much broader task than the duties of the other roles and not limited to healthcare services. SFAs guide their ageing members and reassure them that certain features of the ageing body are perfectly normal, thereby implicitly deconstructing the idea of ageing as a disease. This is most clear in the example of menopause, which is described as a natural feature of the ageing process rather than a disease:



'Menopause is not a disease, even though it is often classified as such. It is a fully natural phenomenon. The activity of the ovaries declines, which reduces the production of oestrogens. It is the end of a woman's fertile period' (Website article – Socialist SFA).

Other examples include a decline in the need to sleep, a decreased sensation of thirst, an enlarged prostate, and forgetfulness:

'Being more forgetful or having problems to concentrate are perfectly normal. This does not necessarily mean that you have dementia. Forgetfulness in old age and dementia are two completely different symptoms' (Website article – Independent SFA).

In one article, the Christian SFA departs from its social insurer perspective but quickly switches to its social movement role. This article focuses on the healthcare budget and the way in which society deals with death. By stating that '*at one point we have to say goodbye to life*', ageing and death are constructed as natural life processes with which we will all be confronted. In the article, they position themselves as defenders of the healthcare budget but they also criticise the way in which society deals with the end of life:

'Physicians do everything in their power to save and prolong lives, but this also has a downside. Dying used to be free. Nowadays, all those unnecessary treatments cost money, a lot of money. But are they worth the money?'

This switch to the perspective of social movement illustrates that positions can be defined by more than one role at the same time.

Contrary to messages drawing on the first and second storyline, in this storyline, ageing is not problematised but constructed as an immutable process that one has to

accept instead of resist. Consequently, ageing persons are positioned as subjects of this natural progression of life. Unlike in the other storylines, ageing persons are not told how they ought to age or urged to take action to avoid the ageing process:

‘These complaints [of menopause] often disappear automatically and seldom need medical treatment’ (Website article – Christian SFA).

## **7.6. Discussion and conclusion**

Contemporary ageing discourses focus on activity and avoiding ageing and age-associated disease, creating a moral framework on how to age well. Starting from this premise, we used press releases and website articles to gain insight into how SFAs position themselves within the societal debate on ageing. Using positioning theory (James, 2014), we illustrated how SFAs take on various positions in the societal debate on ageing. More specifically, they draw on three storylines, ageing as a medical problem, ageing as a natural life process and, ageing as a new stage in life. Each storyline differs in how the ageing process and ageing persons are discursively positioned. We also showed how these positioning acts are related to SFAs’ roles and their associated rights and duties.

With our study, we add to the literature on the reproduction of ageing discourses by (health-)policy stakeholders (Lassen & Moreira, 2014). More specifically, our findings illustrate how SFAs reproduce the moral framework on how to age well as constructed by positive ageing discourses. Both the first and second storylines draw on aspects of positive ageing and contain certain normative assumptions of ‘good’ and ‘bad’ ageing. The first storyline constructs ageing as a medical problem that can and should be avoided by taking preventive health measures and taking on a healthy lifestyle. A central aspect to this storyline is the focus on risk and individual

responsibility. The second storyline, ageing as a new stage in life, constructs later life as a new post-retirement period in which ageing persons actively enjoy their life. Central to this storyline is the focus on activity and the lack of references to dependency. Although there are differences between these storylines, they both create certain social obligations that prescribe ageing persons how to deal with the ageing process.

Although in these storylines, especially in the second one, ageing persons are ascribed a more active role, this moral framework disempowers ageing persons and reproduces ageist stereotypes (i.e. post-ageist ageism). More specifically, in the first and second storylines, ageing persons are positioned as subjects who have a moral duty to take care of themselves and to stay active. Hence, ageing persons do not really have a choice and, although in specific cases, these storylines can be empowering, ageing persons are generally not left a lot of room to decide for themselves. In addition, the group of ageing persons who cannot take care of themselves anymore are either ignored or positioned as weak and dependent. Furthermore, they are still expected to take responsibility for their own health and are blamed for lagging behind. Such forms of malignant positioning, in which a demeaning and even destructive storyline is set in motion, can have a negative impact, such as deleting the right to be heard (Harré, 2008). More specifically, although ageing persons might struggle with their physical health, this does not mean that they cannot make decisions in other parts of life, such as financial decisions (Jolanki, 2009). These practices allow policy-makers to economise and at the same time govern at a distance (Rudman, 2015). Hence, reforms inspired by this neoliberal rationality, such as the evolution of SFAs towards health funds instead of

sickness funds, will only strengthen this moral framework and will not always contribute to the empowerment of ageing persons, although precisely this empowerment is often invoked as a reason for reform.

SFAs' positioning of ageing and ageing persons also varies depending on the role SFAs take on. For example, our analysis illustrates that as private insurers, SFAs only position ageing as a medical problem, while the social movement role is the only role from which ageing is addressed as a natural life process. These findings suggest that the economic, social and political interests (i.e. rights and duties associated to each role) of SFAs play a part in the construction of ageing storylines. This supports what previous authors already suggested (Lamb, 2014; Rudman, 2015); ageing discourses are particular cultural and biopolitical models that mainly reveal how the social forces who construct these discourses believe ageing persons should act and perceive themselves, rather than depicting the actual experience of ageing persons themselves.

This also raises the issue of SFAs' role as social movement. We found that SFAs mainly act as social movement when this enables one of their other roles, which erodes this historical role. Nevertheless, concerning ageing discourses, the social movement role is important as this is the only role from which SFAs can address ageing in an unproblematic way and construct it as a natural life process. In the third storyline, SFAs talk in a more neutral way about ageing and ageing persons, which is important considering the impact these storylines can have on the psychical and mental wellbeing of ageing persons (Angus & Reeve, 2006; Harré, 2008). Hence, it is important to reflect on the economic and political interests that shape these discourses and the way in which ageing persons and the ageing process are framed in these discourses.

As social movements, SFAs also recognise the variety and multidimensionality of the ageing process. Previous research has illustrated that multidimensional and contextual models of ageing correspond to lay views on ageing (Cosco, Prina, Perales, Stephan, & Brayne, 2013; Nosraty et al., 2015). Models that draw on lay views on ageing often overlap with positive ageing models but they also discuss other aspects of the ageing process, such as death and an evaluation of an individuals' total life course (Nosraty et al., 2015). Since our study only focused on SFAs, we were not able to include these lay voices or to analyse the impact of our storylines on ageing persons. Nevertheless, by analysing how SFAs draw on various storylines and by unravelling how ageing persons are positioned within these storylines, we illustrated the importance of recognising the multidimensionality of the ageing process and of including lay voices into health-policy discourses on ageing.

Finally, more research on the policies of ageing in different countries and how they portray ageing persons is needed. Our study and previous studies (e.g. Lassen & Moreira, 2014) suggest that although ageing policies draw on similar ageing discourses, there are, due to national differences, such as the type of healthcare system or the actors involved, differences in the actual application of these discourses.



## CHAPTER 8: In the Land of Pharma: a qualitative analysis of the reputational discourse of the pharmaceutical industry

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The pharmaceutical industry has been battling a negative reputation and has been confronted with accusations such as putting profits before patients and manipulating clinical trial results. In this chapter, we focus on how pharmaceutical companies address what we define as the *Bad Pharma* discourse. Drawing on interviews, press releases, corporate documentation, and ethnographic fieldwork, we analyse the main themes that are used by the Belgian pharmaceutical industry to construct its reputational discourse and we focus on how this discourse is shaped by the *Bad Pharma* discourse. Our results illustrate that on the one hand the industry contests the *Bad Pharma* discourse by generating an alternative discourse. On the other hand, they also partly embrace and reframe this *Bad Pharma* discourse. This way, current societal debates are entextualised in the reputational discourses of the pharmaceutical industry.

## 8.1. Introduction

The pharmaceutical industry is an important asset for the Belgian economy. With its 35,000 employees, it is Belgium's second largest industry (Pharma.be, 2016). In 2016, the Belgian pharmaceutical industry invested 2.89 billion euro in research and development (R&D) and exported 40 billion euros in pharmaceuticals and vaccines, which makes Belgium the third largest exporter of pharmaceuticals in Europe (EFPIA, 2017; Pharma.be, 2016). More generally, the industry plays a key role within the European economy as in 2016 it employed almost 745,000 people and invested 35,000 million euro in R&D (EFPIA, 2017). At the same time, the Edelman Trust Barometer (2017) shows that globally few consumers trust the pharmaceutical industry. The barometer indicates that 80% of the mass public believes that the industry puts profits before patients (Edelman, 2017). This tension between the pharmaceutical industry's focus on profit, their economic interests, and their societal function to serve the needs of patients is the main focus of this chapter.

Compared to other industries, the pharmaceutical industry is unique as its products are necessary, indispensable, and often even life-saving (Droppert & Bennet, 2015; Kessel, 2014; Nussbaum, 2009). This unique societal function creates a high ideal standard that pharmaceutical companies have to live up to in order to be perceived positively by the public. This standard consists of attributes of what a pharmaceutical company should do and allows to distinguish between highly and less esteemed companies (King & Whetten, 2008). It is important to note that in the case of pharmaceutical companies, this standard is not used as an 'ideal'; a standard to which companies can live up to be perceived more positively than other companies, but do not necessarily have to reach. This standard is used as a baseline;



pharmaceutical companies have to meet these requirements. Over the past decade, a combination of various factors has resulted in claims that pharmaceutical companies do not meet this standard (Busfield, 2010; Droppert & Bennett, 2015; Kessel, 2014), which has led to, as the Edelman Barometer (2017) illustrates, very negative perceptions of the pharmaceutical industry. For example, consumers increasingly demand and feel entitled to access to medicines, and journalists have started to focus on conflicts of interest and drug pricing. Moreover, pharmaceutical companies have mainly damaged their reputation through 'self-inflicted wounds' (Busfield, 2010; Kessel, 2014, p. 984). In 2013, two Belgian journalists found out that the company Alexion hired a PR company who used a sick child and his parents to pressure the Belgian government to reimburse Soliris, an expensive medicine to treat atypical haemolytic-uraemic syndrome (FlandersToday, 2013). In 2014, the pharmaceutical companies Novartis and Roche were accused by a Belgian consumer organisation of working together to strengthen the position of Lucentis, a medicine of Novartis to treat macular degeneration. Roche produces a similar and cheaper medicine (Avastin), which is used to treat different types of cancer. By working together, they avoided that this cheaper medicine could be licensed to treat macular degeneration (Test-Aankoop, 214).

These reputational issues and strong societal expectations of how an industry should behave make the pharmaceutical industry an interesting case-study to analyse the social construction of corporate reputations. In this chapter, we focus on how the pharmaceutical industry constructs its reputational discourse. We define this as a set of claims and statements constructed by a company to anticipate, react to, and improve social evaluations about the company. These reputational discourses are

social constructions; they come into being through interactions with the outside world (Deephouse, Newburry & Soleimani, 2016; Fombrun, 1996; Gray & Balmer, 1998; Palazzo & Richter, 2005). By drawing on an extensive dataset of corporate communication documents, we map the main discursive themes in the industry's reputational discourse and, in doing so, we aim to gain understanding of how larger societal discourses shape reputational discourses.

## **8.2. Corporate reputation and reputational discourse**

Corporate identity, image, and reputation are related, but different concepts that are often used interchangeably and are difficult to conceptualise (Balmer & Greyser, 2006; Barnett, Jermier & Lafferty, 2006; Brown, Dacin, Pratt & Whetten, 2006; Fischer & Reuber, 2007; Walker, 2010; Whetten, 1997). Identity is constructed inside the company, by the company and its employees (Brown et al., 2006; Walker, 2010; Whetten, 1997). Identity deals with the question: 'who do we [as a company] believe we are?' (Whetten, 1997, p. 27). Image is the intended mental picture a company projects to an external audience (Gray & Balmer, 1998; Walker, 2010). Reputations are the result of how others perceive and evaluate a company and refer to how audiences actually think about the company (Balmer & Greyser, 2006; Fischer & Reuber, 2007; Walker, 2010). Reputations come into being through interactions of the company with the outside world (Deephouse, et al., 2016; Fombrun, 1996; Gray & Balmer, 1998; Palazzo & Richter, 2005). At this point, it becomes clear that these three concepts are interrelated and mutually shaping (Abratt & Kleyn, 2010; Walker, 2010). In this chapter, although we will sometimes refer to the image pharmaceutical companies want to create, we focus on reputation, as we are interested in how pharmaceutical companies deal with perceptions of the outside world.

Walker (2010, p. 370) defines corporate reputation as ‘a relatively stable, issue-specific aggregate perceptual representation of a company’s past actions and future prospects compared against some standard’. De Castro and colleagues (2006, p. 367) distinguish between two dimensions of corporate reputation: 1) business reputation, which is the perception of a company by stakeholders that are closely linked to a company such as customers, and 2) social reputation, which entails the perception of a company by stakeholders that are not closely linked to the company, such as the general public (de Castro, Navas López & López Sáez, 2006, p. 367). In this chapter, we focus on the latter. We focus on how the general public and the media perceive the pharmaceutical industry.

Reputations thus entail a social evaluation of the company based on a comparison with an ideal standard of what a certain type of company should look like and how it should behave (King & Whetten, 2008; Walker, 2010). Kennedy, Chok, and Liu (2012, p. 71) state that companies will have a bad reputation when they ‘fall short of expectations for various elements of the standard’. Having a good reputation is important for companies as it establishes trust towards the company and its products, attracts employees, and influences investments by shareholders (e.g. Hillenbrand, Money & Ghobadian, 2013; Palazzo & Richter, 2005). Companies that have to deal with a bad reputation often have to deal with negative headlines, hostility, the risk of more restrictive legislation, and social activism (e.g. Fooks, Gilmore, Collin, Holden & Lee, 2013; Grougiou, Dedoulis & Leventis, 2016; Miller, 2013).

In order to enhance their reputation, companies use several communication tools, such as corporate social responsibility (CSR) reports and public relations campaigns

(de Vries, 2016; Droppert & Bennett, 2015; Fooks et al., 2013; McDaniel, Cadman & Malone, 2016; Sones, Grantham & Vieira, 2009; Waller & Conaway, 2011). Several scholars have theorised reputation building as a signalling process in which these communication tools are used to send signals to stakeholders which are then used by these stakeholders to form an impression about the company (Basdeo, Smith, Grimm, Rindova & Derfus, 2006; Musteen, Datta & Kemmerer, 2010; Walker, 2010). In other words, communication tools are used to construct reputational discourses. These reputational discourses can act as defensive practices with which companies try to draw away attention from the negative effects of certain activities or products, rationalise or excuse their activities, and influence decision-making (de Vries, 2016; Fooks et al., 2013; Grougiou et al., 2016). These scholars thus conceptualise reputational discourses as strategic intentional actions that are used to enhance reputations and to improve competitive advantage (Basdeo et al., 2006; Walker, 2010).

Studies on reputational discourse mainly focus on micro social interactions of the corporation with internal and external stakeholders and intentional signals produced by these companies (Dhanesh, 2015). The current study draws on a social constructivist and discourse-oriented approach towards reputation building (Lähdesmäki & Siltaoja, 2010). In our study, we define discourse as a specific way of structuring, thinking, speaking, and writing about reality that defines how individuals and institutions think about and behave in relation to certain phenomena, but that also restricts certain ways of thinking or behaving (Hall, 2001; Hodges et al., 2008; Lähdesmäki & Siltaoja, 2010). Laclau and Mouffe (1985) argue that in society, several discourses co-exist and compete for dominance with each

other. They explain that in this constant struggle over meaning, even though complete dominance is impossible, all discourses try to take on a hegemonic position. Macgilchrist (2007) and Livesey (2001) illustrate that this struggle is a dynamic process that goes beyond discourse versus counter-discourse. In order to counter mainstream discourses, alternative discourses often deliberately embrace or reframe elements of mainstream discourses (Livesey, 2001).

In this chapter, we argue that reputational discourses are not only shaped by individual or group perceptions, but also larger societal discourses, such as global discussions on climate change or discussions on healthcare expenditures, shape reputational discourses, and thus social reputations. These larger societal discourses are historically and contextually situated (Alvesson & Karreman, 2000). Hence, this approach to reputation allows us to analyse how reputational discourses are historically and contextually developed. In what follows, we describe the larger societal discourse with which the pharmaceutical industry is confronted, and which serves as a starting point for us to analyse how the industry's reputational discourse counters, embraces, and reframes this societal discourse.

### **8.3. The pharmaceutical industry's reputation**

As mentioned above, the pharmaceutical industry has, in comparison to other industries, a unique societal function (Kessel, 2014). Pharmaceutical companies are expected to produce innovative, affordable, and effective medicines, and thus to improve and/or save lives (Kessel, 2014; Nussbaum, 2009). These expectations set a high ideal standard that the industry has to live up to. The industry's activities are constantly compared with this standard, which has resulted in a collection of criticisms on the industry's activities and motivations, which we define as the *Bad*

*Pharma* discourse. Several scholars have already analysed and described the attributes of this *Bad Pharma* discourse (Batt, 2016; Declercq & Jacobs, 2018; Kessel, 2014; Parker, 2007). First, the expenses of pharmaceutical companies are questioned. Over the past decades, the number of new innovative medicines entering the market has slowed down (Cockburn, 2004). Pharmaceutical companies explain this by arguing that research on unmet medical needs has become increasingly complex and difficult, and therefore, also more expensive. However, this argument is (partly) subverted by the fact that the industry's marketing budget has significantly increased over time (Kessel, 2014). Second, the earnings of pharmaceutical companies are criticised. Although the development of new innovative medicines has become more expensive, pharmaceutical companies are still highly profitable, which can be explained by the large number of 'me-too drugs' or variations of already existing medicines that keep entering the market (Angell, 2004), and the fact that the prices of these medicines are based on willingness to pay instead of their development costs or added value (Alexander et al., 2017; Light & Kantarjian, 2013; Kantarjian, Steensma, Sanjuan, Elshaug & Light, 2014). Third, the industry has been accused of disease mongering or 'the selling of sickness', which can be achieved in two ways (Moynihan & Cassels, 2006, p. 425). Pharmaceutical companies can expand the definition of disease in order to include milder or presymptomatic forms, such as pre-diabetes. Or they can narrow the definition of health in order to label previously nonmedical problems as medical problems, such as baldness (Moynihan, Heath & Henry, 2002; Woloshin & Schwartz, 2006, p. 452). Meanwhile, diseases that are more frequent in poor countries remain under-researched (Bauchner & Fontanarosa, 2013; Goldacre, 2012; Leisinger, 2005) and undertreated. Fourth, the research done by the pharmaceutical industry has been criticised for manipulating trial protocols,

unreported negative results (Leisinger, 2005), and ethical issues such as harmful clinical trials and animal testing (Akhtar, 2015; Emanuel, Wendler & Grady, 2000). Lastly, the lack of transparency in terms of pricing policy and collaboration with academics, physicians, medicine agencies, and patient organisations has been criticised (Garattini, 2016; Goldacre, 2012; Horton, 2013).

## **8.4. Methods**

### *Sampling*

As we are interested in how the pharmaceutical industry constructs its reputational discourse and how this discourse is shaped by the *Bad Pharma* discourse, we collected corporate communication documents and information that provided insight into the construction of this reputational discourse. More specifically, we combine official corporate communication documents, such as press releases and an annual report, with information in which representatives of the industry discuss their communication strategies, such as interviews and ethnographic fieldwork. These data were gathered as part of a larger interdisciplinary research project that analyses the different interconnected stakeholders involved in the chain of health news discourses, that is, health-policy stakeholders, news media and the general public. Table 8.1 provides an overview of our sample.

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- **Interviews:** 2 representatives of a major international pharmaceutical company, and 2 representatives of the pharmaceutical industry's trade association
  - **28 press releases** of the four largest pharmaceutical companies in Belgium and the industry's trade association
  - **2 policy documents** (general report + brochure)
  - **Corporate communication documents:** annual CSR report and booklet "facts & figures"
  - **Ethnographic fieldwork:** 4 meetings
- 

**Table 8.1.** Sample overview

First, we draw on in-depth interviews, which discuss the pharmaceutical industry's communication strategy. Four representatives of the pharmaceutical industry were interviewed between March and August 2015: a 'managing director' and 'communication officer', representing a major international pharmaceutical company, and the 'communication officer' and 'secretary-general' of the industry's trade association. We selected both the communication officer and a high-ranking management representative as they are the ones that are mainly dealing with reputational issues. Second, we collected all the press releases released by the four largest pharmaceutical companies in Belgium and the pharmaceutical industry's trade association in 2015. We chose these companies because they are anchored within the Belgian economy and also work together in a special lobby group that, among others, focuses on creating a positive investment climate for the Belgian pharmaceutical industry. However, most of these companies did not provide press releases on their Belgian websites. When contacting the Belgian press liaisons, we were referred to their international websites. These international press releases were often only meant for shareholders or specific populations (e.g. United States citizens);



we therefore only used press releases targeting a Belgian audience, written in Belgium's official languages (Dutch/French/German). In 2015, the Ministry of Public Health and the pharmaceutical industry's trade association agreed on several measures to reduce healthcare spending and to stimulate the development of new medicines, which they summarised in a policy document. We included these documents (both the full-length version and the brochure) as well, since they are regularly used to promote the Belgian pharmaceutical industry.

Finally, we draw on ethnographic fieldwork at one of the pharmaceutical companies. The second author conducted fieldwork there between May 2015 and July 2015, and collected data over the course of 15 non-consecutive days. The data set consists of interviews, audio-recorded meetings, informal conversations, field notes, documents collected on site, and extracts from the website. The fieldwork was overt and mainly consisted of participant observation. For this analysis, we selected both written and spoken communication from the fieldwork that dealt with external communication. First, we selected two corporate communication documents, an annual (CSR) report (intended to reach the general public) and a booklet titled 'facts & figures' used by employees of the company to answer questions of journalists or other third parties, and four meetings on external communication. These six sources were scrutinised for the codes as identified by the first author (see next section for detailed information on the method of analysis). After coding these sources, we selected one audio-recorded meeting for further in-depth analysis in order to better understand the relationship between the themes that emerged from our thematic analysis. During the meeting, two of the communication officers met with two editors of a TV channel dedicated to business news. The editors were producing a show on cities and their local

economies. The pharmaceutical company under scrutiny was invited to participate in the episode on a neighbouring city, as they recently started to use geothermal energy to make their production process more sustainable. This particular meeting was selected because 1) the meeting contained all the themes that emerged from our thematic analysis and contained some interesting interactions between them, and 2) the context – during the meeting the company's geothermal energy project was discussed – was slightly different from the documents review context but still highly relevant for the analysis.

### *Data gathering and analysis*

During the interviews, a semi-structured guide with open-ended questions was used and the interviews were transcribed verbatim. Before the interviews and the ethnographic fieldwork, each respondent signed a confidentiality agreement which allowed us to record the interviews and the meetings but also guaranteed the respondents' personal anonymity as well as the organisation's anonymity. We therefore do not mention the names of the organisations in our sample, even though the press releases and policy documents are public information. This agreement was accompanied by a document that explained the research project's scope and privacy procedure. Since the interviews and meetings were in Dutch, the quotes used in this chapter were translated into English and paraphrased if idiomatic language use made literal translations impossible.

Our analysis was guided by the principles of thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006). Braun and Clarke (2006, p. 6) describe thematic analysis as 'a method for identifying, analysing, and reporting patterns (themes) within data'. Our study uses this approach to map common themes within the pharmaceutical

industry's reputational discourse. We see these themes as focal elements that can be combined and adapted to construct reputational discourses. Depending on the combination and adaptation, they allow for highlighting specific aspects, or implicitly or explicitly reacting to other, external discourses.

An important asset of thematic analysis is that it can be applied to all forms of data (Boyatzis, 1998; Braun & Clarke, 2006). Since we used various forms of corporate communication, it was important to use a method that allows us to combine and compare information from different data sources. A second asset is that, in comparison to content analysis, it is not necessary to use a predefined codebook (Vaismoradi, Turunen & Bondas, 2013). We used a data-driven, inductive approach to develop the codes (Boyatzis, 1998; Braun & Clarke, 2006). More specifically, we used our whole sample to develop the codes, instead of selecting a subsample. Previous research has indicated that recurring themes within the corporate communication of pharmaceutical companies are transparency, the industry as a job creator, and showing that the industry cares for patients and society (Esteban, 2008; Nussbaum, 2009; Sonnes et al., 2009). Although we were aware of these themes, we did not predefine the codebook based on these themes. This allowed us to look more openly at our data. A final asset is the systematicity of the coding procedures (Braun & Clarke, 2006). First, each data source was read and coded with the aid of Nvivo 11. This step ended when a first list of themes was established. Subsequently, these main themes were compared, overarching themes were clustered and this resulted in a list of four thematic codes. For each thematic code a definition as well as a description, inclusion and exclusion criteria were provided (see Appendix 4). Once these thematic codes were established, the researchers went through each data source again. All text

fragments that fit under a specific thematic code were identified and placed with the corresponding thematic code (Boyatzis, 1998; Braun & Clarke, 2006). Finally, each thematic code and the relationship between these codes were further analysed by the researchers.

## **8.5. Findings**

The common threads addressed within the reputational discourse of the Belgian pharmaceutical industry can be summarised in four discursive themes; Belgium Pharma country (BPC), Innovation, Patient Orientation (PO) and Ethical Issues (EI). These discursive themes often overlap and enhance each other, but, for the purpose of our analysis, we will discuss each theme separately. We will first discuss the salient aspects of each discursive theme, followed by a discussion of the relationship between each discursive theme and the *Bad Pharma* discourse. We propose that by ignoring the *Bad Pharma* discourse and formulating an alternative discourse the discursive themes contest the *Bad Pharma* discourse. Nevertheless, by recognizing the issue at hand but changing the focus of the discussion, the discursive themes reframe the *Bad Pharma* discourse as well. Finally, we discuss how the themes interact and strengthen each other.

### ***Belgium Pharma country***

The Belgium Pharma country (BPC) theme consists of all references to the important position and contribution of the pharmaceutical industry to the Belgian economy. The industry is described as a stable industry that creates jobs for individual citizens, generates tax revenue, and creates prestige for Belgium and its economy.

The BPC-theme does not explicitly embrace or contest the *Bad Pharma* discourse, but can be seen as an alternative discourse that competes with the *Bad Pharma* discourse for dominance. In doing so, it implicitly contests a central attribute of the *Bad Pharma* discourse; it contests the idea that making profit should be considered to be negative and problematic. The BPC-theme emphasises the positive effects of the large profits these companies make and has several salient aspects that are foregrounded depending on the context in which the theme occurs.

A first way of highlighting the economic contribution of the Belgian pharmaceutical industry is exemplified in the following extract:

‘These new statistics illustrate that Belgium is a leading country in the pharmaceutical industry worldwide. Not only when looking at the GDP [Gross Domestic Product], but also in relation to the population, the sector is doing exceptionally well. With more than 200 pharmaceutical companies and more than 34,000 employees, the pharmaceutical sector is a first-class industry, both on the Belgian and on the European level’ (Press release – Trade association).

The BPC-theme highlights the fact that the pharmaceutical industry not only costs society money, as claimed in the *Bad Pharma* discourse. Therefore, the focus is on the jobs created and the tax revenue generated by the industry.

Second, the BPC-theme emphasises the strength and vitality of the sector:

‘The numbers show the vitality of the Belgian pharmaceutical industry as a driver of growth and constant innovation for the Belgian economy’ (Press release – Trade association).

‘Nowadays the innovative pharmaceutical industry in Belgium is top of the class. However, there is not a single reason for complacency. Other (European) countries are determined to attract innovative industries. If we want to keep and strengthen the pharmaceutical industry in Belgium, we constantly have to monitor its competitiveness’ (Brochure policy document).

These arguments are also related to an implicit fear of regulation. Several arguments of the *Bad Pharma* discourse suggest the need for increased regulation of the pharmaceutical industry. Like most industries, the pharmaceutical industry wants to avoid increased regulation as this could have consequences for the profits they are making. Therefore, in the BPC-theme, the consequences of unfavourable regulation are highlighted. The above excerpt from the policy document consists of two implicit references to these consequences. The excerpt mentions that Belgium could lose its leading economic position, and that if the economic conditions become unfavourable, the industry will leave Belgium.

The third aspect of the BPC-theme refers to the local ties of these companies. Within the *Bad Pharma* discourse, ‘Big Pharma’ are framed as large and threatening multinationals companies. However, several pharmaceutical companies have Belgian roots and started as small, local companies. These companies have strong historical and economic ties with Belgium and the Belgian economy, which are, as the following excerpt illustrates, used in the BPC-theme to reframe the pharmaceutical sector as local, close to the Belgian population.

‘[name of the company] in Belgium is one of the most outstanding companies of the [name]-group. The company which was founded by [name of the founder] when in 1953 he started his own research, has significantly

influenced the evolution of medicine. [Name of the company] has several branches in our country' (Annual report – Pharmaceutical company).

When considering the BPC-theme in the meeting from the ethnographic fieldwork, it could be argued that the theme is embodied in the very idea of collaboration between the pharmaceutical company and the business news TV channel, as the show's central focus was on strong local economies. The company considered this a suitable opportunity to highlight their leading economic position as well as the strong ties they had with the region. The main campus of the company is still in the same area where the founder started his small lab. The two spokespeople raised this connection several times with the editors as an important element to foreground in the documentary, talking about their 'local anchorage'. This is further illustrated in the following quote by the company spokesperson during the meeting, which also shows that the BPC-theme is strongly intertwined with the theme of innovation:

'We intend to depict [city] as an innovative region, which it certainly is because of the third generation geothermal energy technology. From there you can take it even further by referring to the biggest innovator in the region [i.e. the company] [...] because of our fourth generation geothermal energy technology' (Spokesperson pharmaceutical company - Meeting).

A final dimension of the element of local roots and authenticity is that the idea of having a long local history also strengthens the idea of stability and trustworthiness. For example, in several informative boxes the brochure of the policy document gives a historical overview of the pharmaceutical industry in Belgium. These 'intermezzos' carry titles such as: 'a legacy from our ancestors, a duty towards our children' and 'the rise of the giants of the Belgian pharmaceutical industry'. These references to

history and locality reframe pharmaceutical companies as familiar, local, and trustworthy companies, which can be seen as an alternative discourse for the *Bad Pharma* discourse. Finally, these references of familiarity, locality, and trustworthiness also strengthen the Patient Orientation discursive theme, as being local also means being close to patients, and the Ethical Issues discursive theme, as being trustworthy refutes the claim that the industry behaves unethically.

### *Innovation*

A second common thread is made up of references to the importance of innovation. The industry is described as being innovative in two ways. First, they use new technologies and produce new treatments that are different from existing treatments. Second, they use new technologies to make their production process more sustainable. Although using innovative and environmentally friendly technology is not directly related to the *Bad Pharma* discourse, the pharmaceutical industry uses these examples to emphasise their credibility as an innovative and scientific player, to highlight their commitment to innovation, and shift the attention away from the *Bad Pharma* discourse.

The Innovation theme responds to the *Bad Pharma* discourse in several ways. First, by emphasising the innovativeness of the sector and its products, the Innovation theme contests the idea that the industry is only interested in profit and developing me-too drugs. The following quote illustrates this practice:

‘The most important task is, of course, being the driver of research for diseases for which there hasn’t been developed a solution yet. That’s the challenge for innovative industries. To find cures that offer an added value for patients. Nobody is waiting for another me-too drug. Especially not the people who



have to pay for these cures. They are waiting for really innovative medicines that make a difference' (Representative 1 - Pharmaceutical company).

The idea of being innovative depicts the pharmaceutical industry as bringing together scientists who are genuinely interested in discovering how the human body works and who use their knowledge to create new medicines, as this excerpt of the annual report shows:

'We believe that great innovation involves a convergence of the best people, research, technology and care. Together with our parent company, we create strong networks of people capable of combining ideas, technology, and resources in new ways. Our internal scientific research team draws on the best external know-how, science, and ideas. Using this knowledge pool, we develop answers to pressing medical challenges' (Annual report – Pharmaceutical company).

Hence, innovation is linked to curiosity and responding to healthcare challenges, rather than to money.

So far, both the BPC-theme and the Innovation discursive theme can be seen as attempts to mobilise an alternative discourse. However, the pharmaceutical industry sometimes recognises and incorporates some elements of the *Bad Pharma* discourse. Within the Innovation theme, it is recognised that prices of their products are high. Nevertheless, by highlighting the complexity of the development of new innovative medicines, the Innovation theme does reframe the issue. New technologies and the complexity of diseases complicate the development of pharmaceuticals. Therefore, as the following quote illustrates, it is unavoidable that innovative medicines are expensive:

‘The pricing policy of pharmaceutical companies, I think, is something that is often represented in one-sided ways. One only looks at the price a company asks for a medicine and the price to produce them. These are two things you can’t compare just like that. You have to take into account all the research that preceded the production process and also all the research that took place but that failed. These are things that also have a price and that are often ignored in one-sided representations’ (Representative 2 – Trade association).

This example similarly shows how the innovation argument is used to reframe and partly contest the *Bad Pharma* discourse:

‘As pharmaceutical industry we often have a bad reputation. Which is not entirely unjust, I admit. Luckily, we have learned from our mistakes. I believe there is a great need for transparency and we have to keep communicating about what, why and how we do it. For example, when it comes to our pricing policy. We do not wake up in the morning and then decide that the price of our products has to be high. This is the result of a 10-year process where you have, unfortunately, certain factors... I believe that communication and constantly explaining to people what we do, how and why we do things, remains very important’ (Representative 2 - Pharmaceutical company).

In this example, the *Bad Pharma* discourse is reframed as an issue of communication. During our conversation the representative did not contest the *Bad Pharma* discourse and even explicitly recognised that the pharmaceutical industry had made mistakes. Nevertheless, when the representative starts talking about innovation and their pricing policy, this pricing issue is reframed as a problem of communication and transparency. In other words, the price of these products is not too high, the industry just fails at explaining how their prices are determined. This is an argument that the

second author also often heard during the fieldwork and it is closely linked to transparency. While the *Bad Pharma* discourse frames a lack of transparency as a conscious decision to hold back information, the representative frames it as clumsy communication, which is less intentional, and therefore, also less problematic.

The Innovation theme also strengthens the Belgium Pharma Country theme as being innovative is part of economic strength. The previous section already illustrated how the theme of innovation is highlighted in the meeting with the TV channel in which the geothermal energy project is discussed. Throughout the meeting, the company spokespeople repeat that the geothermal energy project is 'a pioneer project' or something 'people might be familiar with already' but to which the company 'adds real innovation'. One of the spokespeople aims to provide proof of their innovative position with the following quote:

'We are now talking with people in Gothenburg who have a similar project. We have to go to Scandinavia, really, to find expertise that can follow and add to our way of thinking' (Spokesperson pharmaceutical company - Meeting).

Having to travel to find the right expertise is a strong argument for innovation. It also implies that the company is bringing in new expertise locally, strengthening their ties with the local economy, and the local economy itself, and finally also their leading position.

Finally, this Innovation theme also strengthens the Patient Orientation discursive theme, as being innovative will also help more patients for which no treatment is available yet.

‘This way pharmaceutical companies can keep focusing on the development of innovative pharmaceuticals for rare diseases, and we can avoid that this will leave Belgian patients with a rare disease in the lurch’ (Press release – Trade association).

### *Patient Orientation*

The third theme relates to the industry being patient-oriented. It emphasises the benefits of pharmaceuticals for patients’ health and the fact that the industry enables patients worldwide to get access to medicines. This discursive theme also relates to the pricing and reimbursement of medicines, as expensive treatments need to be reimbursed by the government in order for patients to get access to these medicines.

The Patient Orientation (PO) theme is more explicitly linked to the *Bad Pharma* discourse. First, by emphasising that patients are what drives these companies, the PO-theme refutes the idea of being solely profit-driven. The PO-theme offers an alternative discourse which puts patients before profits:

‘Of course the patient is what counts patients are very important stakeholders, if not the most important ones. I mean... in the end they are what counts. What matters is how you can help patients, and everything else are means to an end’ (Representative 1 - Pharmaceutical company).

The PO-theme also emphasises that the industry enables patients worldwide to get access to medicines. These arguments reject the idea that the industry is only interested in developing lucrative solutions for diseases in rich countries:

'We also develop solutions for patients outside the classic Western world. Tuberculosis is a classic example, but also several solutions for worm diseases, HIV gels. We develop a lot of medicines for very specific and severe conditions in countries where there often is no one to pay for them. We work together with the people of UNICEF and the Red Cross to get these medicines to patients in a responsible way. This is an important consequence, which I think is the right one. And one that relates to the fact that we sometimes have to go back and forth between R&D investment and pricing, but so far it has been going quite well' (Representative 2 – Pharmaceutical company).

Second, the PO-theme emphasises that medicines are being developed for patients who are in urgent need of a treatment. Hence, by focusing on patients and diseases for which there are no treatments yet, the issue of me-too drugs is addressed.

'Our team has managed wonderfully to turn the company in a worldwide scientific pioneer who helps patients with serious diseases to live a normal live' (Press release – Pharmaceutical company 2).

The booklet from the ethnographic fieldwork further illustrates how pharmaceutical companies actively engage with the *Bad Pharma* discourse. This booklet offers many examples of our four themes, and more specifically relate to the PO-theme as follows:

'[name of the company] puts patients first, and makes every effort to develop and market innovative medicines that meet the most challenging medical needs' (Booklet facts & figures – Pharmaceutical company).

In this example, the PO-theme is linked to the Innovation theme; when responding to unmet medical needs, companies are forced to be more innovative as well.

Finally, the PO-theme accounts for the high prices of pharmaceuticals. We illustrate this by using an excerpt of a press release:

‘These innovative, short-term antiviral therapies have an exceptional high chance of complete recovery, and have significantly fewer side effects, and a 95 per cent success rate. We plead for an extension of the conditions of reimbursement of this essential therapy in order to provide wider access for infected patients’ (Press release – Trade association).

By emphasising the innovativeness and benefits of these new therapies, its price is legitimised. Moreover, by referring to the government and their role in gaining access to new therapies, this responsibility is transferred to the government. In other words, it is not the price of these therapies that prevents patients to access new therapies, it is the government. Furthermore, by referring to the responsibility of the government, the industry does not address the *Bad Pharma* discourse. They merely keep repeating the argument that access to new therapies instead of the price of these therapies is the key problem. In this example, the PO-theme is linked to innovation as well; only with true innovation can patients be helped.

When turning to the ethnographic data and the recording of the meeting, we also see that, more generally, the pharmaceutical industry tries to construct a discourse that puts society, and thus also patients, before profits. Although the patient is not discussed, as the subject of the documentary is geothermal energy, the spokespeople do construct a closely related discourse on social engagement and corporate social responsibility, as illustrated by the following quote:

'Additionally, there's a social engagement, that we have to discuss carefully and thoughtfully, because we could make some of the warmth available for society. [...] It's an industrial project, but with possible social engagement outcomes too. We have to be careful here not to make any promises we can't keep or to seem like we're not authentic. We shouldn't go too far, but social engagement is essential for our company; we just should be very thoughtful when speaking about it' (Spokesperson pharmaceutical company - Meeting).

The social engagement aspect of the project is important and mentioned several times. Interestingly, we see a lot of hedging and a fear to miscommunicate this aspect, and, consequently, to be accused of not being authentic. The spokesperson seems to be aware of the *Bad Pharma* discourse and the danger of strengthening it, as a result of potentially exaggerating the societal outcomes and benefits. Hence, the aspect of social engagement and transparency intersect here.

### *Ethical issues*

A final common thread is made up of references to Ethical Issues (EI). These arguments refer to two types of ethical behaviour. First, the industry draws on ethical frameworks to guide their activities in terms of patient and animal rights, ethical pricing, and respect for the environment. A second type of arguments concern transparency, in terms of research, conflicts of interest, marketing, and in terms of profit and expenditures.

The EI-theme is more implicitly related to the *Bad Pharma* discourse and can be seen as an alternative, competing discourse. There are varying degrees in which it refutes and recognises the *Bad Pharma* discourse. First, the EI-theme consists of several references to the ethical frameworks that guide the industry's activities. By referring

to ethical guidelines, the industry suggests that, as they have to conform to these guidelines, it is impossible for the industry to act unethically. Hence, this EI-theme refutes the idea that the pharmaceutical industry behaves unethically:

‘Responsible marketing is an integral part of these principles. It is also based on the ethics codes of [name of trade association], the Mdeon directives (Mdeon is the common ethical platform constituted of associations of physicians, pharmacists, veterinarians, dentists, nurses, the pharmaceutical and medical devices industry) and the relevant Belgian legislation’ (Annual report - Pharmaceutical company).

Nevertheless, these guidelines are mostly self-regulatory and seldom binding. By referring to these guidelines, pharmaceutical companies try to avoid more restrictive legislation.

Second, the EI-theme regularly refers to transparency. These assertions more overtly recognise the transparency issue. Nevertheless, they reframe a lack of transparency as something from the past, as clumsy communication (see section on Innovation), or as a result of society that has changed. We use an example from the policy document to illustrate this:

‘Of course in 2015 the project is not finished. Although most pharmaceutical companies act ethically and responsibly, unfortunately, several incidents, in Belgium but also abroad, have illustrated that some companies still find it difficult to act inherently responsibly in the societal field in which they are finding themselves in. Also the context changes rapidly. An example: 50 years ago patient organisations were unknown and did not participate in the healthcare system. Nowadays, they are valuable stakeholders with which



pharmaceutical companies try to build solid business relations' (Policy document).

Finally, when considering the ethnographic data, the previous example of the meeting already illustrated the importance of transparency, and the company's careful approach to communicating concrete social participation plans. Another example of this careful approach can be found in the following example. The communication officer of the pharmaceutical company tells the journalist that the current mayor used to work for their company. Although this was more than 10 years ago, the journalist seems to think this is a fun fact and wants to include it in the news item:

Editor: Yeah well I think it's quite fun it immediately connects the dots.

Spokesperson 1: Yes but I would discuss with him whether he wants to be on the show

Spokesperson 2: We shouldn't create the impression that it's a way to-

Spokesperson 1: Because it isn't; there is no conflict of interests. Our main local governments are [names of two other cities], not [the city that is the subject of the series], or only to a lesser extent. It's a fun fact for you guys, but I wouldn't mention it in the show.

There is a particular interplay of different aspects of the EI-theme in this fragment: the imperative of being transparent and the imperative of avoiding conflicts of interest. There is no actual conflict of interest as the mayor is no longer involved in the company's management, and the information on the mayor's current and past mandates is publicly available online, and in that sense, there is no issue of transparency either. However, the spokespeople are afraid to create the impression

that there is a conflict of interest. This fragment suggests that pharmaceutical companies have internalised some parts of the *Bad Pharma* discourse.

This EI-theme is also linked to the other themes. For example, by referring to the ethical guidelines to which the industry conforms, some of the aspects of the BPC-theme are strengthened. More specifically, it suggests that no extra regulation is necessary and it strengthens the arguments around the trustworthiness of the industry (see section on the BPC-theme).

## **8.6. Discussion and conclusion**

In this chapter, we have illustrated how the pharmaceutical industry's reputational discourse is shaped by the *Bad Pharma* discourse. More specifically, our case-study reveals how the industry formulates an alternative discourse that both contests, (partly) embraces, and reframes the *Bad Pharma* discourse.

This chapter used a social constructivist and discourse-oriented approach towards reputation building. We show that the pharmaceutical industry's reputational discourse is shaped by a large societal discourse that is linked to attributes of how a pharmaceutical company should act. We have illustrated that reputational discourses address these expectations. Reputational discourses refer to, and are shaped by, certain historically and contextually situated societal discourses and are, therefore, products of current societal debates. More specifically, a few decades ago pharmaceutical companies were highly respected (Li, 2014; Parker, 2007). Now, due to self-inflicted wounds, changes within pharmaceutical companies, and several societal changes, the industry is contested and their reputational discourse reflects these societal discourses. Hence, in order to fully grasp the meaning behind

reputational discourses, it is necessary for researchers to map larger societal discourses that transcend individual and group perceptions, such as the *Bad Pharma* discourse or discourses on climate change. This approach to reputation building can offer more insight into how, and why, reputations and reputational discourses change over time. Furthermore, our study illustrates that the pharmaceutical industry's reputational discourse is more than a defensive practice or strategic business tool. We have shown that besides reacting to the *Bad Pharma* discourse, pharmaceutical companies also internalise the attributes of this discourse, which means that the *Bad Pharma* discourse also becomes part of how the spokespeople think and act. It becomes part of their identity. Although this illustrates that identity and reputation are interrelated concepts and it suggests that identity plays a role in the construction of reputational discourses, this goes beyond the focus of our study. Since our sample focused on external communication, we were not able to study identity formation within pharmaceutical companies. Future research could focus on this relationship between reputational discourse and identity.

Although we have only focused on the pharmaceutical industry – which is unique as it produces products that are necessary, life-enhancing and/or life-saving for individuals – and on the Belgian context, some of these discursive themes transcend the specific characteristics of the pharmaceutical industry and are also relevant for other industries and contexts. For example, after several incidents (e.g. the collapse of the Rana Plaza building in Bangladesh) the matters of transparency and ethical behaviour have become more important for the clothing industry. Several studies illustrate that these themes are used by other industries and in other contexts (e.g. Berens & Van Riel, 2004; Livesey & Kearins, 2002; Waller & Conaway, 2011). For

example, Nike used the job creator argument in its communication campaign (Waller & Conaway, 2011), which is similar to the Belgium Pharma Country theme. Berens and Van Riel (2004) find that scales measuring the expectations of stakeholders regarding companies often include 'leadership in the industry' and 'doing something good for society'. Livesey and Kearins (2002) illustrate that 'transparency' and 'care' are metaphors that are often used in reputational discourses, which relate to our Ethical issues and Patient Orientation theme. Our study, therefore, offers opportunities for comparative research into the content and construction of reputational discourses. Quantitative, cross-industry comparative studies examine these themes to compare the reputational discourses of various industries.

Finally, we were only able to gain insights into the construction and not in the reception of these corporate messages. Further research could address how this reputational discourse actually leads to a better reputation and increased trust in the pharmaceutical industry. Schmeltz (2017) illustrates that a tight fit between CSR communication and consumer values contributes to the success of CSR communication. This illustrates the importance of the discourse-oriented approach used in our study. Since reputational discourses are shaped by societal discourses, this also means that reputational discourses that address these societal discourses will be more closely aligned with the ideal standards of how a company should behave.

## CHAPTER 9: (Dis)entangling medicine and media: a qualitative analysis of the relationship between the fields of healthcare and journalism

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Previous research has illustrated that journalists play an active role in the production of health news. The current chapter explores the relationship between the fields of healthcare and journalism from a healthcare perspective. Drawing on Bourdieu's theory of fields and Gieryn's concept of boundary-work, this chapter employed elite interviewing to analyse how the relations between these two fields were reflected and negotiated in the discourses of Belgian health-policy stakeholders.

Our analysis illustrated that health-policy stakeholders perceived medicine and the news media as two different cultures and, therefore, discursively positioned news media actors as outsiders. Additionally, we showed that the nature of the relationship between health-policy stakeholders and the news media was linked to health-policy stakeholders' position within the healthcare field. Through this analysis, we illustrate the value of using the concept of boundary-work as an analytical instrument to study the relationships between fields.

## 9.1. Introduction

Over the past decades, the variety of stakeholders involved in the healthcare field has significantly increased (Conrad, 2005; Pereira Gray, White, & Russell, 2016). Besides an increase in the number of stakeholders involved in the healthcare field, there is also a more general rise in societal and journalistic interest in health (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Weitkamp, 2003). This interest has intensified the interactions between health and media professionals. This relationship between medicine and journalism is often conceptualised as a translation process. That is, media transmit biomedical knowledge in lay terms, hence translating it to a broader audience (Seale, 2002). Several studies, including this one, refute this idea of linear transmission by illustrating that journalists play an active role in the processes of co-production from which health news emerges (e.g. Briggs & Hallin, 2016; Declercq, 2018). However, while these studies have examined this relationship from a journalistic vantage point, few studies have explored a perspective from within the domain of healthcare. Drawing on Bourdieu's theory of fields (Bourdieu, 1983, 2000) and the concept of boundary-work (Gieryn, 1983), our goal is to gain more insight into the complex and often contested relationship between the fields of healthcare and journalism. More specifically, we analysed how these relations are reflected and negotiated in the discourses of health-policy stakeholders, such as government institutions, pharmaceutical companies, and sickness fund agencies<sup>9</sup>. Drawing on elite interviews with health-policy stakeholders who operate within the Belgian health insurance system, this chapter addressed the following research questions:

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<sup>9</sup> Sickness fund agencies are non-profit private health insurance organisations which collect health insurance contributions. Within social health insurance systems, health insurance is organised through these organisations.

- ◆ What is the relationship between health-policy stakeholders and the news media?
- ◆ What position do health-policy stakeholders occupy within the healthcare field?
- ◆ How do health-policy stakeholders discursively position the news media with reference to the healthcare field? And what motivates them to do so?

Firstly, by studying the interactions of health professionals and journalists, this chapter advances scholarly understanding of health news production. This is important because health news can have a significant impact on audiences; it is more trusted than information on the Internet (Van Slooten, Friedman & Tanner, 2013) and it influences behaviour. Matthews and colleagues (2016), for instance, show that media coverage of the side effects of statins resulted in decreased therapy adherence. Secondly, we also hope to advance insights regarding the relations between fields, an area which is still less developed than other parts of Bourdieu's field theory (Albright, Hartman, & Widin, 2018). Lastly, this chapter aims to understand some of the struggles that are going on within the healthcare field as a result of heightened societal and journalistic interest in health issues.

## **9.2. Bourdieu's theory of fields**

In order to analyse the relationship between health-policy stakeholders and the news media, it is useful to conceptualise the healthcare domain as a field (Bourdieu, 1983; Lewis et al., 2017). A field is 'a relatively autonomous domain of activity that responds to rules of functioning and institutions that are specific to it and which define the relations among the agents' (Hilgers & Mangez, 2015, p. 6). Collyer, Willis,

Franklin, Harley and Short (2015) explain that a field is not only a social space but also a network of relations between social actors, i.e. 'a site of struggle and contestation' (p. 690). Each field operates according to its own logic and rules and is structured around a set of actors who have certain economic (e.g. material assets) and/or cultural (e.g. knowledge) resources at their disposal. Based on these resources, each actor adopts a certain position within this field. Bourdieu (1983) defines this process as position-taking.

In accordance with Bourdieu's field theory, Collyer (2018) argues that the healthcare sector can be conceptualised as a field. First, being centred around a particular goal (i.e. curing people and/or improving their health) distinguishes the healthcare field from other fields (Collyer, 2018; Thomson, 2008). In order to achieve that goal, the healthcare field operates according to a dominant set of rules and truths (i.e. the (bio)medical model of illness). Although the healthcare field involves various realms (e.g. clinical medicine, science) and thus multiple objectives and truths, all actors are expected to pursue this central goal. However, this does not necessarily mean that actors are actually pursuing this goal nor that this is their main goal (e.g. Van den Bogaert et al., 2018). Second, the healthcare field generates a specific form of capital (i.e. medical knowledge) that is used by actors within the field to gain legitimacy and to determine 'whose main holders are the elites of the field' (Hilgers & Mangez, 2015, p. 6). Third, the healthcare field is characterised by key actors (e.g. physicians) and a structured set of, often historically formed, positions, e.g. physicians versus nurses or the roles of healthcare providers within specific health insurance systems (Collyer, Willis & Lewis, 2017). Finally, the healthcare field operates as a site of struggle between the various actors involved (Collyer et al., 2017). For example, Lewis and



colleagues (2017) state that the healthcare field 'is an arena in which actors struggle for control over its conditions and what is valued, influencing, for instance, the availability of healthcare services and the very meaning of health itself' (p. 3). Nevertheless, while different ideas of health and illness circulate within the healthcare field, the biomedical model still largely dominates.

### **9.3. Field relationality and boundary-work**

A wide range of (new) stakeholders, such as patient organisations, pharmaceutical companies, and news media, are increasingly involved in the healthcare field (Clarke et al., 2003; Pereira Gray et al., 2016). Indeed, the healthcare field is structured around these struggles. On the one hand, the field consists of actors that represent economic and political capital. These actors can be seen as representing external forces that can change the dynamics of the field. This is the heteronomous pole of the healthcare field. On the other hand, the field consists of actors that represent the capital of the field (i.e. medical knowledge) and who want to maintain or improve their position within the field (Benson, 1998; Bourdieu, 2000; Collyer et al., 2015). These actors represent internal forces within the field, and represent the autonomous pole of the healthcare field. As a consequence, fields are dynamic because actors are constantly protecting their position within the field which results in a continuous process of position-taking. In these struggles, the *doxa* (Bourdieu, 2000) or dominant set of rules and truths of the field is at stake, and thus defines the rules of the game (Collyer, 2018; Thomson, 2008). In this case, the *doxa* consists of evidence-based medicine and the (bio)medical model of illness (Wagner, Polak & Świątkiewicz-Mośny, 2018). In other words, what is at stake is the definition of health and illness. Collyer (2018) explains that that this *doxa* strengthens the position of dominant actors, allowing

them to defend biomedicine against ‘anecdotalism’ or claims that are not rigorously supported by scientific evidence, such as those based on a physician’s personal experience or case reports. Additionally, the institutionalisation of this doxa impedes other actors, such as alternative practitioners, from claiming legitimacy.

This process of positioning and drawing of boundaries between fields is often a discursive process (Broom & Tovey, 2007; Burri, 2008; Kerr, Cunningham-Burley & Amos, 1998; Mizrachi, Shuval & Gross, 2005) in which actors use several strategies in order to (re)establish their position and challenge the position of other actors (Roberts, Hsiao, Berman & Reich, 2004; Suddaby & Viale, 2011; Zietsma & Lawrence, 2010). These discursive strategies can be grouped into two types. The first strategy is demarcation (Broom & Tovey, 2007; Kerr et al., 1998), which consists of field actors drawing a line between what is considered as true/good and false/bad within their field (Mizrachi et al., 2005). For example, within the healthcare field, biomedicine is an evidence-based and therefore legitimate form of knowledge production (Wagner et al., 2018). Alternative medicine, on the contrary, is constructed as lacking such legitimate forms of evidence and alternative practitioners, in turn, are cast as not having a scientific mind (Broom & Tovey, 2007). In other words, the strategy of demarcation consists of constructing boundaries around the types of knowledge, procedures, and resources which (do not) belong to the healthcare field. A second, and related, strategy is ‘task division’ or ‘division of labour’ (Broom & Tovey, 2007; Burri, 2008; Mizrachi et al., 2005). By clearly defining the content, specific tasks, and expertise regarding a certain position, actors within a field try to keep other actors out of this position. Mizrachi and colleagues (2005) illustrate how healthcare professionals secure the boundaries of biomedicine by restricting alternative

practitioners to the treatment of the illness experience, thereby making sure that they, as biomedical professionals, stay in charge of the diagnosis and treatment of diseases. Contrary to the first strategy, which attempts to establish the boundaries for the field as a whole, the second strategy defines the internal boundaries of the positions within a field.

What these strategies have in common is that they strengthen the authority and expertise of the actors using them, while at the same time challenging the expertise and motives of other actors who are then positioned as not belonging to or not able to participate within the field (Eldridge, 2016). Additionally, previous studies have shown that this process of discursive positioning is not random, but instead is related to the position an actor takes on within a field (Bourdieu & Wacquant, 1992; Mizrachi et al., 2005). For example, Broom and Tovey (2007) have illustrated that physicians working in a hospice or palliative care context are less negative about alternative medicine than physicians working in a hospital.

The above-mentioned strategies illustrate that boundary-work takes place in this context. Gieryn (1983) describes boundary-work as 'an ideological style found in scientists' attempts to create a public image for science by contrasting it favourably to non-scientific intellectual or technical activities' (p. 781). He uses the term boundary-work to analyse scientists' attempts to demarcate science from non-science (Albert, Laberge, & Hodges, 2009). Nevertheless, the concept can also be used to analyse 'the ways in which professionals [in general] seek to establish their skills and jurisdiction over a particular domain of work' (Slembrouck & Hall, 2013, p. 62).

#### 9.4. Field relationality: the journalistic field as a case-study

The examples discussed in the previous section illustrate that the boundary-work performed by healthcare professionals focuses on restricting the use of so-called non-scientific forms of health knowledge, such as alternative medicine. Another particular type of non-scientific health knowledge production is routinely exercised within the journalistic field<sup>10</sup>. While this form of knowledge production is certainly not exclusive to actors within the journalistic field, it has gained more attention over the past two decades because the means for cheaply producing, disseminating, and consuming information have grown exponentially (Clarke et al., 2003). It is therefore surprising that so few sociological studies have attempted to tackle the relation between, on the one hand, the healthcare field and, on the other hand, the journalistic field.

Marchetti (2010) explicitly draws on Bourdieu's field theory to analyse the interactions between the fields of medicine and journalism. More specifically, he provides a historic account of the mediatisation of medicine in France (Marchetti, 2010). Another example can be found in the work of Briggs and Hallin (2016). They argue that these fields of healthcare and journalism cannot be perceived as separate fields, as they constantly draw on each other's logics and practices. For instance, biomedical actors have established press offices and given media training to their staff. Journalists, due to the complexity of contemporary biomedicine, rely heavily on health professionals to interpret biomedical information (Petersen, 2001).

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<sup>10</sup> The domain of journalism can also be conceptualised as a field as it is a rather independent social space that is centered around a particular goal (i.e. news production) and draws on specific logics, professional values, and practices (Benson, 2006) that distinguishes this field from other fields.

Although Briggs and Hallin (2016) convincingly illustrate that health and media are closely connected, this does not mean that health-policy stakeholders accept journalists and the knowledge they produce as legitimate actors and forms of knowledge within the healthcare field. These tensions are often ascribed to 'cultural' differences. That is, these actors 'differ in their definition of what is newsworthy, their styles of communication, and their vision of the media's role' (Nelkin, 1996, p. 1600). Here Gieryn's (1983) concept of boundary-work offers opportunities. Eldridge (2016) uses the concepts of field and boundary-work to study how journalists deal with the rise of user-generated content and citizen journalists. In order to maintain legitimacy, professional journalists establish boundaries by clearly defining what it means to be a journalist, thereby positioning citizen journalists outside the realm of professional journalism. With his study, Eldridge (2016) illustrates the value of using the concept of boundary-work to understand this complex process of position-taking. The current study applied both concepts (i.e. field theory and boundary-work) to investigate the relationship between the healthcare and journalistic fields, as we believed this framework would permit us to unravel some of the intricacies of this relationship.

## **9.5. Methods**

### *Sample*

This study formed part of a larger transdisciplinary research project that investigated the complex networks involved in communication on health issues. The project consisted of different research lines which each focused on a different aspect of the health news production process, such as news content (content analysis). The current study formed part of the first research line and drew on elite interviewing in order to

chart the different interconnected stakeholders involved in the healthcare field. For the purpose of this larger project, a health-policy stakeholder was defined as an organisation that holds an interest in the Belgian health insurance system or could have had an active influence on the decision-making and implementation process (Bryson, 2004). Therefore, patient organisations and not individual patients were included as health-policy stakeholders in our sample. Patient organisations, as opposed to individual patients, we posited, have the resources and capacity to actively participate within the healthcare system, while the latter can only influence health-policy indirectly (Ramírez, 2001).

Our sample of health-policy stakeholders was constructed along six categories (see table 9.1). These categories were based on the categories that were most often used in the literature (Britten, 2008; Busfield, 2010). Additionally, these categories were evaluated by two experts who were familiar with the Belgian system. Our final sampling model included 18 organisations or health-policy stakeholders. Subsequently, elite interviews, which are interviews with 'those who occupy senior management and board level positions within organisations' (Harvey, 2011, p. 5), were conducted with key informants within each organisation between March and October 2015. Two key figures per organisation were interviewed in order to distinguish between the official organisational rhetoric and personal views. This is a valued approach because it offers an additional quality check (Berry, 2002; Patton, 1999). First, high-ranking management representatives such as Chief Executive Officers and managers were interviewed. Second, since this study was concerned with understanding the interactions of health-policy stakeholders with the news

media, communication officers were also interviewed. Table 9.1 provides an overview of the interview sample.

<b>Type of organisation</b>	<b>Number of organisations</b>	<b>Number of interviews</b>
<b>Pharmaceutical industry</b>	3	5
<b>Government institutions</b>	4	8
<b>Sickness Fund Agencies</b>	2	6
<b>Patient organisations</b>	4	4
<b>Organisations of scientific medical experts</b>	2	2
<b>Associations of healthcare professionals</b>	3	5
<b>TOTAL</b>	<b>18</b>	<b>30</b>

**Table 9.1.** Elite interview sample

### *Data gathering and analysis*

During the interviews, a semi-structured interview schedule containing questions about the organisations' relationship with media professionals and their communication policy was used. Each respondent signed an agreement which guaranteed their anonymity and allowed us to record the interviews. This agreement was accompanied by a document that explained the research project's scope and privacy procedure. Full recording, verbatim transcription of the interviews, and CAQDAS techniques to support data management were used to ensure the quality of the data (Aberbach & Rockman, 2002). All the transcriptions were coded and scrutinised for discursive devices that exemplified the position-taking of health-policy stakeholders and the boundary-work they performed. These coded fragments were then further analysed through constant comparison. Since the interviews were

in Dutch, the quotes used in this paper were translated into English or paraphrased if idiomatic language use made literal translations impossible.

## **9.6. Findings**

In this section, we discuss the complex dynamics observed between health-policy stakeholders and the news media. First, we analyse how health-policy stakeholders drew on media logics and practices, thus illustrating the entanglement between the two fields. Second, we analyse the discursive strategies that were used to position news media actors as outsiders. We then go on to examine whether and how this discursive positioning was related to health-policy stakeholders' position within the healthcare field.

### *Entanglement between the healthcare and journalistic fields*

Our results illustrate a complex interplay between the logics and practices of health-policy stakeholders and journalists. The stakeholders in our sample explained that they were often contacted by the media. Journalists contacted these organisations to double check a story, or to obtain statistics or contact information of media-genic patients – those seen by the media as appealing to the audience – or of an expert on the topic at hand. As journalists may lack the medical knowledge to fully comprehend a new study or medical development, they required the expertise of someone from the field. Furthermore, consulting expert sources fits the journalistic ideal of objectivity which at the same time boosts the credibility of a story. The health-policy stakeholders in our sample knew this and, therefore, had started to anticipate the questions of journalists in order to secure better coverage for their news messages. The following excerpt illustrates that when health-policy



stakeholders send out press releases, they often provided contact information of academics or healthcare professionals to whom journalists could turn for further information:

‘We also guide them towards possible interviewees. This morning, even though it was our press release, it was a physician of the academic hospital of Louvain who was interviewed. We know the press prefers someone in a white coat over someone with a tie [laughs]. [...]. We take care of our press releases. They aren’t makeshift press releases. We choose our words carefully and they are more or less ready-made’ (Government institution 1).

The above quote also illustrated that by sending out ready-made bits of information health-policy stakeholders anticipated the needs of journalists, since these ‘information subsidies’ (Gandy, 1982) can greatly facilitate the news-making process. The following excerpt illustrates that health-policy stakeholders employed this media logic for their own purposes:

‘The better your press release, the more it will be copied by journalists. Journalists increasingly have to deal with time constraints. It is convenient for them if a press release is well written and easy to understand. This allows them to copy-paste the message, which is also convenient for us because then we are sure that everything they say is correct’ (Government institution 2).

These examples illustrate that journalistic logics have entered the healthcare field. Furthermore, the following example shows that health-policy stakeholders actively incorporated these logics into their own professional routines:

'Communication officer 1: We have an overview of the number of news articles that were published about us and the topics that were more popular than other topics.

Communication officer 2: We use several indicators to measure what works and what doesn't work.

Interviewer: And what do you do with these results?

Communication officer 1: We discuss them with our sickness fund agencies and, based on these results, we decide on the subjects of future studies and communication activities.

Communication officer 2: For example, when we notice that some topics are not very popular so uhm

Communication officer 1: And others such as depression or ...yes

Interviewer: And you do not cover these less popular topics anymore?

Communication officer 2: Not really no no

Communication officer 1: If we notice that a certain topic is not covered by the press or that it doesn't appear anywhere, perhaps maybe by a couple organisations. Well, then you have to draw conclusions of course' (Sickness Fund Agency 2).

Health-policy stakeholders provided media training for their staff, monitored the uptake of their information subsidies, analysed which topics might interest journalists, and adapted their communication strategy accordingly. In other words, health-policy stakeholders have adapted to the rising interest of journalists in health.

### *Disentangling the fields of healthcare and journalism*

Notwithstanding the incorporation of journalistic logics and practices into the healthcare field, our analysis reveals that health-policy stakeholders mainly focused on the differences between medicine and the news media, since they discursively positioned the news media as belonging to a different field with its own goals, logics, and practices and still considered the production of health news as a translation exercise.

First, health-policy stakeholders emphasised the importance of what they considered to be 'good' health information, which, according to them, had to be produced by medical experts. The following excerpts illustrate this positioning of journalists as lacking medical knowledge:

'Our press releases have to be as clear as possible. We do not just have the experts write them, with all due respect, I mean, but we also have them read by a lay person because it is a lay person who will write the article. It's also often frustrating for our scientists that they have to explain the problem to a journalist who is not familiar with the topic and who will write about another subject, such as soccer, an hour later. But that's the way it is' (Government institution 2).

'The problem is... those people. It is always someone else and they aren't specialists. Every newspaper maybe has one journalist specialised in health and the others are just journalists who are unenlightened' (Organisation of healthcare professionals 1).

Although health-policy stakeholders did not question the skills of journalists to write news messages, and thus to perform their job as a journalist, they did question their

expertise concerning health-related topics, thereby questioning the value of the health information produced by journalists.

Second, the health-policy stakeholders in our sample also clearly defined the tasks of actors within the healthcare field (cf. task division), which focus on curing people and improving their health. Journalists' communication styles and judgements of newsworthiness were constructed as not aligning with those of the healthcare field:

'It was one of the goals formulated by the Flemish Government when we started our project. We would be a place where journalists could get reliable information. We already warned them [the Flemish Government] that they [journalists] wouldn't contact us very often because the goal of journalists is to cover news. They want to be the first to tell a story. We are often an obstacle because we question their stories. We ask them 'is that really interesting?'. We often have to tell them that the story is of no use, that it's too soon. So we often have to slow them down and they don't like that.' (Organisation of medical experts 2).

The above interview excerpt illustrates a journalistic emphasis on newness and speed. Journalists want to be the first to report on a new study, but those often contain preliminary findings or results that are yet to have an impact on patients. Hence, despite journalists' good intentions, their motives are challenged, thereby positioning them as not belonging to the healthcare field.

All the health-policy stakeholders in our sample drew on these discursive strategies. However, we noticed that the reasons behind this boundary-work depended on health-policy stakeholders' position within the healthcare field and the extent to

which they belonged to the autonomous or heteronomous pole of the healthcare field.

Those stakeholders representing the capital of the field and, thus, belonging to the autonomous pole, can be divided into two groups. First, there were government institutions and organisations of medical experts. These organisations held a relatively stable position within the Belgian healthcare system, and, therefore, did not really have to defend their position within the healthcare field. The main focus of these organisations was the production of scientific information and the development of evidence-based guidelines. These actors constructed medicine and media as two very different cultures and felt that journalists did not belong to the healthcare field because of their style of communication and their definition of the types of health-related issues deemed newsworthy. The representatives in our sample lamented that reporters often sought out extraordinary or sensational angles for covering health-related news, at the expense of scientific accuracy:

'I think what often happens is that certain scientific evolutions are immediately constructed as a breakthrough, while in reality you need another 20 years to know if it's really a breakthrough. So that's what happens... the sensational aspect is often used in news coverage about healthcare. The black sheep or a terrible nursing home. They [news media] often pay a lot of attention to the wrong ...they focus on a single issue.' (Government institution 4).

This feeling may be strengthened by the fact that these stakeholders did not perceive the media as a necessary tool for consolidating their own position within the healthcare field.

Nevertheless, the following example illustrates the complexity of the relationship between these health-policy stakeholders and the news media. One of the representatives of a government institution in our sample felt so strongly about this that she organised a workshop to teach journalists how to interpret and cover scientific information:

‘We once organised a workshop for journalists because we noticed that there were a lot of “eureka” news articles about new scientific studies. And they all say “wow look at that” but then you discover that it has only been tested on mice. [...] We organised that workshop to teach them how to analyse those press releases. What should you be looking for? Are there conflicts of interests? How do you interpret that?’ (Government institution 1).

Interestingly, during the workshop, the government institution not only focused on dealing with scientific information but also on searching for conflicts of interests, which is a journalistic logic rather than a scientific one. Hence, this example illustrates that despite the boundary-work performed by these government institutions, journalistic and scientific logics are strongly intertwined.

A second group on the autonomous pool are associations of healthcare professionals. Their main resource within the healthcare field is the medical knowledge and expertise they hold. Contrary to government institutions and organisations of medical experts, these associations are much more concerned with the impact of news coverage on the public’s perception of their profession. The following excerpt illustrates these concerns:

‘Representative: the press are looking for something that is newsworthy and that’s not always easy. If we communicate about the role of [name of

profession] that is not sexy enough for the press. We notice that they mainly contact us when there is a problem. [...]

Interviewer: Are there topics that deserve more media attention?

Representative: A positive message and in-depth coverage of a certain topic. This is something that is hard to get into the news. You have to find something that catches their eye, otherwise they do not cover it. And that's a shame. It all has to be flashy and short and I don't know what else. There isn't enough in-depth coverage of positive news. I think that we still have a lot of things to tell about [name of profession] which the general public doesn't know about the [name of profession], but we don't get the chance' (Association of healthcare professionals 1).

Before turning to two health-policy stakeholders that can be considered as representing the heteronomous pole of the healthcare field, we examine one stakeholder that represents both poles; sickness fund agencies (SFA). SFAs are embedded within the healthcare system, because health insurance is organised through them. So, on the one hand, they possess a certain amount of medical knowledge and expertise and a rather stable position within the field. On the other hand, SFAs are also economic and political actors, which makes them actors drawing on the heteronomous pole of the healthcare field. More specifically, they are social entrepreneurs that offer services such as cleaning services to their members, private insurers who offer complementary private health insurance, and they also want to attract new members in order to be able to weigh more on policy-decisions. These various functions play a role when SFAs communicate to the news media. When asked about their reasons to communicate to the media, the communication officer of a SFA explained:

'Partly because of the image. If you communicate it is always to make sure that you [as organisation] look good' (Sickness fund agency 1).

The possible impact of news media on SFAs' reputation played an important role in sickness fund agencies' communication policy. SFAs, therefore, had to find a balance between the content they want to deliver and the marketing aspect of this message:

'It's difficult to find a balance between...yes we [sickness fund agencies] compete with each other for members. So, marketing is important for us. It's a shame that I have to say that but it's like that. Sometimes we find our messages [the ones that are picked up by the news media] a little bit too trivial. Other messages, on which we worked really hard, are more difficult to understand, and are, therefore, not picked up by the news media. That's frustrating (Sickness fund agency 2).

The above quote also illustrates the complex interplay between SFAs and journalists. On the one hand, we noticed that the representatives in our sample found it hard to get media attention for certain topics and believed that some topics were neglected by the news media. They perceived journalists as holding differing definitions of newsworthiness. On the other hand, in order to gain publicity, they adapted their communication messages to these journalistic values.

Finally, there were two groups of health-policy stakeholders, the pharmaceutical industry and patient organisations, who represented forms of capital (i.e. economic capital and lay knowledge) that belonged to the heteronomous pole of the healthcare field. First, the pharmaceutical industry can be considered as a strong economic force, since they are the second largest employer in Belgium and invest billions in research and development (Pharma.be, 2016). Due to their economic position, they



are included in various consultation bodies and are able to influence health-policy decisions. Nevertheless, they constantly have to defend their position, since their motives are often questioned by other actors, such as sickness fund agencies or patient organisations (Test-aankoop, 2016). They also have a rather difficult relationship with the media. One representative explained that they were often confronted with hostile journalists and negative headlines:

‘We have noticed that it isn’t easy as a pharmaceutical company... in the media... how do I have to explain that... to get a fair chance. It is not about good or bad, it is about getting a fair chance.’ (Pharmaceutical industry 3).

It is not surprising that the industry’s definition of newsworthiness did not align with that of the news media, given the industry wants to avoid stories that might lead to more restrictive legislation or questions about their pricing policy (Van den Bogaert et al., 2018).

A second actor representing the heteronomous pole were patient organisations, which are rather new actors within the healthcare field. Historically, SFAs were seen as the defenders of patients. However, gradually, SFAs have taken on more and different roles, thus creating opportunities for patient organisations to improve their position within the field (Van den Bogaert, Ayala & Bracke, 2017). Although increasingly included in various consultation bodies, patient organisations are still excluded from substantial parts of the health policy-making process. In order to position themselves as legitimate actors within the healthcare field, patient organisations actively collaborated with news media. For instance, when talking about the content of their communication messages, the representatives explained that they always included their policy demands because, given their peripheral

position within their own field, they hoped to gain more leverage via the mainstream media:

‘Our messages contain an overview of the problem at hand or the research that was conducted. We report the findings and then we formulate our policy demands. What has to change in order to solve the problem or improve the situation.’ (Patient organisation 2).

Patient organisations perceived news coverage as an instrument for establishing their expertise in the eyes of the public. As such, journalists were viewed as allies rather than opponents in patient organisations’ struggles to contribute to the healthcare field. Consequently, they less explicitly positioned the news media as outsiders. Nevertheless, as the following excerpt illustrates, by explicitly positioning themselves as experts on which the news media can draw to obtain more information, they implicitly drew a boundary and positioned the news media as lacking medical expertise:

‘Representative 1: We are often contacted. If they [journalists] read something from abroad about a new study, they ask us if that is interesting, or they ask us to refer them to an expert who can tell them more about that study, or to comment on the study.

Interviewer: And do they call often?

Representative 2: Actually, they do.

Representative 1: Yes yes.

Representative 2: I think that they call us first before they call a professor or a hospital.’ (Patient organisation 4).

For journalists, patient organisations might be interesting because they represent lay viewpoints and because they can be useful for locating patients who can share their personal experiences. These examples illustrate the complexity of the relationship between patient organisations and journalists and suggest that although patient organisations drew on journalistic logics and practices, their expectations of journalists' roles might differ from how journalists themselves perceive their own role.

### **9.7. Conclusion**

Drawing on elite interviews, this chapter has analysed the intricate interplay between health-policy stakeholders and news media actors. Contrary to previous research, which investigated this relationship from the media perspective (Briggs & Hallin, 2016; Declercq, 2018), this chapter focused on the perspective of health-policy stakeholders and also studied how health-policy stakeholders try to make these fields seem separate.

Drawing on Bourdieu's (1983) field theory and Gieryn's (1983) concept of boundary-work, we illustrated that despite the existence of intricate interdependencies among actors from both fields, health-policy stakeholders discursively positioned news media actors as outsiders, thus, engaging in boundary-work. Consequently, our analysis advances the scholarly understanding of this relationship. Firstly, our study illustrates that health-policy stakeholders' discourses reflect the two cultures trope (Nelkin, 1996). Journalists were positioned as lacking the knowledge to define what constitutes health and illness, as having a different definition of newsworthiness, and as having a different style of communication. This is an interesting finding because it illustrates that health-policy stakeholders use boundary-work to deal with the

complex entanglement between medicine and the news media. By referring to the two cultures trope, health-policy stakeholders on the one hand acknowledge news media's involvement in the health news production process, as they do not question journalists' skills to write news messages. On the other hand, by referring to different cultures, news media actors are positioned as outsiders. Secondly and most importantly, we unravelled that the nature of the relation between health-policy stakeholders and news media actors was linked to health-policy stakeholders' position within the healthcare field. We showed that actors who were strongly embedded within the healthcare field, such as government institutions and organisations of medical experts, were not actively trying to engage with the news media to consolidate their position within the healthcare field. However, they did engage with the news media for other purposes, such as communicating the results of a new study to lay audiences. Other stakeholders, such as SFAs and patient organisations, actively drew on the news media in order to consolidate their position. This link between an actors' position within the healthcare field and their approach towards the news media is clearly illustrated in the case of SFAs who mainly drew on news media for safeguarding their economic and political position. The pharmaceutical industry and associations of healthcare professionals were more cautious when it came to interacting with journalists, because the news media could destabilise their position within the healthcare field by turning public opinion against them. Therefore, the news media were approached either with suspicion or not at all. Finally, patient organisations perceived news media as a partner in their struggle to improve their position within the healthcare field.

Additionally, we illustrated that the concept of boundary-work could provide a valuable analytical instrument for understanding how relationships among fields are shaped, contested, and consolidated, because it specifically focuses on these relationships. Moreover, our study illustrated that by focusing on field relationality, we were able to shed light on how the field as a whole and its boundaries are constantly (re)constructed. For instance, the discursive strategies used by the health-policy stakeholders in our sample revealed that biomedicine and the biomedical model were seen as central to the healthcare field and that, in order to be considered as legitimate, knowledge production within the field had to follow its rules.

Notwithstanding these contributions, our study is limited to health-policy stakeholders and their perceptions of the journalistic field. Since the assumptions of health-policy stakeholders about the journalistic field do not always align with the reality of the news room, future research may benefit from complementing the current results with an analysis of the boundary-work performed by journalists. Additionally, since the healthcare field is increasingly permeated by various fields, future research could examine the interactions of the healthcare field with other fields. For instance, the involvement of large multinational pharmaceutical companies and the marketization of health and healthcare, which has brought economic logics and practices to the healthcare field, could provide interesting terrain for analysis (Clarke et al., 2003; Busfield, 2010).

Finally, although our study is limited to the Belgian context, these changes within the healthcare field form part of a more global evolution of the healthcare field, from a space mainly occupied and dominated by the medical profession towards an increasingly diverse and contested space (Busfield, 2010; Clarke et al., 2003). This

struggle over knowledge and positions within a field is also not unique to the healthcare field; they form part of a more general trend in which knowledge is increasingly diverse and contested. For instance, a similar struggle is currently underway within the journalistic field, where journalists struggle with the rise of digital journalism and the news produced by these digital interlopers (Eldridge, 2016).

## CHAPTER 10: General discussion and conclusion

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The healthcare space has become increasingly complex and diversified (Cheek, 2008; Pereira Gray et al., 2016). It has evolved from a field mainly dominated by the medical profession towards and increasingly diverse and contested domain as new stakeholders and meanings of health and illness have entered the field (Brosnan & Kirby, 2016; Metaforum, 2015; Wagner et al., 2018). In this dissertation, I have analysed how these transformations have challenged the healthcare field. More specifically, drawing on concepts from medicalisation studies and field theory, I analysed the discourses of health-policy stakeholders and investigated how these discourses are related to the interests and position of these stakeholders within the healthcare field. In doing so, I unravel some of the layers surrounding these discourses in order to 1) gain more insight into how various meanings of health and illness are constructed and negotiated by stakeholders within the healthcare field and 2) investigate the impact of these discourses on the healthcare field and knowledge production within this field.

In what follows, I first discuss the main findings of the dissertation. In order to distinguish between the general findings of this dissertation and findings that contribute to a specific body of research, I divided them into two separate sections. Subsequently, the societal implications and the limitations of the research are discussed. I end the chapter with my suggestions for further empirical research.

## 10.1. Main findings

### *Discourses on health and illness do not (only) deal with health-related issues*

My results show that health-policy stakeholders' discourses on health and illness do not always only deal with health-related issues. This claim is not new; medicalisation scholars have already argued that the construction of meanings on health and illness is not value-free but based on 'social ideas of what is (not) acceptable' (Conrad & Barker, 2010, p. 568). However, I want to take this a step further and argue that although these stakeholders use a medical frame (i.e. (bio)medical vocabulary, claims and research techniques), the underlying goal these stakeholders want to attain is not always health-related. Health-policy stakeholders use this medical frame to justify or hide these underlying goals. For instance, references to the health of patients are used by the pharmaceutical industry to justify its pricing policy (Chapter 8). Sickness fund agencies draw on the storyline of ageing as a medical problem to promote their supplementary health insurance package and other commercial services (Chapter 7). Healthcare professionals draw on the argument of quality of care in order to advocate for higher fees (Chapter 6). Using a medical frame is beneficial for health-policy stakeholders as it strengthens the credibility and legitimacy of their messages (Declercq, 2018b; Wagner et al., 2018) because medical knowledge is an important and accepted resource within the healthcare field (Collyer, 2018; Wagner et al., 2018). Declercq (2018b), for instance, illustrates how non-biomedical stakeholders draw on biomedical vocabulary and claims to talk about the health-benefits of certain types of food, such as coconut sugar. By drawing on this medical frame, these claims about coconut sugar gain credibility.



Moreover, my results illustrate that health-policy stakeholders are also concerned with several non-health-related issues, such as cost containment or convincing the Minister of Public Health. I showed that the discourses of health-policy stakeholders reflect and reproduce these political, economic, and organisational goals. This suggests that meanings of health and illness and certain political, economic, cultural, etc. processes are mutually constituted. For instance, sickness fund agencies have to help their members stay healthy but they also guard the healthcare budget. By drawing on ideas of positive ageing, they create an image of ageing as a process that is manageable and avoidable, which ageing persons can manage on their own by living an active and healthy lifestyle. While at the same time, sickness fund agencies ageing discourses also (re)produce the political ideas of active citizenship and governing at a distance, which are strategies of cost containment (Rudman, 2015). These results show that health is also used as a tool for depoliticisation. Depoliticisation refers to 'a range of tools, mechanisms and institutions through which policy-makers attempt to move to an indirect governing relationship or seek to convince others that they can no longer be held responsible for a certain issue' (Flinders & Buller, 2006, p. 55). In the case of health, the responsibility for health is transferred to the individual and linked to the individual body (Rudman, 2015) or to health professionals and medical technology (Bambra, Fox, & Scott-Samuel, 2005), thereby making it an individual problem or a problem for medicine and thus hiding the underlying political dimension.

For these reasons (i.e. stakeholder's use of a medical frame and health as a tool for depoliticisation) it might be more appropriate to (also) label some of these discourses as political or economic discourses, as they deal with issues such as reputation

management, marketing, or policy strategies. Approaching these discourses as political or economic discourses might shed light on issues that otherwise stay hidden. It is essential to understand the multiple layers of these discourses as they can have an impact on health-policy decisions (Lassen & Moreira, 2014; Lupton, 1992). Additionally, health-policy stakeholders are still important sources of health news (Stroobant, De Dobbelaer & Raeymaeckers, 2018). Health-policy stakeholders' discourses thus also influence the news production process. It is therefore useful to deconstruct these discourses, especially since news media are still important sources of health information for lay people (Van Slooten et al., 2013) and they, as a consequence, can have a significant impact on the health-related knowledge and behaviour of their audience (Grilli, Ramsay, & Minnozzi, 2002; Matthews et al., 2016).

#### *Health-policy stakeholders' discourses reflect the structure of the healthcare field*

By mapping health-policy stakeholders within the Belgian SHI system, this dissertation showed how health-policy stakeholders and their discourses are embedded within the larger context of the healthcare field. Health-policy stakeholders' discourses reflect their position within the Belgian SHI system. This is illustrated by Chapter 7 which analyses how sickness fund agencies' position within the SHI system is reflected in how they talk about ageing and how they position ageing persons. In doing so, I illustrated the value of using discourse analysis to study the various positions stakeholders take on within the healthcare field. My discourse-analytical approach allowed to grasp this continuous process of positioning of these stakeholders and, thus, the richness and diversity of discourses and positions within the healthcare field. This is important as processes of (bio)medicalisation and pharmaceuticalisation are multidimensional and complex

(Clarke et al., 2003). However, previous research has not always been able to capture this diversity and few researchers have proposed a specific method to empirically study these processes. I hereby contribute to an area within medicalisation studies that researchers only recently have started to explore (Bell & Figert, 2015), which brings me to the next section.

## **10.2. Contributions of the research to medicalisation studies and field theory**

### *Medicalisation studies*

With this dissertation, I have addressed some of the critiques on medicalisation studies and have contributed to the more recent research tradition within medicalisation studies that focuses on the complexity and multidimensionality of these processes (e.g. Bell, 2017; Bell & Figert, 2015; Busfield, 2017; Clarke et al., 2010). The main contribution of my dissertation to the domain of medicalisation studies is that it provides a response and empirical evidence for several claims that have been made within this body of research. In what follows, I will discuss these claims and my contribution to each of them.

First, my work adds to the conceptualisation of medicalisation. By focusing on the Belgian SHI system and the main stakeholders involved, I address the critiques (Davis, 2006) concerning the decoupling of medicalisation from the institution of medicine (i.e. medicine's institutional dominance and prestige (Bell, 2017)). On the one hand, I illustrate that due to the involvement of various stakeholders, such as patient organisations and the pharmaceutical industry, there is to a certain extent a decoupling from medicine's institutional dominance. Medicine and medical professionals do not dominate the whole healthcare field. Chapter 6, for instance,

illustrates how associations of healthcare professionals have to negotiate and compete about their fee schedule and the healthcare budget with sickness fund agencies. On the other hand, my research shows that the health-policy stakeholders in my sample are still strongly informed by the institution of medicine. For instance, Chapter 9 shows how health-policy stakeholders draw on medical knowledge and practices to establish their own position within the healthcare field and to position news media as outsiders. Here my results add to the work of Bell (2017) who argues that processes of medicalisation are driven by various actors but that these actors are still informed by the institution of medicine. However, I also extend this work as I show how health-policy stakeholders draw on the institution of medicine and use it to frame their messages in order to strengthen the credibility and legitimacy of these messages. This can be seen as an example of institutional isomorphism, which refers to the process in which organisations try to resemble certain institutions, such as the institution of medicine, in order to gain political power and institutional legitimacy (DiMaggio & Powell, 1983).

Additionally, by focusing on stakeholders and the healthcare field, I went beyond a definitional approach towards medicalisation. This is important as it allows to study more implicit processes of (bio)medicalisation and pharmaceuticalisation. Focusing on definitions of medical problems is a very straightforward and observable way of studying medicalisation, while stakeholders and their practices sometimes more implicitly contribute to this process. For instance, by lobbying for a larger healthcare budget, sickness fund agencies and associations of healthcare professionals indirectly increase medicalisation. In addition, my dissertation illustrates the added value of drawing on field theory to go beyond this definitional approach towards

medicalisation as it offers concepts, such as position-taking, that allow to map the stakeholders driving these processes of medicalisation.

A final contribution of this dissertation to the conceptualisation of medicalisation is that it combines and integrates the concepts and theories of medicalisation (Chapter 6, 7), biomedicalisation (Chapter 7, 9), and pharmaceuticalisation (Chapter 8). This is rather new within the domain of medicalisation studies, as some researchers perceive these concepts as mutually excluding or they prefer to focus on only one of them (Abraham, 2010; Clarke et al., 2003; Williams, Gabe & Davis, 2008). I illustrated that these three concepts often appear alongside each other. For instance I showed how sickness fund agencies construct ageing as a medical problem but also how they perceive ageing bodies as bodies that can be transformed in order to delay or even avoid the ageing process (Chapter 7). Each concept also provided a framework to think about the specific research aims of each chapter, e.g. I used Clarke and colleagues' discussion (2003) of the five processes through which biomedicalisation is consisted as a starting point to think about the relationship between medicine and news media. The six dimensions of the pharmaceuticalisation of society (Williams et al., 2011a) offered insight into the pharmaceutical industry's reputational discourse, as it pinpointed me to certain processes, such as the construction of innovative medicines as the best way to save patients' lives.

Second, this dissertation contributes to the external validity of medicalisation studies. Previous studies have mainly focused on the institutional setting and healthcare system of the USA (Bell & Figert, 2012; Conrad & Bergey, 2014; Olafsdottir, 2010). This setting differs from the Belgian setting, as medicalisation within the USA is a purely market-based and therefore private enterprise. In Chapter 6, I have argued

that market forces encourage medicalisation. Hence, the institutional setting of the USA has offered us mainly insights into processes of medicalisation. The Belgian SHI system, on the other hand, includes both public and private interests. I illustrated that this public-private mix offers interesting insights into medicalisation as it results in counter-forces or countervailing powers (i.e. balancing of power of one group by another group) (Busfield, 2006; Galbraith, 1952; Light, 1995), which results in processes of medicalisation and demedicalisation. Sickness fund agencies and associations of healthcare professionals can be seen as such forces. Sickness fund agencies advocate for a reasonable fee schedule and focus on cost containment (i.e. demedicalisation) while associations of healthcare professionals want to raise their fees and increase their autonomy (i.e. medicalisation). These tensions between sickness fund agencies and associations of healthcare professions create stability as they bring each other into balance. These examples also illustrate that the institutional setting matters as it defines the positions stakeholders can take on and thus the impact they can have on meanings of health and illness. For instance, I argued that the umbrella organisations representing several patient organisations are still rather new and are trying to obtain permanent positions in various consultation bodies of the Belgian SHI system. In other countries, such as the UK, patient organisations are already more involved in health-policy making (Baggott & Forster, 2008). However, research has shown that this embeddedness means that these patient organisations are also more strongly affected by policy changes (Baggott & Jones, 2014b).

Third, my work also shows how medicalisation, biomedicalisation, and pharmaceuticalisation can be studied. My results illustrate the added value of a

discourse-analytical approach as a method to study the multidimensionality of medicalisation (and related processes), as through its focus on the sociological use of language this approach allowed to study discourses about health and illness as well as the actors and practices that hide behind these discourses. In addition, I developed specific indicators, such as the share in the GDP of a country by the pharmaceutical industry or the degree of state intervention related to cost containment, which improve the measurement of medicalisation and demedicalisation (Chapter 6). These indicators can be used to, for instance, measure the degree of medicalisation and demedicalisation across countries or across types health insurance systems. I thus offer scholars within medicalisation studies tools that can be used to further develop and extend the empirical work on the fluid and multidimensional nature of medicalisation as well as demedicalisation.

### *Field theory*

Following a rather recent research tradition within health sociology (e.g. Brown et al., 2008; Collyer, 2018; Kurunmäki, 1999; Wagner et al., 2018), the current dissertation used Bourdieu's concept of the field to gain a deeper understanding of the healthcare field. The main contribution of this dissertation to field theory is that it adds empirical evidence from a different institutional setting to research on the healthcare field and most importantly, evidence on field relationality. This is an area within field theory, but also in research on the healthcare field, that has been underdeveloped (Albright et al., 2018). In what follows, I further discuss these two contributions.

First, I add empirical evidence from a different health insurance system to research on field theory and the healthcare field, as previous research has been mainly

focused on theory (e.g. Collyer, 2018) or focused on the institutional context of Australia (Collyer et al., 2015; Collyer et al., 2017 ), the UK (Brown et al., 2008), and Finland (Kurunmäki, 19991), which are examples of national health insurance systems (van der Zee & Kroneman, 2007). In this dissertation, I showed how the struggles and positions of the stakeholders involved in the Belgian social health insurance system are entextualised within contemporary discourses on health and illness. I illustrated, for instance, that the pharmaceutical industry's reputational discourse reflects the discussions on how they are expected to behave (Chapter 8). I also showed that patient organisation's struggle for legitimacy is reflected in their communication towards the news media (Chapter 9). In addition, Chapter 6 and 7 showed that sickness fund agencies focus on lifestyle and individual responsibility is related to their struggle for cost containment and the financial responsibility they have towards the SHI system.

Second, by also focusing on field relationality, I contribute to previous research on healthcare as a field and provide more insight into the interconnectedness of the healthcare field with other fields. More specifically, I demonstrate that these intersections have an impact on how knowledge is produced within the healthcare field. Chapter 9, for instance, illustrates how health-policy stakeholders draw on media logics and adapt their communication strategy accordingly and, as a result, do not communicate about certain topics anymore. In Chapter 6, I showed how sickness fund agencies compete in the health insurance market and how they in their struggle for new members promote alternative medicine. In order to gain a deeper understanding of the healthcare field and thus to further develop this body of literature, it might therefore be essential to focus on the intersections of the



healthcare field with other fields and to look for instances where the logics and/or actors of the field contradict with other logics and/or actors. This will be further developed in section 10.5, in which I discuss directions for future research more extensively.

### **10.3. Implications for health-policy stakeholders**

Since I have only grasped one part of this very complex healthcare field it is not easy to formulate implications that are relevant for health-policy stakeholders or the health-policy level. Nevertheless, there is one implication of my results that I believe to be particularly relevant for health-policy stakeholders themselves.

I showed that discourses on health and illness are multi-layered, complex, and linked to the various positions and interests of health-policy stakeholders. These findings have important implications for initiatives that want to raise the health literacy of the population. Health literacy is ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (Institute of Medicine, 2004, p. 32). Initiatives that want to increase health literacy focus on various aspects, such as knowledge of health-related vocabulary but also the ability to understand and interpret health-related materials (Baker, 2006). A common strategy is to focus on increasing patients ability to critically evaluate health information (Nutbeam, 2000). Here one starts from the assumption that with the help of certain guidelines, patients are able to distinguish between good and bad health information. These guidelines consist of questions such as ‘who has written the message?’, ‘where does the message come from?’, and ‘why was this message written?’ (CM, 2017). However, after my analysis of the multiple layers of the discourses of Belgian health-policy stakeholders and due

to the fact that it is already difficult for lay people to deal with this overload of information (Metaforum, 2015), one could question if this approach does not shift too much responsibility to patients themselves. First of all, in order for these guidelines to work, there already needs to be a certain level of health literacy in the population. Moreover, health-related issues are very personal and emotional for patients, which can make it more difficult for patients to evaluate this information rationally (Metaforum, 2015). Research has shown that due to an information overload, patients increasingly turn to personal and bodily experiences to evaluate health risks (Kristensen, Askegaard & Jeppesen, 2013).

Some of these strategies to increase health literacy might thus focus too much on individual responsibility. Here I think it is important to raise health-policy stakeholders' awareness of this issue. As health-policy stakeholders are often sources of health information for other actors, such as lay people but also journalists, they need to understand the responsibility they have as providers of health information. Instead of transferring the responsibility for health to patients or leaving it up to journalists themselves to interpret health information, health-policy stakeholders need to take their responsibility in this matter. For instance, sickness fund agencies could more explicitly take up their social movement role and develop initiatives that are targeted to their most vulnerable members who often do not have the knowledge and/or means to select useful and reliable health information. In addition, in terms of enhancing transparency there is still a lot of work that can be done. Health-policy stakeholders can be encouraged to, when they produce health information, include a statement that briefly sketches who they are and where they stand for as well as a declaration of any conflict of interests. Since patients increasingly adopt experiential

models of health (Clayman et al., 2016), these measures can help to establish more trust in these organisations and the medical knowledge they produce.

#### **10.4. Limitations of the research**

Although I have discussed some limitations at the end of each empirical chapter, there are limitations that transcend these individual chapters. In the following section, I discuss what I believe to be the main limitations of this dissertation.

##### *Power dynamics*

In the introductory chapters, I explained that both medicalisation studies and field theory deal with issues of power. More specifically, they investigate the stakeholders who try to influence the construction of these meanings of health and illness and the discursive power struggles between these stakeholders. The empirical chapters of this dissertation contain several examples of such struggles. For instance, I illustrated the power struggle between associations of physicians and sickness fund agencies but also between patient organisations and the pharmaceutical industry. Within medicalisation studies and field theory, power dynamics are seen as relational and context-specific (Gaventa, 2003). Power is not held by the actors themselves, it is the result of an actors position vis-à-vis other actors within the field and the actor's position within the field itself. I have illustrated that health-policy stakeholders take on various positions within the healthcare field and that these positions shift and depend on who health-policy stakeholders are interacting with, resulting in a continuous process of positioning and repositioning. As a result, my dissertation shows that none of these stakeholders can be considered as completely powerless nor do they dominate the whole field. My point here is that in order to unravel power

dynamics within the healthcare field, it is important to study the interactions between the various stakeholders involved in the healthcare field.

Nevertheless, the data gathered in this dissertation – elite interviews and official documents – provided only limited options in relation to the extent to which I was able to capture these interactions and power dynamics. Since in these interviews the interviewees acted as representatives of their organisation and the documents that I gathered were public information, I mainly captured the professional and official discourses of these organisations and their representatives. Consequently, these interviews and documents can be considered as parts of the *frontstage* discourse of these health-policy stakeholders (Goffman, 1959). Goffman (1959) explains that the frontstage is a setting in which we present an idealised version of ourselves, which is linked to a specific role. In case of the health-policy stakeholders in our sample, this means that the accounts these organisations give of themselves and their relationships with other stakeholders are linked to the image they want others to have of them. In other words, health-policy stakeholders give a performance that provides ‘others with impressions that are in agreement with the desired goals of actors’ (Van Praet, 2010, p. 216). Moreover, since power is not always visible (Lukes, 1974) and some health-policy stakeholders, such as the pharmaceutical industry, will want to keep some of their interactions (e.g. interactions between pharmaceutical companies and patient organisations) out of the spotlight, for instance due to conflicts of interest, these frontstage discourses are not always suitable to analyse the interactions between health-policy stakeholders. In order to gain more insight into these interactions and the power dynamics that go along with them, we need to capture their *backstage* discourses and behaviours. These backstage discourses and

behaviours are interesting subjects of analysis as the backstage is a 'place, relative to a given performance, where the impression fostered by the performance is knowingly contradicted as a matter of course' (Goffman, 1959, p. 112). In the next section (10.5. Suggestions for further research), I discuss how we can grasp these backstage discourses.

### *Design: limitations of sample & method*

The two other limitations of this dissertation that I want to discuss are related to the research design. First, in this dissertation I made certain sampling decisions. Although I used several criteria in order to obtain a meaningful and manageable sample, choices had to be made. For instance, I decided to focus on the policy level of the Belgian SHI system. This meant that I focused on everything that happened at the federal level. However, in Belgium some healthcare domains, such as public health, are the responsibility of the regions (i.e. the Flemish, French and the German-speaking community) (Corens, 2007). This means that there is a whole other policy level that I did not include in my sample. This is important because public health and lifestyle issues, such as food and exercise, are increasingly medicalised (Salant & Santry, 2006; Welch, McMacon & Wright, 2012; Wray & Deery, 2008). Self-acclaimed food experts and bloggers but also the food industry have contributed to the (de)medicalisation of these topics (Declercq, 2018b; Leggatt-Cook & Chamberlain, 2012). Furthermore, these topics are useful to study the multiple layers of discourses on health and illness, as a (bio)medical frame is often used to talk about these topics (Declercq, 2018b) although the results of nutritional research are contested (Ioannidis, 2018). The food industry, for instance, uses health claims as a marketing strategy (Bech-Larsen & Scholderer, 2007). In this dissertation, I have mainly focused on

rather 'traditional' medical actors, such as medical professionals or the pharmaceutical industry. Focusing on public health and lifestyle issues would allow to include 'non-traditional' actors in research on the healthcare field. Some stakeholders, interests and health-policy domains might, thus, be missing from my dataset. Nonetheless, this focus on the federal level also has its advantages. It allowed me to stay at the level of the healthcare system and thus offers more opportunities to compare my results with insights from other healthcare systems. Furthermore, I decided to not focus on the regions because the main health-policy decisions, such as decisions about reimbursements or pharmaceutical policy, are made at the federal level. Most of these stakeholders also participate at both levels. For instance, concerning public health, the sickness fund agencies negotiate with the regions.

Another limitation related to my sample is the fact that I was not able to interview the umbrella organisation representing Flemish patient organisations. This umbrella organisation is an important new actor within the Belgian SHI system that is increasingly included in health-policy decisions. They are seen as a more reliable stakeholder to defend patients by some health-policy stakeholders, such as the Minister of Public Health, as they are independent from any political background. Being able to include them in my sample would have allowed me to gain more insight into how relatively new stakeholders are able to obtain a position within the SHI system, and into how lay voices are involved in the construction of meanings of health and illness. When the umbrella organisation refused, I could have chosen to interview the French-speaking umbrella organisation. However, I decided not to because this organisation would not be representing the patient organisations in my

sample and thus they would not have a lot of contact with each other. Furthermore, because language still is an important issue when it comes to policy and politics in Belgium, I expected, and also learned from my interviews, that the sickness fund agencies (I interviewed the Dutch-speaking representatives) and the association of Flemish general practitioners would be mainly in contact with the Flemish-speaking umbrella organisation. Therefore, in order to at least gain some information about this umbrella organisation, I tried to ask the health-policy stakeholders in my sample about their relationship with this umbrella organisation.

Additionally, the method of analysis used in this dissertation, discourse analysis, has its limitations. Here, I will focus on the critique that discourse analysis is too subjective. According to this criticism, discourse analysis relies too much upon a scholar's interpretation of the text (Lupton, 1992; Malterud, 2001). Although the openly acknowledgement of discourse analysis that subjectivity matters is a strength of this approach, this issue of subjectivity does raise questions about the generalisability of the dissertation's result. It is indeed difficult to generalise my results, as the context in which these discourses are produced (e.g. the healthcare field/the SHI system) and the role of the researcher play an important role in the construction of these results. However, this is not my aim. My emphasis is on transferability instead of generalisability (Lincoln & Guba, 1985; Malterud, 2001; Maxwell & Chmiel, 2014). Transferability 'does not require the discovery of the general conditions under which a finding or theory is valid; instead, it involves a transfer of knowledge from a study to a specific new situation' (Maxwell & Chmiel, 2014, p. 541). Several measures were taken to enable transferability, such as providing rich data, multisite investigation (i.e. multiple stakeholders), and a

systematic approach (Slevin & Sines, 1999). I do believe the empirical chapters of this dissertation offer insights that are transferable to other situations. For instance, in Chapter 6, I have developed indicators for medicalisation and demedicalisation that can be used to study (de)medicalisation in various institutional contexts. But also the storylines from Chapter 7 can be applied to other contexts. They can, for instance, serve as a starting point to analyse ageing discourses of other stakeholders or even ageing persons themselves. Chapter 8 studies the reputational discourse of the Belgian pharmaceutical industry. Pharmaceutical companies are multinational global companies (Busfield, 2006) and *Bad Pharma* stories are not limited to the Belgian context (e.g. see Goldacre, 2012). The thematic analysis used in Chapter 8 can, therefore, also be applied to study the reputational discourse of the pharmaceutical industry in other countries or on a global level. Furthermore, the ideas I developed around boundary-work and field relationality can also be applied to analyse other intersections and challenges for the healthcare field. For instance, the concept of boundary-work could be used to study how medical experts deal with the growing number of non-expert and pseudo-knowledge sources within the healthcare field.



## 10.5. Suggestions for further empirical research

The previous section discussed the limitations of this dissertation. In this section, I present several specific suggestions for further empirical research.

### *Ethnographic research*

In the previous section, I indicated that I was not able to fully grasp the interactions and power dynamics between the health-policy stakeholders in my sample. I argued that, besides the frontstage discourses of health-policy stakeholders, we also need insight into their backstage discourses and behaviours. One way of obtaining 'backstage' information is by doing ethnographic research (Jacobs & Slembrouck, 2010). More specifically, observing the interactions between the various health-policy stakeholders in my sample would add new insights to this research. Therefore, future research could take the shape of an ethnographic study that, for instance, focuses on the interactions of one specific stakeholder with other stakeholders or on the interactions within the consultation bodies of the Belgian SHI system, as observing alliances and conflicts between stakeholders is a good way to chart the interrelationships and power dynamics between stakeholders (Currie, Pouloudi, & Whitley, 2016; Light, 1995). Previous research has already illustrated that ethnographic research can offer interesting insights into power dynamics (Van Praet, 2010). These observations can be combined with interviews, in order to gain more insight into the motivations behind these behaviours. I would also extend this sample with a document analysis of, for instance, press releases about the topics that were discussed during these meetings. This would allow researchers to further unravel processes of influence and agenda-setting.

As a theoretical framework, Lukes (1974) three-dimensional model of power offers a lot of possibilities for further research that focuses on these backstage discourses. Gaventa's (2006) reformulation of these three dimensions offers a clear framework to think about and analyse power dynamics. These three dimensions of power (visible, invisible and hidden) can grasp the observable influence of health-policy stakeholders on the decision-making process (i.e. visible power) as well as how health-policy stakeholders are able to control what gets, or does not get, on the agenda (i.e. hidden power). Additionally, the third dimension (i.e. invisible power) allows to grasp how through the production and control of the flow of information, stakeholders shape what people think and want (Gaventa, 2006). I believe that especially these two last forms of power are important within the context of the healthcare field, as they deal with trying to influence meanings of health and illness. I believe invisible and hidden power can be studied by observing processes of agenda-setting within the consultation bodies of the SHI system and by studying how health-policy stakeholders try to control the flow of information (i.e. reports, press releases, decisions about reimbursement,...) that result from these consultation bodies.

This ethnographic approach is also important for my second suggestion for further research. The current dissertation can be seen as a first exploration of the stakeholders and social networks of the healthcare field. In this dissertation, I have focused on the interests and position of health-policy stakeholders within the healthcare field, and thus on the relationality of the construction of discourses on health and illness. This means that my focus was primarily on an actor's position vis-à-vis the healthcare field and the other actors within the field, and less on the social interactions between these actors. Bottero and Crossley (2011) argue that this focus

on objective relations is an important limitation of Bourdieu's field theory, as concrete social interactions between stakeholders within a field are ignored. To further investigate the dynamics of the healthcare field, it would therefore be interesting to examine these interactions, such as the previously described processes of coalition forming. As fields are networks of relations between social actors, one way to further explore these networks is using the ethnographic design as described above to execute a qualitative social network analysis (Hollstein, 2011).

### *Going beyond the Belgian case*

In this dissertation I focused on Belgium as a case-study. However, health and healthcare, and processes such as medicalisation, are becoming increasingly global (Bell & Figert, 2015; Conrad & Bergey, 2014). An important, but often overlooked, level when it comes to healthcare is the level of the European Union (EU). Although the member states are responsible for the organisation of healthcare, the EU also has a Health Strategy, sets laws and standards, and the European Medicines Agency is also an important player (European Union, 2018). Pharmaceutical companies and patient organisations therefore have associations that represent them at the European level, and also sickness fund agencies are represented at this level by the International Association of Mutual Benefit Societies (AIM). The importance of this European level cannot be underestimated. For instance, in 1995, the pharmaceutical industry lobbied (and succeeded) for a mutual recognition procedure which allowed them to choose the regulatory agency they want to undertake their marketing authorisation assessment. The other EU regulatory agencies have to mutually recognise this assessment (Abraham, 2002). This EU level is thus important and will only become more important, due to the high prices of new innovative therapies and

pharmaceuticals, such as immunotherapy. Therefore, several European countries (i.e. Belgium, the Netherlands, Luxembourg, Austria and Ireland) have already started working together and formed an alliance, i.e. Beneluxa, in order to obtain affordable prices for new pharmaceuticals (Beneluxa, 2018). Moreover, there is already a lot of lobby work going on at the European level. The Innovative Medicines Initiative (IMI) is such an example. The IMI is the world's largest public-private partnership in life sciences (Innovative Medicines Initiative, 2018). It is a partnership between the European Union and the European Pharmaceutical industry that brings together various health-policy stakeholders at the European level. For these reasons, it is important to also take this European level into account. Future research could analyse the discourses of health-policy stakeholders and the various positions they take on at this level as well as the interconnection between different policy levels.

Finally, this dissertation has focused on the specific context of the Belgian social health insurance system. Sickness fund agencies, for instance, are stakeholders which are specific to this type of system. It is therefore plausible that the findings related to sickness fund agencies' roles are inherent to the current institutional setting. National health insurance systems are state-led and private health insurance systems strongly rely on market forces, it is possible that these differences result in other dynamics, for instance another view on ageing or other indicators of (de)medicalisation. However, this does not mean that there are no similarities between the various health insurance systems. Sickness fund agencies' role as private insurer, for instance, aligns with private insurance companies in PHI systems. I have also argued that ageing discourses are similar across European countries, as they are (partly) based on European directives (Rechel et al., 2013). Therefore, in order to further develop and

validate some of my results, they need to be applied to other institutional settings. In the previous section, I referred to how some of my insights, such as the ageing storylines (Chapter 7) or the indicators of (de)medicalisation (Chapter 6), are transferable to other settings. These insights can serve as a starting point for quantitative cross-national comparative research in which, for instance, the storylines from Chapter 7, are compared across healthcare systems and across countries.

### **10.6. In sum**

Bourdieu (2006, p. 17) has argued that:

*‘The function of sociology, as of every science, is to reveal that which is hidden. In so doing, it can help minimize the symbolic violence within social relations and, in particular, within the relations of communication’.*

With this quote, Bourdieu (2006) argues that one cannot understand phenomena and the impact they have without looking into the subjective meanings that are part of these phenomena. With this dissertation, I have illustrated the relevance of analysing the stakeholders and the network of relations that shape discourses on health and illness because they unveil what we are truly (not) talking about.



## Appendix

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## **Appendix 1: Contribution of the doctoral student to each empirical study**

**Chapter 6:** Van den Bogaert, S., Ayala, R. & Bracke, P. (2017). Beyond Ubiquity: unravelling medicalisation within the frame of health insurance and health-policy making. *Social Theory & Health*, 15(4), 407-429.

*Contribution:* The elite interviews and organisational documents used in this study were gathered and analysed by the doctoral student who also wrote the paper. The second author provided feedback on the analysis and structure of the paper. The third author was consulted for his advice on the content and specific focus of the study.

**Chapter 7:** Van den Bogaert, S., Ceuterick, M., & Bracke, P. (2018). The silver lining of greying: ageing discourses and positioning of ageing persons in the field of social health insurance. *Health*. Advance online publication. doi: 10.1177/1363459318800171

*Contribution:* The website articles and press releases were gathered by the doctoral student. The second author scrutinised the press releases and decided which press releases would be included into the final sample. The specific focus of the paper was developed through discussions between both the doctoral student and the second author. Both the doctoral student and the second author independently coded the whole sample. Afterwards, they discussed the coding until analytical consensus was reached, and selected and translated the most illustrative excerpts. The main body of the paper was written by the first author, while the parts related to positioning theory were written by the second author. Both the second and third author provided feedback on the manuscript and on how to best integrate feedback from external reviewers. The doctoral student adapted the manuscript accordingly.

**Chapter 8:** Van den Bogaert, S., Declercq, J., Christiaens, T., Jacobs, G., & Bracke, P. (2018). In the land of pharma: a qualitative analysis of the reputational discourse of the pharmaceutical industry. *Public Relations Inquiry*, 7(2), 127-147.

*Contribution:* The doctoral student collected the interviews, press releases and organisational documents used in this paper. The second author conducted the ethnographic fieldwork and also analysed the data from the ethnographic fieldwork. The main body of the paper was written by the first author, while the parts related to the ethnographic fieldwork were written by the second author. The three other authors were consulted for their expertise concerning the specific focus of the study and also provided advice on how to best integrate the feedback we received from external reviewers. The feedback was integrated by the doctoral student into the final manuscript.

**Chapter 9:** Van den Bogaert, S., Stroobant, J., & Bracke, P. (2018). (Dis)entangling medicine and media: a qualitative analysis of the relationship between the fields of healthcare and journalism. *Health Sociology Review*. Advance online publication. doi: 10.1080/14461242.2018.1537131

*Contribution:* The elite interviews used in this study were gathered and analysed by the doctoral student who also developed and wrote the paper. The second author was consulted for her expertise on news media and provided feedback on the theoretical framework, analysis, and structure of the paper. She also provided linguistic support. The third author was consulted for his advice on the content and specific focus of the study.

## Appendix 2: Interview schedule

### 1. The organisation

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#### 1.1. Position of the representative within the organisation

- *Within this organisation you are responsible for... Can you tell me about your job?*

#### 1.2. Goals and functioning of the organisation

- *What are the main goals of the organisation?*
- *Your organisation is responsible for... Are there other activities that can be considered as main activities of your organisation?*
- *What is the target population of these activities?*
  - o Why?
  - o Are there other target groups that are important for your organisation?
  - o Are ageing persons an important target population for your organisation?

#### 1.3. Position of the organisation and relationship with other organisations

- [If applicable] *What is the role of the umbrella organisations representing your organisation?*
- [If applicable] *You represent several companies/patient organisations. How does that work?*
  - o How are the viewpoints of your organisation constituted?
  - o How does your organisation communicate to its members?
- There are several organisations that deal with topics such as health, illness and pharmaceutical. *With which organisations does your organisation have contact?*
  - o Government institutions, pharmaceutical companies, sickness fund agencies, patient- and consumer organisations, associations of medical professionals, associations of scientific experts? Which organisations? Why?
- *Can you give me examples of topics about which you communicate with other organisations and interest groups?*
  - o What are the most important reasons to do this?
  - o Which channels do you use to communicate these messages?
  - o Do you differentiate between organisations? How do you adapt your messages then?
- *Are you aware of the information about health and illness that is produced by other organisations and interest groups?*
  - o Can you give me an example of how this information affects your organisation?
- *Are you often contacted by other organisations? Can you give me examples of the questions they ask?*

## 2. Definitions of health and illness

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- *Can you give me examples of health problems that are important for your organisation?*
- *If your organisation communicates about health, what do they communicate about?*
  - o *If your organisation communicates about illness, what do they communicate about?*
- *Where do you base these definitions on?*
- *Do you think pharmaceuticals are important in order to become healthy again? Why?*
- *Do you think pharmaceuticals are important to stay healthy?*

## 3. Communication and media

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- *Can you give me examples of topics about which your organisation communicates to the general public?*
  - o *Does your organisation have a specific target population in mind?*
  - o *Patients are increasingly positioned as being better informed and more outspoken. Have you noticed this? Can you give me examples of its impact on your organisation's communication?*
- *What are, for your organisation, important reasons to communicate to the general public?*
- *What definitely has to be included in these communication messages?*
- *Are you involved in the content of these communication messages? How?*
- *Are you involved in the distribution of these communication messages? How?*
- *Which media does your organisation use?*
  - o *Which medium is the most important one for your organisation? Why?*
  - o *Can you give me examples of information that your organisation distributes via the internet?*
  - o *Do you think your messages reach your audience? Why (not)?*
- *What is the relationship between your organisation and the news media?*
  - o *How do you communicate with the news media?*
  - o *How is the communication established?*
  - o *Are you often contacted by journalists or do you contact them?*
- *Which topics deserve more media attention?*
- *Which topics are at risk for misunderstandings?*
- *Which topics get too much media attention?*

## 4. End

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- *Do you have any further comments/remarks you would like to share?*
- *Do you have questions?*

### Appendix 3: Confidentiality agreement

Deze vertrouwelijkheidsovereenkomst wordt gesloten in het kader van het project '(De)constructing Health News' van de onderzoeksgroep Health, Media & Society. Met '(De)constructing Health News' wil een transdisciplinair team van 4 doctorandi, 6 promotoren en een postdoctoraal onderzoeker inzicht krijgen in de productie, interpretatie en werking van medioren (55+) en senioren (65+) gerelateerd gezondheidsnieuws. Enkele maatschappelijke tendensen waarin dit project zich situeert zijn de oplopende kosten van de gezondheidszorg, de vergrijzing van de bevolking en de veelheid aan media die het lekenpubliek te verwerken krijgt, in het bijzonder de steeds groter wordende groep vijftigplussers, die bovendien steeds meer bezig zijn met gezondheid. Het onderzoek is in grote lijnen op te breken in vier onderdelen waar telkens 1 doctorandus op werkt:

- **Stakeholder analyse.** In dit sociologisch onderzoek wordt in kaart gebracht welke organisaties en belangengroepen bijdragen tot of een rol spelen in het landschap van gezondheidsinformatie en -nieuws, en hoe zij reflecteren over gezondheid en medioren/senioren.
- **Productieprocessen.** Dit taalkundige luik onderzoekt hoe senioren-gerelateerd gezondheidsnieuws tot stand komt, en wil in kaart brengen welke factoren van belang zijn bij het schrijven van een persbericht, nieuwsartikel, artikel in een magazine en andere vormen van communicatie.
- **Contentanalyse.** Dit communicatiewetenschappelijke onderdeel brengt in kaart wat er allemaal in de media aan senioren-gerelateerd gezondheidsnieuws te vinden is. Wat staat in de kranten en magazines en hoe ziet het nieuws eruit?
- **Publieksonderzoek.** Ten slotte wordt onderzocht hoe het seniorenpubliek omgaat met gezondheidsnieuws: wat zijn hun bronnen, hoe interpreteren ze de aangereikte informatie en hoe beïnvloedt hen die in het dagelijkse leven?

Deze vertrouwelijkheidsovereenkomst wordt gesloten tijdens het eerste luik van dit onderzoeksproject, de stakeholder analyse.

#### De ondergetekende:

Naam: Van den Bogaert

Voornaam: Sarah

Adres: Korte Meer 5

Postcode: 9000 Gent

Instelling: Universiteit Gent

Verder te noemen de 'interviewer'.

**komt overeen met:**

Naam:

Voornaam:

Adres:

Postcode:

Organisatie:

Verder te noemen de 'geïnterviewde'.

**Artikel 1.**

De interviewer stemt erin toe dat zij door de geïnterviewde wordt voorzien van vertrouwelijke informatie. Deze informatie moet het voeren van onderzoek mogelijk maken en zal eveneens enkel gebruikt worden in het kader van het bovenbeschreven doel.

- a) De interviewer verplicht zich bij elke afwijking van het bovenbeschreven doel toestemming te vragen aan de geïnterviewde.
- b) De interviewer zal de bekomen informatie vertrouwelijk behandelen

**Artikel 2.**

De geïnterviewde geeft *geen toestemming* tot het gebruiken van de naam van de organisatie bij het formuleren van de resultaten van dit onderzoek.

**Artikel 3.**

De geïnterviewde stemt toe met het opnemen van het gesprek. De opgenomen interviewfragmenten dienen enkel ter ondersteuning van de interviewer. Deze geluidsfragmenten worden bewaard op een door paswoord beveiligde computer en staan enkel ter beschikking van het onderzoek. Deze geluidsfragmenten zullen nooit ter beschikking gesteld worden van derden.

**Artikel 4.**

Deze overeenkomst wordt opgemaakt in twee exemplaren.

**Ondertekening**

Naam:

Naam:

Datum:

Datum:

Handtekening:

Handtekening:

## Appendix 4: Thematic codes

Name of theme	Definition	Description	Inclusion and exclusion criteria
<b>Belgium Pharma country</b>	The text or person refers to the important position and contribution of the pharmaceutical industry within/to the Belgian economy	Indicators are all references such as “Belgium is an important pharma country” or “the leading position of Belgium”	<p><u>Inclusion:</u> All references to the important contribution of the industry to the Belgian economy.</p> <p><u>Exclusion:</u> References to the economy in general. The statement has to highlight how important the pharmaceutical industry is for Belgium.</p>
<b>Innovation</b>	The text or person describes how innovative the pharmaceutical industry is and/or stresses the importance of innovation	Indicators are all references to innovation and revolutionary therapies by the pharmaceutical industry.	<p><u>Inclusion:</u> All references to innovation by the pharmaceutical industry.</p> <p><u>Exclusion:</u> References to the development of medicines in general, references that do not highlight the innovative or revolutionary character.</p>
<b>Patient orientation</b>	The text or person refers to the fact that everything the industry does is, in the first place, for patients. They do these things for patients to get access to medicines and to improve their health.	Indicators are references that state “for patients”.	<p><u>Inclusion:</u> References that highlight that it is good for patients, that patients will get access to medicines or will become healthier.</p> <p><u>Exclusion:</u> References that mention patients but do not stress their centrality or importance.</p>
<b>Ethical issues</b>	The text or person refers to the need for the pharmaceutical industry to develop or follow ethical guidelines and to be more transparent	Indicators are all references to “transparency”, “ethics” and “conflict of interests”	<p><u>Inclusion:</u> References mentioning the need for transparency, ethical guidelines, or conflicts of interests.</p> <p><u>Exclusion:</u> References that mention transparency or ethics but that do not relate to the behaviour of the industry.</p>



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## Summaries

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### English Summary

Historically, health and illness were topics that were mainly entrusted to physicians. They were seen as those who possessed the knowledge and expertise to define what constitutes health and illness. Today, the healthcare field consists of a wide range of stakeholders, such as patient organisations, pharmaceutical companies, and sickness fund agencies. This evolution has complicated interactions between these stakeholders and has complicated the construction of meanings of health and illness within the healthcare field. Therefore, instead of one stakeholder, there are many different stakeholders who produce discourses on health and illness. Moreover, these stakeholders all have their own agenda. Previous research has already illustrated that this diversity has an impact on the construction and production of discourses on health and illness. However, this research has failed to map the diversity and multidimensionality of this process because of a one-sided focus on either individual stakeholders or the broader context of the healthcare field.

My dissertation addresses this shortcoming by drawing on a more comprehensive approach in order to gain a better understanding of how discourses on health and illness have an impact on our knowledge about these issues, and therefore ultimately on our health itself. That is why, in this dissertation, I have not only focused on what different stakeholders say about health and illness, but also on how this relates to their interests and their position within the healthcare field. This resulted in two main objectives. First, I want to gain insight into *how* stakeholders construct and

negotiate meanings about health and illness. Second, I want to examine *the impact* of these discourses on the healthcare field and knowledge production within this field.

These objectives resulted in four empirical chapters, in each of which I focused on stakeholders active within the Belgian social health insurance system. The first empirical chapter focuses on the various stakeholders that operate within this system and examines how they contribute to the construction of certain problems as medical problems. In the next two chapters, I analyse the discourses of two specific stakeholders; Belgian sickness fund agencies and the pharmaceutical industry. In the second empirical chapter, I study the ageing discourses of Belgian sickness fund agencies and examine how these discourses are related to the various roles these stakeholders occupy within the Belgian social health insurance system. In the third empirical chapter, I analyse how the discourse of the pharmaceutical industry is linked to negative stories, i.e. the *Bad Pharma* discourse, about the industry. In the fourth and final empirical chapter, I analyse the relationship between the healthcare field and the journalistic field. In each of these chapters, I use qualitative data such as interviews, policy documents and public communication (e.g. website articles and press releases).

The most important finding of this dissertation is that discourses on health and illness do not merely discuss these themes, but also serve as a cover to advance other underlying objectives. Stakeholders use a medical framework to strengthen the credibility and legitimacy of their messages, even though the underlying objective of these messages is not always health-related. In addition, my research shows that these discourses on health and illness are used to depoliticise a message. After all, the underlying political dimension of a message remains hidden when these discourses

shift the responsibility for health to the individual and/or medical professionals. Consequently, I conclude that these discourses should also be labelled as political or economic discourses in order to gain insight into these underlying themes.

Finally, I discuss the implications of my results on the current strategies to increase health literacy. These strategies often work with guidelines for patients that allow them to select useful and reliable health information. Given the multidimensionality of discourses about health and illness, these strategies might transfer too much responsibility to patients themselves. It is therefore important that Belgian health-policy stakeholders become more aware of their role as information providers and the responsibility that this entails.

## Nederlandstalige samenvatting

Ziekte en gezondheid zijn thema's die voorheen hoofdzakelijk aan artsen werden toevertrouwd. Artsen werden gezien als diegenen die de kennis en expertise bezaten om te bepalen wat we moeten verstaan onder ziekte en gezondheid. Vandaag de dag bestaat het gezondheidsveld echter uit een heel divers aantal stakeholders, zoals bijvoorbeeld patiëntenorganisaties, farmaceutische bedrijven en ziekenfondsen. Deze evolutie heeft de interacties alsook betekenisgeving binnen dit veld complexer gemaakt. In plaats van één stakeholder zijn er bijgevolg heel veel verschillende stakeholders die discourses rond ziekte en gezondheid produceren. Bovendien houden die verschillende stakeholders er ook allemaal een eigen agenda op na. Voorgaand onderzoek heeft reeds aangetoond dat deze diversiteit een impact heeft op de constructie en productie van discourses rond ziekte en gezondheid. Desalniettemin is dit onderzoek er niet in geslaagd om de diversiteit en multidimensionaliteit van dit proces in kaart te brengen omwille van een eenzijdige focus op enerzijds de individuele stakeholders en anderzijds de ruimere context van het gezondheidsveld

Mijn doctoraat tracht deze tekortkoming aan te pakken door een meer allesomvattende aanpak te hanteren om op die manier een beter inzicht te krijgen in hoe discourses rond ziekten en gezondheid een impact hebben op onze kennis over ziekte en gezondheid, en dus uiteindelijk ook op onze gezondheid zelf. Daarom heb ik in dit doctoraat niet enkel gefocust op wat verschillende stakeholders zeggen over ziekte en gezondheid, maar ook op hoe dit gerelateerd is aan hun belangen en hun positie binnen het gezondheidsveld. Ik stelde hierbij twee doelstellingen voorop: inzicht krijgen in *hoe* stakeholders betekenissen rond ziekte en gezondheid

construeren en onderhandelen en *de impact* nagaan van deze discoursen op het gezondheidsveld en kennisproductie binnen dit veld.

Deze doelstellingen resulteerden in vier empirische hoofdstukken, waarbij mijn focus telkens lag op stakeholders actief binnen de Belgische ziekteverzekering. Het eerste empirische hoofdstuk focust op de verschillende stakeholders die opereren binnen dit systeem en gaat na hoe zij bijdragen tot de constructie van bepaalde problemen als zijnde medische problemen. In het tweede en derde empirische hoofdstuk analyseer ik de discoursen van twee specifieke stakeholders, namelijk de Belgische ziekenfondsen en de farmaceutische industrie. Bij de Belgische ziekenfondsen bestudeer ik hun discours rond ouder worden en ga ik na hoe dit gerelateerd is aan de verschillende rollen die zij innemen binnen het Belgische ziekteverzekeringssysteem. Bij de farmaceutische industrie analyseer ik hoe hun discours gelinkt is aan negatieve berichtgeving over de industrie. In het vierde en laatste empirische hoofdstuk bestudeer ik de relatie tussen het gezondheidsveld en het journalistieke veld. In elk van deze hoofdstukken doe ik beroep op kwalitatieve data zoals interviews, beleidsdocumenten en publieke communicatie (o.a. websites en persberichten).

De belangrijkste bevinding van dit doctoraat is dat discoursen over ziekte en gezondheid niet louter deze thema's bespreken, maar ook als dekmantel dienen om andere onderliggende boodschappen naar voor te schuiven. Stakeholders maken gebruik van een medisch kader om de geloofwaardigheid en legitimiteit van hun boodschappen te versterken, terwijl de onderliggende doelstelling van deze boodschappen niet altijd gezondheids-gerelateerd is. Daarnaast toont mijn onderzoek aan dat deze discoursen rond ziekte en gezondheid gebruikt worden om

een boodschap te depolitiseren. De onderliggende politieke dimensie van een boodschap blijft immers verborgen wanneer deze discourses de verantwoordelijkheid voor gezondheid afschuiven naar het individu en/of de medische wereld. Bijgevolg besluit ik dat het deze discourses ook gelabeld zouden moeten worden als politieke of economische discourses om op die manier inzicht te krijgen in deze onderliggende thema's.

Tot slot, bespreek ik ook de implicaties van mijn resultaten met betrekking tot huidige strategieën om de gezondheidsgelletterheid van mensen te verhogen. Deze strategieën werken vaak met richtlijnen die patiënten kunnen gebruiken om bruikbare en betrouwbare gezondheidsinformatie te selecteren. Gegeven de multidimensionaliteit van discourses rond ziekte en gezondheid leggen deze strategieën te veel verantwoordelijkheid bij het individu zelf. Het is daarom belangrijk dat de stakeholders binnen de Belgische ziekteverzekering meer bewust worden van hun rol als informatieverstrekkers en de verantwoordelijkheid die hiermee gepaard gaat.



