

**Blame it on her Genes:
On Performativity, Politics, and the Consumption of Prevention**

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Abstract

This thesis examines the politics of performativity and its effects in everyday life. The context of the study is the practices surrounding the consumption of preventive solutions for hereditary breast and ovarian cancer, and a specific set of genes, the BRCA genes, which are associated with an increased risk of developing the disease over a lifetime. By integrating concepts developed within the sociology of health and illness with those that are informing the area of market studies, this thesis looks across a range of market actors with a particular emphasis upon the positioning of the individual as a consumer of prevention in the era of genetic citizenship.

Combining three key concepts from Discursive Psychology, this thesis addresses the effects of performativity by scrutinising how morality is actually indexed by market actors in everyday speech. By treating text and talk as a form of action, the analytical framework focuses on how subject positions are located in interaction with the 'other', as well as wider ideological domains. This proves helpful to bridge between the situated and the broader cultural/historical contexts. Through the analysis of naturalistic data, which provides rich and detailed accounts of interactions, this thesis moves beyond the elaboration of thick descriptions to engage with the politics behind performatives.

A particular scrutiny is put on the set of practices, rights and duties that constitute the basis for a genetic/biosocial membership. Under this understanding, the practice of consumption of prevention becomes constitutive of the at-genetic risk subjectivity, and not only an outcome of a diagnosis. The enquiry examines the intertwinement between these practices and the mainstreaming of biomedical rationalities, as well as the different modes of responsibility. By studying the politics of performativity, this thesis presents insights on the synergies and tensions between the different modes of responsibility.

Key words: *Performativity, Deconstruction, Politics, Consumption of Prevention, Hereditary Breast and Ovarian Cancer, Genetics, Responsibilisation, Discursive Psychology.*

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Chapter 1: Introduction

“The *pharmakon* would be a *substance* – with all that word can connote in terms of matter with occult virtues, cryptic depths refusing to submit their ambivalence to analysis, already paving the way for alchemy – if we didn’t have eventually to come to recognize it as ant substance itself: that which resists any philosopheme, indefinitely exceeding its bounds as nonidentity, nonessence, nonsubstance; granting philosophy by that very fact the inexhaustible adversity of what funds it and the infinite absence of what founds it”

(Derrida, in *‘Plato’s Pharmacy’*, 1981, p. 75-76, emphasis in original)

1.1. The market of prevention:

The human genome can be described “like the torn pages of a giant novel, written in an unknown language, blowing about helter skelter in an airconditioned, enclosed space such as Houston’s Astrodome” (Wallace, 1992 – cited in Nelkin, 2001). The field of genetics, which object of study is the human genome, has profoundly shaped how we think of the human body, human behaviour, and most importantly health and illness. Recent advances in the field of genetics, such as gene-editing techniques, digital marketplaces for personal genomics, or the swift development of biobanks, are particularly exciting and scary at the same time; whether taken from a scientific, bioethics or business perspective.

The footprint of genetics is particularly visible across the area of health and illness. Through the discovery of disease-causing genes, science says that we can anticipate and prevent the occurrence of those diseases for both the carrier of the ‘faulty’ gene,

as well as their progenies. Controversial options such as the in vitro fertilisation could even allow the identification of faulty genes prior to the implantation of the embryos. An alternative method 'gene-editing embryos', which is still at an early stage of development and marketisation, enables the correction of pathogenic gene mutations at the level of embryos. The proponents of such methods argue for its provision of the control of diseases, as long as the method is not used for the screening of non-disease-related traits. Prevention, within this perspective, would allow us to have further control over our bodies with regards to risks of illnesses, as well as a help reduce healthcare treatment costs, especially for chronic and rare diseases (Centers for Disease Control and Prevention, 2009).

On the other hand, if we consider the act of prevention as contingent on the delineation of what it is to prevent, then we face a problem of definition. Without going in depth into the sociology of prevention of disease at this stage (which will be addressed in chapter three), I would like to draw the attention here onto the taken-for-grantedness of the notion of prevention as framed by biomedical rationalities and neoliberal targets for cost-efficiency. This is particularly relevant when considering the tremendous growth for the market of prevention, ranging from medical interventions such as surgery, to chemical interventions such as pharmaceutical drugs, as well as lifestyle services such as dietetic services and the fitness market, or the growing market for mobile health' monitoring technologies and devices. Within this thesis, I focus on the market of prevention; more specifically, I address the practices around the consumption of prevention of genetic disease.

1.2. Scope of the thesis:

Performativity is currently an en-vogue term in market studies, and social science terminology more broadly. This thesis examines performativity at work, and its effects in everyday life. More specifically, it is located within the timidly growing scholarship addressing the politics of performativity, and aims to extend it through a focus on how morality is actually indexed by market actors in their everyday practices.

My study integrates concepts developed within the sociology of health and illness with those that are informing the area of market studies, in order to better understand the different processes at work and their effects. The objective of my study is to examine the performativity of knowledge claims about the gene, the body and the disease affecting the newly redefined at-risk entities; as well as the new consumption practices targeted at these entities, centred on risk prevention and the reconstruction of the heteronormative body. In keeping with a market studies perspective, I look across a range of market actors with a particular emphasis upon the positioning of the individual as a consumer of prevention in the era of genetic citizenship (Kerr, 2004).

Within this study, I scrutinise the set of practices, rights and duties that constitute the basis for a genetic/biosocial membership. Under this understanding, the practice of consumption of prevention becomes constitutive of the at-genetic risk subjectivity, and not only an outcome of a diagnosis. The possibility of risk calculation as well as the credibility of the calculation models constitute important devices as part of the construction of a category associated with a genetic disease. In order to sustain the category membership, at-genetic-risk subjects need to fulfil the duties of a good genetic citizen through the consumption of preventive solutions. Thus, self-care becomes a responsibility, and an enterprise embedded within biomedical rationalities and neoliberal targets for maximisation of health capital and cost efficiency. Using a framework combining a Butlerian/Derridean view on performativity with a theorisation of power drawing from Foucault's governmentality, I explore the possibility of studying the at genetic as an entrepreneur of himself. Through a Derridean lens, I scrutinise the processes that bring into being this new market entity, and thereby move beyond a study of subjectification in markets to discuss the tensions and conflict in making sense of, belonging to, and sustaining a category membership.

The focus of this thesis is on the practices surrounding the consumption of preventive solutions for hereditary breast and ovarian cancer (hereafter HBOC), and a specific set of genes, the BRCA genes (BRCA1 and BRCA2). The inheritance of a BRCA mutation is

associated with an increased risk of developing HBOC over a lifetime. I use a documentary analysis of online publicly available data. Analysis deploys notions from discursive psychology, and connects three key concepts in order to bridge between the 'micro' and 'macro': the discourse action model of description and attribution as informed by Edwards and Potter (1993), ideological dilemmas as informed by Billig et al. (1988), and positioning theory as informed by Davies and Harré (1990). It attends to unravel the politics of performatives and their effects.

Before moving into an overview of the thesis' structure, I briefly introduce myself and my background, and how this shaped the course of the present study.

1.3. About the researcher:

The title of this section will be the only instance where I will be locating myself using the third person, within this thesis. To do so, I mainly use the first person pronoun 'I'.

The interdisciplinary nature of this study, has been very much informed by my eclectic academic and professional backgrounds. I initially completed a degree in Pharmacy at the faculty of Medicine, Oran in Algeria (my home country). I also completed a Masters of Business Administration delivered by ESG Paris (École Supérieure de Gestion) part-time, while holding various positions in commercial and clinical operations functions in leading pharmaceutical companies (Novartis, Sanofi and NovoNordisk). Despite being on track for a successful career within the pharmaceutical industry, my experiences stimulated my interest in initial questions surrounding healthcare ethics, business ethics, and their impact on society. This ultimately led me to pursue and complete my MRes in Advanced Marketing Management at Lancaster University, where I further developed my knowledge and interest around Market Studies, Critical Management Studies, and Business Ethics. This has profoundly shaped the course of my PhD journey, as I had to review my scientific knowledge through a sociological lens, while developing the skills to connect this new take (at least for me at the time) on biomedical science with critical approaches to markets and consumption.

Another challenge that I faced throughout my PhD journey was located within the domains of the philosophical and methodological. I come from a 'hard' science background, with a training in biostatistics methods, laboratory research methods, and other quantitative research techniques. The challenge was not purely technical, as it required from me to negotiate my beliefs with regards to the nature of 'stuff' and the nature of knowledge. There have been lots of moments of struggle, but I am now at a place where I can see how different research techniques can be appropriate for specific purposes. Thus, the most important for me is to stay alert, and not take for granted certain aspects of research that have been black-boxed and assumed to be common knowledge (Pinch and Bijker, 1984; Latour, 1987).

1.4. Structure of the thesis:

This thesis comprises nine chapters in total, including the present chapter, which introduces the thesis' research topic.

Chapter two explores some of the recent developments within the area of market studies, with a particular focus on the performativity thesis. I start with an overview of dominant approaches to the notion of 'market', especially those derived from neo-classical economics; before introducing critical approaches such as those of market studies. A particular attention is given to the notion of performativity, where I contrast the various approaches to studying it, with respect to its roots in Austin work. The discussion centres on Callon's performativity on the one hand, and the Buterian/Derridean performativity on the other hand. Finally, I discuss the main influences of this thesis, in order to develop a study that engages with the foundational work on performativity and attends to its politics.

Chapter three engages with some of the developments within the sociology of health and illness, in order to develop a strong and thorough theoretical framework when approaching the case under study. In line with the market studies tradition, the discussion centres on the interaction between human and non-human actors such as genes, diseases as well as technologies of screening and audit of the body. I adopt a historical perspective on the field of genetics in order to better understand the

intertwinement between genetics and market ideologies, particularly with regards to the rhetoric of individual choice. Finally, I present the causal associations between the genome, disease, and prevention with healthcare discourse.

Chapter four bridges the concerns articulated in chapter two and three, and locates the framework of power as used in this thesis. I start with a discussion the discourses of risk and control and how they shape the applicability and commercialisation of genetics knowledge. Responsibilisation, as a mode of neoliberal governance, is identified as bridging genetics and market ideologies. I then move onto a discussion on power, where I review the traditional conceptualisations of power within STS-influenced market studies, as well those studies that drew a Foucauldian view on power – with a particular focus on his developments on governmentality. Finally, I locate this thesis within a Foucauldian framework of responsibilisation under neoliberalism.

Chapter five presents the research questions, and discusses the philosophical commitments underpinning this thesis, as well as the research methods. First, I present the research questions, and explain the grounding of this thesis within a social constructionist approach, including a discussion on sociomateriality. The second part of the chapter discusses discourse analysis, with a particular focus on the challenges of a too narrow focus on the local-situated context, in contrast with the over-grandiose approaches that avoid looking beneath the macro-system context. This leads me to discuss the analytical framework that I have developed, which connects three concepts within discursive psychology, a ‘branch’ of discourse analysis. The three key concepts are: the discourse action model of description and attribution, ideological dilemmas, and positioning theory. Finally, I discuss how this analytical framework helps bridge between the ‘micro’ and ‘macro’ context, by locating subject positions in interaction with the ‘*other*’, as well as wider ideological domains. The final sections of this chapter discuss the research methods for this thesis. I discuss the use of naturalistic data, and present the latest research methods and ethical debates in the context of linguistically focused computed-mediated communication’ research. Most importantly, I present the specifics of my data collection, including the details of

data sampling and refinements, as well as a discussion on the ethical process for this study. I conclude the chapter with a reflexive account of being and as acting as a feminist male researcher writing about such personal female issues.

Chapter six marks the start of the data analysis and discussion, with a focus on hereditary breast and ovarian cancers in the media. First, I present a discussion centred on hereditary breast and ovarian cancers, the BRCA gene mutation, and the consumption of preventive solutions. I scrutinise the dominance of the discourse survivorship, and its effects. Moving forward I present a review of breast cancer in the media, and an analysis of the practices surrounding breast cancer activism as shaped by the discourse of survivorship. Utilising the framework discussed in chapter five, I present the analysis and key findings of a central piece published by the actress Angelina Jolie in *The New York Times* in June 2013.

Chapter seven presents the analysis and findings from the online forum part of my dataset. I start by discussing the website FORCE as a market device, before presenting a summary of the key narratives analysed in the chapter. The remainder of the chapter is organised in five main sections, where each scrutinises the work of a specific category of linguistic devices. I start with an analysis of quantification rhetoric within the data, which tackles both numerical and non-numerical forms of quantification, and leads to a discussion on the effects of the quantification of the body on shaping the practices surrounding the consumption of prevention. The second section is centred on pronouns and the discursive production of selves, where the discussion focuses on the responsibility attached to different subject positions, and how these are located in speech. The third section takes the analysis to the business of blame attribution through the usage of extreme case formulations, where the strategies for presenting hesitation and doubt are connected to the various modes of accountability. The fourth section scrutinises the use of passivisation in everyday interaction, and its function of agency deletion in speech drawing the focus on processes, with the effect of reframing the attribution of responsibility and accountability. The fifth section focuses on metaphors and takes a historical approach to scrutinise their role within the management of responsibility through their linkages with wider ideological systems. The final section presents an analysis and discussion

centred on knowledge, empowerment and power. Through the analysis of empowerment as a discourse shaping practices, rather than a movement of power from *a* to *b* that results in the emancipation and independence of individuals, I dissect the interconnectedness between empowerment and responsabilisation as a governance tool.

Chapter eight provides elements of answer to the research questions, by connecting the various elements discussed in the analysis chapters to the literature gap. I organise the discussion around the entrepreneurial self, category membership, responsabilisation, clashes of modes of responsibility, and process. Drawing on Foucault, I discuss the at-genetic-risk subject as an entrepreneur of himself, and contrast the findings from the present case with Foucault's discussion on human capital. I also discuss the process of the bringing into being of this entity, and its functions as part of the practices surrounding the category membership around hereditary breast and ovarian cancers. Following that, I locate the self-entrepreneur in an arena where different, and sometimes conflicting, modes of responsibility coexist.

Chapter nine concludes this thesis by articulating the thesis main contributions, organised around the research questions. I present the methodological contributions in the field of market studies, as well. Finally, I conclude this chapter and this thesis with directions for potential avenues for research within market studies.

Chapter 2: Performativity and politics in ‘markets’

This chapter focuses on the recent developments within the market studies group, and its commitments to better understand markets. The centre of the discussion is around the notion of performativity with its various developments since its inception in Austin’s seminal work ‘how to do things with words’. I focus particularly on two approaches: Callon’s performativity on the one hand, and the Butlerian/Derridian performativity on the other hand; and locate this study within these different stances.

This chapter is structured as follows. First, I discuss the taken-for-grantedness of the notion of ‘market’ within neoclassical economics and the mainstream marketing research. Second, I discuss the efforts within the market studies group to better understand markets. Third, I move to the core of this chapter, which the discussion on performativity, and locate this work within the various perspectives. Finally, I articulate the research gap that this study attempts to fill.

2.1. One hand to rule them all:

“In the beginning, there were markets”. Williamson (1975, p.20)

What is a ‘market’? Until the last decade or so, marketing research has tended to take the answer to this question for granted. Within the mainstream marketing research, markets are frequently represented as passive backgrounds, where economic transactions occur (Araujo et al., 2010). Traditional scholarship focuses on identifying behavioural patterns, design frameworks to increase customer retentions, or develop cognitive profiles of buyers and sellers.

The above dictum by Williamson perfectly summarises the natural givenness of the market in neo-classical economics theory, which hugely informs mainstream marketing research. Neo-classical economics constructs a model of markets stripped of any material or social constraints: it holds to an abstract, value free, idealised conceptualisation of the market (Geiger et al., 2012). Within this view, the market is conceptualised as the outcome of the actions of atomistic individuals; yet represents itself as an active agent to which the individual actor responds (Dilley, 1992). The market as a principle, or the so-called '*invisible hand*', operates as a self-regulating, self-structuring agent. Such conceptualisation presents the market as a game where rationality is key, and rational actors are supposed to obey the rules in this perfect, idealised form. Yet, the market is also a place for the survival of the fittest where self-interest, opportunism, appropriation and violations of rules are common practices (Williamson, 1975). The '*invisible hand*' of the market repackages this notion of self-interest under "the private pursuit by individuals and firms of their own greatest profit" (Lubaz 1992, p. 37). This pursuit of profit is individual, and devoid of benevolence and altruism. Neo-classical economics identify this '*invisible hand*' with the perfect market balance.

The '*invisible hand*' of the market is a recurrent term in the narrative of the '*laissez-faire*' ideology. Preston (1992) breaks down the notion of the market in the '*laissez-faire*' capitalist system, as informed by neoclassical economics theory. He describes it as a tissue of interrelated definitions organised under a central claim of maximising human welfare through utility maximisation. However, and for the sake of efficiency and effectiveness, this utility maximisation has to be done under conditions of scarcity. I summarise these claims, as described by Preston, in figure 1.

Economically

- The claim is that as free markets act efficiently to distribute knowledge and resources around the economic system, material welfare will be maximised

Socially

- The claim is that as action and responsibility for action reside with the person of the individual, the liberal, individualist, social systems will ensure that moral worth is maximised

Politically

- The claim is that as liberalism, ancient or modern, offers a balanced solution to problems of deploying, distributing and controlling power, such systems maximise political freedom

Epistemologically

- The whole package is supplemented and buttressed by the claim to genuine positive scientific knowledge thus we have a claim to maximise knowledge and thus effective action

Figure 1: 'laissez-faire' capitalist systems' central claims

Source: Adapted from Preston (1992)

Many commentators have lamented the insufficient attention paid to markets within the marketing scholarship, and have urged for the need to develop a better understanding of this central facet of the subject (Araujo et al. 2008; Vargo, 2007; Kjellberg et al. 2012). As Venkatesh and Peñaloza (2006, p. 147) put it: “markets are not universal, self-contained entities, but rather take on distinct discursive forms and material practices across various social contexts and over time”. Drawing heavily on Science and Technology Studies (hereafter STS), the market studies group have been vocal about the taken-for-grantedness of the notion of ‘market’ in marketing. The next section will elaborate on the recent development in this area.

2.2. Markets in the making:

The market studies area has been concerned with the socio-material construction of markets or, put differently how markets and different understandings of the market are *brought into being*. It challenges the traditional neo-classical economics view of the market as a pre-existing entity, and draws focus on markets as an analytical element, rather than a passive background against which exchange practices are supposed to occur. A foundational principle, within market studies, is the idea that markets are a product of a continuous construction process: they are constantly *in the*

making (Kjellberg et al. 2012). As Çalışkan and Callon (2010) contend, the movement towards markets, or marketization, is yet another form of economization of society; and as such, market studies aims to scrutinise this movement.

Drawing primarily on Science and Technology Studies but also economic sociology and anthropology, markets studies is committed to a fine-grained analysis of markets. It scrutinises the various discursive and material resources that come together to bring markets into reality, or what Callon (2005) calls '*socio-technical agencements*' (hereafter STA). The notion of agencement was first introduced by Deleuze and Guattari (1998) to refer to an assemblage enabled with the capacity to act. This capacity to act varies depending on their configuration, meaning that the construction of its own meaning is part of the agencement as stated by Callon (2007). Following Latour's (2005) emphasis on the importance of the material alongside the textual in an assemblage, the adjective 'socio-technical' was added subsequently by Callon, to describe a view of agencement that fully embraces the material and non-human. This approach puts, therefore, an emphasis on the importance of materialities in the processes of marketisation. These (materialities) include, but are not limited to, calculative instruments or devices, metrics, 'sciences' and techniques, standards and rules, and other material infrastructure involved in market shaping. Another key analytical element of STA is knowledge, with its various forms: academic/lay, explicit/tacit, and so on. Thus, the discipline of marketing, for instance, becomes conceptualised here as a heterogeneous set of agencies working towards "the reproduction and transformation of market structures" (Araujo, 2007, p.223).

Michel Callon's influential work, '*The laws of the markets*' (1998), has played an important role in setting the direction for the field of market studies. Callon is critical of the idea of the market as an outcome of the actions of atomistic individuals, as advanced by neo-classical economics. He rejects the notion of the market as a pre-existing space, where self-interested individuals act in a rational way, and whose actions imply rational trade-offs between alternative ends and a range of means to achieve them (Callon, 1998). On the other hand, he is equally critical of the notion of social embeddedness of markets (Granovetter, 1985). Callon makes a distinction between a socio-technical and a purely social construction. He contends that social

embeddedness reduces the economy to human actions that are determined by social institutions. Thus, it downplays the importance of the role of materialities (including calculations tools) in the construction of markets and market practices. For instance, he views the process of conferring value to things as a result of not only social but also material processes, such as the circulation and transformation of objects (Çalışkan and Callon, 2009).

His work brings a twist to earlier critiques of '*homo economicus*'. Callon contends that "homo economicus' does exist, but is not an a-historical reality" (Callon, 1998, p. 22). He views '*homo economicus*' as a construction: that is the result of a process of configuration (Callon, 1998; Anderson et al., 2008). Without rejecting the role that social structures play in shaping market exchanges, Callon's approach draws the focus onto the practices and devices that construct markets and market exchanges. It directs our attention towards the '*intermediating realities*'; that is the various bodies and practices that are mobilised to bring '*homo economicus*' into being. His 'reality' materialises through his ability to perform in the political arena of the market (Callon and Muniesa, 2005; Callon, 1998).

This strand of research is committed to abolition of the ontological asymmetry between things and humans; more specifically the "ontological asymmetry between valuating subjects/agents and valuated things/objects/goods" (Çalışkan and Callon, 2009, p.393). Value is conceptualised as constructed locally in a co-productive process; that is not due to human evaluations only, nor to some natural intrinsic value. Asymmetries become an outcome of practice, rather than a prior ontological distinction. The major influence of such an ontological commitment is *Actor-Network-Theory* (hereafter ANT) as developed by Bruno Latour. ANT is a "disparate family of material-semiotic tools, sensibilities, and methods of analysis that treat everything in the social and natural world as a continuously generated effect of the web of relations within which they are located" (Law, 2008, p. 141). ANT theorists are interested in debates on the nature of technology's content and context, and view society as produced and re-produced through the mutually constitutive interaction of human and non-human entities.

ANT takes its roots in the sociology of association (Latour, 1992) and translation (Callon, 1984). These fields have explored the mutually elaborated generation of technology's content and context; and by doing so, positioned themselves against the idea of the context determining the content. This approach therefore helps reconsider traditional dichotomies such as social/technical, technology content/context, production/consumption, inside/outside and human/non-human (Simakova, 2013). Callon and Law (1989) argue that an analytical emphasis should be put on the interaction between different actors, and how these interactions constantly draw and re-draw boundaries between what is considered to be within the realms of the technical or the social. Scholarship, influenced by the actor network approach to markets, has offered various considerations of the accountability for the distribution of agency in market interactions. It has been attributed to the market itself (Callon, 1998), the collectives (Akrich et al., 2002), and the rational calculative agent (Callon and Muniesa, 2005).

Such a perspective urges us to consider the various actors involved in the market making activities. For instance, Slater (2002) demonstrated how an apparently simple example of supermarket shelving can be extraordinarily complex. Its performance involves way more than manufacturers and retailers only, particularly when the act of categorisation is put under scrutiny. A detailed analysis of this activity highlighted the intertwinement of activities of regulatory bodies, scientific advisors, consumer groups, trade groups, standardisation agencies, and how this shapes the definition of a category and the process of categorisation. Activities such as health activism and the concern with product information on the packaging are an example of a framing of the practice of categorisation. Other examples of the influence of ANT on the re-formulation of traditional marketing research include the work of Geiger and Finch (2010), who take on the network picture metaphor in industrial marketing research. They extend the traditional views, and propose a *situated version* of network pictures. This version suggests to view managers' cognitive maps as actants that contribute to the shaping of business interactions. Carrying a similar concern, Hopkinson (2015) revisits the notion of graffiti, and presents it as an alternative to the network picture metaphor. Whilst still within the vein of ANT research, this conceptualisation takes a

more political turn on the question, by focusing on the reproduction as well as the resistance to ideologies in business interactions. This directs our attention to the multiplicity, as well as the conflicting nature, of market practices; as well as the contribution of tension and synergy to the stabilisation and de-stabilisation of certain market forms (Araujo et al. 2008).

All in all, developments within market studies call for a shift to study performance rather than representations. The economy becomes “a series of competing projects to establish calculative spaces based upon socio-technical regimes involving a variety of devices including organisation, measurement, representation, and rules” (Araujo et al. 2010, p. 6). These efforts mould markets in correspondence to specific templates. The study of the making of markets, market actors, and market practices has frequently been put under the umbrella of the performativity thesis. The next section will explore the notion of performativity, which is at the heart of the present study.

2.3. Performativity thesis:

As discussed in the previous section, a key concern for market studies is how markets are brought into being or *performed*. This section looks at the various developments within the performativity thesis, including the different extensions and other distortions. It is structured as follow: first, I introduce the notion of performativity, before exploring what constitutes performativity in economic sociology as developed by Michel Callon. I then focus on the various developments that market studies has brought to Austin’s performativity, before moving to its critique. Finally, I present the key influences for the way I approach performativity in the present study, as well as the contributions it can bring to the performativity thesis within market studies.

Performativity is currently an en-vogue term in social science terminology. Callon (1998) strongly contributed to the popular status of the concept within economic sociology. He extended the concept from its original focus on language and discourse to include several features of economics such as theories, humans, skills, techniques and various other devices. This conceptualisation spread to other disciplines such as

accounting (Miller, 1998), finance (Mackenzie and Millo, 2003), and marketing (Cochoy, 1998).

The concept of performativity has been initially developed by John Austin in his seminal work *'how to do things with words'* (1962). Austin argued that actions are performed by uttering a sequence of words; a sentence that performs action, or what he labels a performative utterance. As he put it, a performative utterance is one "in which to *say* something is to *do* something; or in which *by* saying something we are doing something" (Austin 1962, p. 12; emphasis in original). A famous example to illustrate what a performative utterance is, is the sentence *'I now pronounce you husband and wife'*. Austin contends that if uttered in the right context and by the right sovereign authority, *'I now pronounce you husband and wife'* does produce a husband and wife. In *'how to do things with words'* (1962), Austin outlines the conditions that need to be met for a given speech act to be performed *feliculously*. These conditions include the right context and the right sovereign authority as indicated in the previous example, but also the intentionality of the speaker. The latter refers to the speaker's genuine intent, as opposed to say a satiric one. I will get back to this particular aspect in a latter section, when discussing Derrida's notion of iterability (1972, 1988), and engagement with Austin's work.

Since Austin's work, there have been several developments and adaptations of the concept of performativity. Lyotard's version of performativity (1984) stresses notions of efficiency and effectiveness in organisations, and sheds light on a dominant organisational culture that accentuates the importance of measurable inputs/outputs. His work focused on educational systems from a critical perspective. Butler's (1990, 1993) version, strongly influenced by Jacques Derrida's engagement with Austin's work, has focused on gender performativity. Butler challenges the naturalness of gender and its understanding as a fixed category, and proposes to view it as performed in and through discourse. She scrutinises the way various discourses shape our relationship with our bodies, by focusing on the analysis of the materiality of bodies through discourse. The work of Butler and Derrida will be explored in further detail in the next section, as they are highly influential on my present work. Finally,

Callon's performativity, which is the focus of this section, has introduced the concept to economic sociology. His central idea is that economics does not merely describe 'economy'; it shapes the phenomena it describes. Economics is said to have a performative relationship with the economy. His work has been influenced by developments within STS, mainly Latour's ANT.

Overall, the key concern of performativity is to challenge established lines of thought. These various developments have deconstructed dominant traditions within their respective disciplines, and Callon's performativity has set the foundation for the field of market studies as a sub-discipline.

2.3.1. Callon's performativity:

Callon's performativity directs our attention to the practices that actors engage in to construct and problematize markets. As Araujo et al. (Araujo et al. 2008, p.8) observe: "markets are in constant evolution both in terms of the practices that shape them as well as the forms they assume as a result". Rather than viewing economy as embedded in society, Callon sees it as embedded in economics, in that there is no economy without economics (Callon, 1998, 2005, 2007; Çalışkan and Callon, 2009). He suggests that "economics in the broad sense of the term performs, shapes and formats the economy, rather than observing how it functions" (Callon, 1998, p. 2). However, Callon's performativity goes beyond the simple movement of economic theories into lay population speech, as it addresses the relationship between theory and practice (Araujo, 2007). Callon's approach put economic intervention under scrutiny, analysing how it shapes practices at specific times, and in specific places.

What distinguishes Callon's approach to other stances on performativity, is its position on materiality and the insistence on material embeddedness. His main critique of Austin's original performativity is located within its overemphasis on discourse. Callon views this focus as a confinement to linguistic categories (I will get back to this aspect in further detail in the next section). In his contribution to Mackenzie and colleagues' collection (2007) '*Do Economists Make Markets? On the Performativity of Economics*', He elaborates on how his approach extends Austin's. As he put it in the notes section:

“To extend Austin, we have to [go in another direction and] question the actualization of the contexts and subjectivities that are implied by the utterance. (...) The critique of Austin should not exclude the notion of performativity but rather should enrich and complete it, first by insisting more on the fact that the context of enunciation is included in the enunciation (semiotic turn) and, second, by taking into account the materialities composing that context (ANT turn)” (Callon, 2007, p. 353).

Callon is equally critical of Butler’s approach to performativity, and draws on Annemarie Mol’s work, *‘the body multiple’* (2002), to articulate his critique. Mol views Butler’s approach as wrongly dismissive of the natural entities, parts of the body, and materialities in general. In her critique of Butler’s gender performativity, Mol points out to the natural existence of the vagina as an organ and its contribution towards the constitution of a woman. She views identity as a flow, constantly under construction; and its temporary stabilisation is a result of the involvement of materialities. Mol proposes the notion of enactment to address the question of identity, in order to differentiate from a Butlerian approach. Again, this is another aspect that I will revisit in the next section. Callon’s performativity provides a hybrid of what is located in the realm of the material and what is in the realm of the semantic/social.

The notion of market devices is central to the shaping of markets according to Callon’s performativity. These devices aim at ‘rendering’ things ‘economic’, or as Muniesa and colleagues put it “enacting particular versions of what it is to be ‘economic’” (Muniesa et al., 2007, p.4).

Market devices participate in shaping markets by becoming part of the socio-technical agencements (which I have discussed in the previous section). They are “the material and discursive assemblages that intervene in the construction of markets” (Muniesa et al, 2007, p.2). In line with an ANT commitment to a hybridisation between human and non-human entities, Callon refers to Deleuze’s conceptualisation of *‘device’*. The term *‘device’*, within this tradition, highlights the relationship between objects and agency. Devices do things, “they act or make others act” (Muniesa et al., *ibid.*). Back to the notion of STA, the selection of the term *‘agencement’* is very specific itself. It emphasises the interconnections between agencies and arrangements with “the

capacity to act and give meaning to action” (McFall, 2009, p.270). Deleuze (1989) argues that the subject is not external to the device in use. Instead, he views subjectivity as enacted in the device.

The way market devices give meaning to action enables specific modes of calculations, and ‘disentangle’ agents from their social relations granting their abstraction and categorisation (McFall, 2009). This meaning or framing of action draws the boundary around which economic interactions take place (Callon, 1998). This stresses, therefore, the material embeddedness of economic calculations. Economy and economic processes are conceptualised as *performed* in use; more specifically, the use of market devices that correspond to economic theory. The notion of enrolment is also key to Callon’s performativity. Economics is said to enrol theories, concepts and techniques from other disciplines, including social sciences, medicine and natural sciences, in its journey of market construction. This enrolment mobilises and stabilises a network of knowledge around the economic calculative model. The resulting *agencement* produces individual human agencies that are equipped with the capability to calculate, and driven by a commitment to rationality and interest. Those individual interests range from a financial compensation to indexes of satisfaction, or other metrics of welfare. They can also operate according to hierarchical systems, and other modes of recognition. It is important to note that those interests are presented in a measured or measurable way, so they can be included in the calculation process. Variations of this conceptualisation includes qualitative evaluations, and the extension of this concept with the notion of ‘*qualculation*’ (Cochoy, 2008). Thus, the ‘human’ becomes an outcome (partially) of the performativity of economics.

To sum up, Callon’s performativity is concerned with how economics (and its deriving disciplines such as marketing, as he explains) performs things rather than just describes them. As Mason et al (2015) argue, the concept of performativity is essential to address key concerns within the discipline of marketing such as the gap between marketing theory and practice, as well as critical debates around the way marketing participates in the construction and operation of contemporary consumer society. The present study sits broadly within the latter concern.

Market devices and their enactment of the 'economic' have had a fairly considerable attention as objects of social inquiry. The market studies literature has explored the role of market devices in shaping markets on topics such as analyst reports and the role of analysts as frame makers (Beunza and Garud, 2007), the shaping of consumers' choices and their identities (Cochoy, 2007; Dubuisson-Quellier, 2007; Grandclément-Chaffy, 2008), actors, action and *chartism* in financial markets (Hardie and MacKenzie, 2007, Preda, 2007), the structures of production and consumption (Shove and Araujo, 2010), consumer empowerment (Dubuisson-Quellier, 2008), the role of market research techniques such as focus groups in shaping markets and how these experimentally generated conversations are translated in experts reports (Lezaun, 2007), and market strategy matrices in the realm of pharmaceutical markets (Finch and Geiger, 2011). The diversity of market devices has been said to enable the performance of a variety of market activities such as identification, categorization (Dubuisson-Quellier, 2013a), commensuration (Espeland and Stevens, 1998) and legitimization of products (Dubuisson-Quellier, 2013b).

Literature on market devices has been successful in providing thick description of the situated, distributed and material character of market processes. However, critics have pointed out the apolitical character of this scholarship (Fine, 2003, 2004; Whittle and Spicer, 2008). Some have argued that this is due to the overall concern to analyse ever-changing STA, without any stable social structures or market norms, leading to a focus on 'banalities' (McFall, 2009; Geiger et al, 2012). The commitment to a fine-grained analysis of STA resulted in, albeit providing thick descriptions, the initial political interest of ANT being lost in translation. Other critiques take a more radical position, and attributes the politically mute stance of Callon's performativity to a departure from the core of political economy analyses of categories such as class, gender and capital. Whittle and Spicer (2008) point towards the focus on materiality, as influenced by ANT, as the driver of this political muteness. They argue that ANT "misses the point that the domain of politics is properly reserved for human relations and lacks the conceptual tools to understand how systems of domination might be resisted" (Whittle and Spicer, 2008, p. 621).

In the next section, I discuss in further depth the critiques of Callon's performativity, particularly those addressing its lack of involvement with politics. Following that, I present the key references I draw on for the present study.

2.3.2. Derrida, Butler and the importance of 'effects':

"Language enters life through concrete utterances, and life enters language through concrete utterances as well." Mikhail Bakhtin (1981), The Dialogic Imagination

So what is this political mutism due to? Is it the result of the overall empirical endeavour to explore and describe fine-grained details of market mechanisms? Or is it inherent within the ontological commitment? Or maybe it is actually a deliberate choice? I shall argue that it is a combination of the three factors. In this section, I build on the main critique of Callon's performativity, and explore the options to overcome this issue, as well as develop a critically-infused performativity agenda.

2.3.2.1. Constituencies and effects:

As discussed in the previous section, performativity has proved to be a useful concept to 'denaturalise' dominant concepts such as state (Mitchell, 1999), gender (Butler, 1990), or economy (Callon, 1998). It questions the overriding understanding of certain notions and categories as pre-existing, and scrutinises what favoured their existence in a specific form, at a specific time and place. In a sense, performativity provides us with an alternative to traditional causal frameworks when theorising effects, and presents yet another manifestation of the counter-positivism movement (Butler, 2010). What we do with this alternative, depends very much on us and our axiological commitments as researchers.

Callon's approach to performativity, and the subsequent developments particularly, have been accused of a narrow focus on stabilizing processes, or put in another way on '*how things are brought into being*' (Butler, 2010; Overdeest, 2011; Pakk, 2017). As du Gay (2010, p. 177) elaborates, there has often been "a tension between detailed

description on the one hand and philosophical reconstruction (and metaphysical speculation) on the other” in both Callon and Latour’s works. If we look for instance at Butler’s work on gender, it started with questioning the existence of gender as a stable category, and scrutinised practices that were constructed as a gendered expression (Butler, 1990). Her starting point was a deconstruction of the seemingly ‘natural’ flowing of gender from the duality of anatomical sexes. Moving forward from these descriptions, Butler explores the production and iteration processes of outwards realities, that is the gendered subject. This gendered subject is an effect of gender as a stable category, or an ‘*outward performance*’, which doesn’t require anymore the repetition of the ‘*inward act*’ (the performance of gender) to be sustained (Bell, 2006). The next stage for Butler was putting under scrutiny the mechanisms of power underlying the construction of the opposition of form and matter, and subsequently the sex/gender performativity (Butler, 1993). Her work therefore moves beyond the borders of feminist epistemology of privilege that was predominant at the time, and draws attention onto how epistemological categories shape the ontological order (Artukovic, 2013); thus, moving beyond the focus on ‘ontological effects’ of Callon’s performativity. Butler’s work deals with the ideological problems related to epistemological categories, and traces the historical process of their naturalisation. On the other hand, when looking at a number of developments within market studies’ performativity thesis, the sole focus appears to be on a description of ‘ontological effects’: a narrative of the ‘*bringing into being*’, ‘*making of*’, and other ‘*shaping*’ of categories, entities and subjectivities (with the exception of certain recent developments that I discuss later in a further section). Almost as if it is shying away from discussions around morality and ideology.

Therefore, the notion of ‘effects’ is indeed important for a study of performativity that considers the political alongside the economic. Unfortunately, it is a notion that has sometimes been overlooked in the current performativity thesis within market studies; mainly through a blurring of the line between effect and constitution.

Austin distinguished between two types of performative utterances: *illocutionary* and *perlocutionary* performatives. Illocutionary acts and perlocutionary effects can be

differentiated in the way they stress the difference between constitution and causation. The direct link between uttering words and doing things is one of constitution: this represents the illocutionary act. For instance, uttering '*I assume*' constitutes the act of assuming or making an assumption. I am not describing a pre-existing action. Yet, the act of assuming is not an effect of my utterance. The very act of uttering the sentence '*I assume*' is to make the assumption; that is the act is constituted by the utterance. In other terms, to utter sentences is *to do things*. This is what illocutionary acts mean, and it has been so far the primary concern of the performativity thesis within market studies. Economics are said to be performative in the sense that they participate in the organisation of the object of their enquiry, ie. The market. The notion of STA brings about market devices in conceptualising the organisation of the construction of markets.

The other type of performatives that has received less attention within market studies is perlocutions. Perlocutionary performatives bring effects when certain other conditions are met. Therefore, they depend on external 'realities' for their effects to materialise. We move from a focus on ontological constitutions produced by illocutionary performatives, to perlocutionary effects (discursive and non-discursive). As Butler (2010, p. 151) put it: "If illocutions produce realities, perlocutions depend upon them to be successful". Thus, perlocutions depend on the sequencing of events and felicitous conditions in order to be effective. Mäki (2013) draws on a simple and effective example given by Austin to illustrate perlocutionary effects. Consider the utterance '*in saying I would shoot him I was threatening him*'. Mäki explains that this represents an illocutionary speech act. Whereas in a perlocutionary act, the utterance could be formulated as follow, '*by saying I would shoot him I alarmed him*' (Austin 1962, p. 122). The way to approach this, is to grasp the action performed by the utterance. Threatening is not a distinct effect of '*I'd shoot you*', whereas alarming is. To say '*I'd shoot you*' is to threaten. On the other hand, threatening may have an alarming effect. Thus, the performance of an illocutionary act may have perlocutionary effects that are *separate* from it (Mäki, 2013). Those effects come about through a causal process. Which brings back a notion I discussed earlier; of

performativity operating as an alternative to traditional causal frameworks when theorising effects.

The previous example on perlocutionary effects is uttered in the past tense. It is therefore possible for the narrator to reconstitute the effect within the formulation of utterance (whether the narration is a 'mirror' to a reality of past events or not, is another matter that will be discussed in the methodology chapter). I provide now another example from a personal experience to illustrate perlocutionary effects, where the narrative is in the present tense. Let me start with a little background to my story before presenting the utterance and analysing the illocutionary and perlocutionary performatives. I do a little bit of dancing in my spare time. My technique is probably terrible, but I really enjoy it – particularly street dance. About a year ago or so, we shot a dance video with my dance mates. It was not meant to be a professional dance video, but we wanted a good quality video nevertheless. I was responsible for liaising with the person responsible for filming and editing the video. Let's call the video artist 'Casey', for the sake of the narrative. Our budget was quite limited, so we hired a fine arts student that had a decent-enough equipment. The editing took forever. During my interaction with Casey, I remember reading a lot '*I promise to get a draft version to you by xx*'. I use 'xx' to refer a deadline that was either proposed by Casey, myself, or mutually agreed. The promise to deliver the deadline is constituted within the utterance. '*I promise*' is not a description of a pre-existing action, nor the cause of the action: It constitutes the promise; or put differently, brings it into being. This is the illocutionary act performed by the utterance. I could stop here, and discuss how promises are performed in informal business interactions (there was no business contract, and Casey was working on a freelance basis – just starting as a video artist). A thick description of the subsequent events and related narratives will help theorise how promises are constituted in informal business interactions. However, I need to push the analysis further and explore the potential perlocutionary effects. What would be the effect of the promise that has been *brought into being* by the illocution? The answer is not as straightforward, and I would need to consider different aspects 'external' to the utterance. Perhaps, the effect is an agreement on different milestones. Another effect could be Casey just gaining time, because she

works at a slow place and is fed up of my constant reminders, or she might be prioritising other freelance projects, and needed that extra time to do so. Or, the effect of the promise could be me being unhappy after several unfulfilled promises. The effect depends also on how I position Casey. If I position Casey as a non-trustworthy person, or heard rumours positioning her as such, I may be considering the utterance as an act of gaining time, and its effect would be me losing patience. There needs to be therefore a consideration of the social, cultural and historical context of the interaction, when exploring perlocutionary effects, whether they result in stabilisation or de-stabilisation effects. For instance, within the way I have written this story, I have used specific formulations that can be indicative of my positioning of Casey. For instance, I judged necessary to specify that *'the editing took forever'*. My use of the extreme case formulation *'forever'* is an indicator of a rhetorical move from my part to shift the responsibility and blame of the delay onto Casey (Pomerantz, 1986). Thus, the understanding of the effects of the utterance *'I promise (...) to you'* is already tainted by the way I formulated the narrative. Another notable aspect is my use of the passive form in *'the editing took forever'*. The use of passive form has an effect of reifying the process and deleting the agent from the narrative (Billig, 2008). I am, therefore, not making any apparent direct attributions of blame, concealing any interest from my part to damage Casey's reputation of trustworthiness. Thus, I am positioning myself as making a more or less neutral and objective judgment on the quality of her services. The analysis can obviously be pushed further, but all in all, this brief discussion on perlocutions within this example provides some hints on tensions and conflict in informal business interactions. From this simple example, it can be appreciated that a movement towards perlocutionary effects helps unravel politics behind performatives and go beyond a descriptive analysis.

The perlocutionary effects' dependency on aspects external to the utterance, shed the light on the multiplicity of scenarios of failure and disruption, and invite us to consider aspects of tension and conflict. Whereas an over-emphasis on illocutionary acts will narrow our vision to constitution and stabilisation effects mainly. This example gives a taster of how the study of perlocutionary effects can highlight moral and political implications. I will be providing a detailed analytical framework in chapter

four, as well as a variety of examples regarding the case under study in chapter five and seven.

2.3.2.2. Iteration:

Another key aspect from Butler's approach has been borrowed from Derrida's engagement with Austin's work. In his essay '*Signature, Event, Context*', Derrida (1972) brings to the fore the notion of *iterability* when approaching performativity. *Iterability* is directed toward Austin's positioning of the authenticity of the speakers' *intentions* as part of the felicitous conditions for the performative utterance to be successful. Derrida argues that the success of a performative is not related to *intention*, but to *citation* and *iterability*. Iteration indicates how an utterance needs to be recognised as somehow confirming or relating with an identifiable and iterable model. This iterable process will bring about new things into being or shape the trajectory of existing things. If the utterance cannot be identified or related to any recognisable model, then it constitutes a citation. It is not the intention of the priest that will constitute a married couple after uttering '*I now pronounce husband and wife*', but the iterable nature of the utterance; as we have been socialised in attributing a causal link between this mode of uttering and the making of a husband and wife. For the marriage ceremony to be a fully serious performative, it needs to refer to certain iterable elements (discursive and material) within the ceremonial tradition; elements that depend on social, cultural and historical references. Another example to illustrate *iterability* at work is the construction of academic knowledge. Traditionally, research builds on previous work within the field, either answering to research 'gaps', or exploring new venues but still with some kind of (be it close or loose) relation to existing work; therefore building on identifiable and relatable models. Obviously, other conditions, discussed earlier (Austin's work (1962) remains the unconditional reference for a discussion on felicitous conditions), still need to be present for the performative to be felicitous, as *iterability* addresses *intentionality* primarily. In a nutshell, intention is not prior to the citation, as the authority is repositioned within the utterance (Artukovic, 2013). In the words of Butler (1993, p. 2): "performativity must be understood not as a singular or deliberate 'act' but, rather,

as the reiterative practice by which discourse produces the effects that it names". However, this is not to say that the performative depends on pre-existing structures. On the contrary, it brings into being the context, the self, the 'law' (Miller, 2009). However, this 'creation' process is not performed *ex nihilo* at each and every performance, but happens through an iterative and regenerative process.

Butler's reading of iterability highlights the processes iterability within the material. Her argument revolves around the iterative power of discourse. According to Butler, discourses shape how we conceive of our bodies, and constitute the gendered self. They also work into regulating and controlling this creation (gender). In other terms, the category (gender in this case) is not prior to its citation (discursive and material practices expressing gender). Yet, it does not follow it either. It "emerges only within and as the matrix of gender relations themselves" (Butler 1993, p. 7). Butler links iterability to the importance of the instance of perlocutionary effects. She argues that a focus solely on illocutionary acts can obscure the concept of performativity by equating it to some sort of 'social magic' (Butler, 2010), where effects are produced out of nothing (whereas the tracing of this production is discursive or material). Performativity, therefore, involves an ongoing process of enacting a discourse in various ways. In a Derridean sense, the sedimentation of a performative act results in an ephemerally stable ontological effect. The constantly work-in-progress and iterative nature of illocutionary acts work towards the perlocutionary effects, with several possibilities of infelicities, misfires and abuses along the way. By taking a 'deconstructionist' stance, which takes the analysis of construction a step further, Derrida introduces *undoing* as a necessary part of the *doing*. This paves the way for the analysis of possibilities of failure in the initial process of the doing, as well as things-could-have-been-otherwise alternative narratives.

I need however a conceptualisation of markets that is coherent with this approach to performativity. I have found such an approach within some work in anthropology and STS with the likes of Woolgar, Neyland, Diley and Carrier. The next section addresses this approach in detail.

2.4. Market as Discourse:

Following the discursive approach to studying market in Anthropology, Science and Technology Studies and Marketing (Dilley, 1992, 1999; Miller, 2002; Carrier, 1997; Woolgar, 1991; Simakova and Neyland, 2008; Simakova, 2013; Cameron et al. 2010), the 'market', as used in this study, is defined in terms of "the discursive organisation of relations between producers and users of artefacts" (Simakova, 2013, p. 10). Indeed, if artefacts do not speak for themselves (Grint and Woolgar, 1997), then defining the properties of an object is a social act (Whittle & Spicer, 2008). The discursive approach to the market puts emphasis on the importance of language as constitutive of the properties of material artefacts (Simakova, 2013; Simakova & Neyland, 2008). As Potter has argued: "constructing the research topic as discourse marks a move from considering language as an abstract system of terms to considering talk and texts as parts of social practices" (Potter, 2003a, p. 785). This approach highlights the importance of the discursively accomplished boundary work of persuasion, in establishing claims of evidence of technical capacities, and hence claims of agency (Simakova, 2013).

A discursive approach is concerned with how various agents use the frame of the market to achieve their agenda. Studying markets becomes then concerned with how the ideological stance of the market has developed. Thus, there is a need to emphasise the "degree to which economics and other abstract models were managing to accrue such power that they were able to transform economic practices, making them accord more with these same models" (Miller, 2002, p. 229). The deployment and invocation of these abstract models by diverse groups becomes a matter of political and social commitments (Dilley, 1991). The politics of privileged representation, and the claims of certain voices to 'scientific' status, are crucial issues for the present case. Market ideology 'filters' down the interpretive repertoires held by social actors.

Dilley (1992) stresses the fetishisation of exchanges and the market, which creates in turn the illusion that the social world is made to appear as purely a matter of transactions and exchanges. The ability of market-based metaphors to represent social totalities needs to be problematised, as dominant representations of the social

totality frequently draw on diverse market metaphors and the notion of exchange. As Dilley (1992, p. 19, emphasis in original) further argues:

“The power of encompassment of market discourse as a form of dominant ideology is that it is represented *both as a non-human agent* as well as being constituted by *individual human agency*, that is, the *double image* of market agency. The market model thus appeals to individuals as a means of achieving social empowerment – the realisation of their own abilities by taking responsibilities on themselves; yet, the market also imposes its own disciplines and is an agent empowered to transform social contexts.”

This approach urges us to stay alert to the multivocality of the market. Market narratives are thus said to be “moral tales about the consequences of disrupting accepted social boundaries” and an “index of cultural responses to new and potentially frightening social arrangements” (Woolgar, 1998, p. 450). Following Douglas (1982) and Dilley (1992), I analyse markets as *‘modes of accountability’*, as this approach draws the attention to “the nature and extent of object fetishism, the bases of control which exchange hides, the forms of agency and personhood represented in exchange” (Dilley, 1992, p. 23). The notion of modes of accountability as employed by Dilley refers “to the way a culture attributes and holds responsible specific forms of agency or aspects of social persons in their representations of exchange. These representations, of which the market is one, are predicted on specific constructions of personhood and notions of individual agency” (Dilley, 1992, p.24). This perspective suggests the possibility of thinking of the market for preventive solutions for breast and ovarian cancer analytically as sets of narratives attributing agency, identities, responsibilities and capabilities to a ‘product’, a ‘technology’, a ‘producer’, a ‘prescriber’ (whether it be a marketer or a doctor), a ‘subscriber’ (patient/consumer), etc. I am interested here in dissecting the performative character of market narratives. The next section addresses the research gap in detail.

2.5. Politics, criticality and the performative 'turn':

There have been several calls recently to engage with the foundational work on performativity, consider the politics of performativity, and undertake a more critical perspective (Gond et al., 2016; Cochoy et al., 2010; Roscoe and Chillas, 2013).

Some recent developments within market studies have shown a good start towards this direction. Highlighting the moral consequences of performativity, the work of Roscoe (2013) on 'organ markets' traces the valuation of transplant organs. Influenced by the work of McCloskey *'Rhetoric of Economics'* (1986), Roscoe unravels the tensions between the discourses of bioethics on moral obligation and worth on the one hand, and those of economic values on the other hand; thus, stressing the intertwinement between economic models and language. Drawing our focus onto 'performative agency', Pahk (2017) explores the street food market in San Francisco. He scrutinises instances of performative failure and misappropriation. Exploring the messiness and tension at the encounter of value and morality, Pettinger (2013) provides us with a detailed analysis of the various conceptualisations of value in *'Punternet'*; a website collecting customers' reviews of commercial sex encounters. By treating Punternet as a calculative device, she draws our attention onto how morality, constructed at the customers' level, constitutes a determinant of value and values. *'Value for money'* becomes a matter of expectations of customers, driven by a cis-male heteronormative moral perspective. Cova and Cova (2012) denote the paradoxical effects of the construction of customers by marketing discourses, operating as both an empowering and disciplining device. Drawing on the thesis of governmentality, and enriching it with a discussion on the critical reflexivity of consumers, they document the sometimes contradictory marketing discourses and efforts to bring certain consumers facets into being. Exploring the market for male dairy calves, Hopkinson (2017) draws the attention to the relationality between the apparently distinct and dualistic constructs. How is a product constructed as 'alternative' or 'mainstream'? This is the primary concern of Hopkinson (2017) when exploring the tensions, but also the symbiosis, between the different narratives that perform the two categories. Other work within the marketing scholarship has

attempted to re-establish the importance of perlocutionary effects when studying the performativity of marketing (Mason et al., 2015).

The aim of this study is to extend the timidly growing scholarship addressing the politics of performativity, and answer the call to “push OMT (Organisation and Management Theory) scholars to harness the power of Austin’s original insights to develop new theories” (Gond et al. 2016, p. 441). It integrates concepts developed within the sociology of health and illness with those that are informing the development of the market studies area, which I have discussed in this chapter. A key focus is on how morality is actually indexed by market actors in discourse; an aspect that has been underinvestigated so far. In keeping with a market studies perspective, I look across a range of market actors with a particular emphasis upon the positioning of the individual as a consumer of prevention in the era of genetic citizenship.

The next chapter will locate the context of the present study, through a review of the sociology of health and illness perspectives on genetics and genetic interventions.

Chapter 3: Gene, disease' prevention, and responsabilisation

The previous chapter focused on the recent developments within the market studies group, and its commitments to better understand markets, mainly influenced by Actor-Network-Theory. In it, I highlighted the developments of the performativity thesis, and the shaping of markets. I also identified the limited extent to which the politics of performativity have been addressed so far, although work demonstrates the moral dimensions of the intertwined nature of discourses, market objects, values, and so on.

This thesis explores market performativity in the context of an online forum concerned with genetic propensity for breast and ovarian cancers, and possible preventive actions that could be taken. In this chapter, therefore, I step aside from the market studies literature to look at social science perspectives on genetics and genetic interventions. Through doing so, I shall demonstrate how the two literatures are complementary for the present study. Indeed, insights from market studies can help strengthen the sociological literature on genetics and genetics interventions; particularly those related to the performativity of market actors and consumption practices when scrutinising the preventive solutions geared towards genetically redefined diseases.

This chapter proceeds as follows. Firstly, I look at the historic relationship between eugenics and genetics and how genetics has sought to carve out a distinct and untainted area, as well as the critiques of this attempt. Secondly, I look at the commercialisation of genetics drawing on concepts from the sociology of health and illness as well as anthropology. Finally, I look at the causal attributions between genetics, disease and prevention, drawing on the sociology of health and illness. This

final section paves the way for the discussion on the case under study in the following chapters.

3.1. The shadow of eugenics:

In this section, I look at genetic science in the context of former eugenics movements. The historical context and efforts to clearly demarcate genetics from eugenics, demonstrate the discursive working of the field of genetics, the credence and power attained through the way genetics is performed and the construction of new subjectivities and ways of relating to the world through a *biological citizenship*. This in turn will help establish the parameters through which political agency in markets for healthcare might be understood.

Eugenics has frequently been described as a dark episode within the history of the science of genetics. The movement of eugenics started at the beginning of the 20th century with an aim to create a better, fitter society. One of its main strategies, to reach such a target, was to control the breeding of the human species by (1) selectively procreating for desired traits (almost similarly to an agricultural model of breeding), and (2) cut the undesired traits by preventing people carrying them from marrying or procreating. The link to agricultural models of breeding are due to the roots of genetics (and eugenics ideology) in Mendel's research on heredity, with his study on the breeding of peas that set the basic principles of genetics. This is obviously a very simplified and brief outlook on the strategy and ideology of eugenics. The aim of this section is not to provide an extensive historical account for the history of eugenics (for a throughout historical review, please refer to "The Gene" by Siddhartha Mukherjee (2016)). I will however provide a brief snapshot of its fascinating history and its linkages to genetics and the present case under study.

Siddhartha traces eugenics to Mendel but also to Charles Darwin's evolution theory. Although Darwin's work did not really address an underlying mechanism for heredity, several cornerstones of his philosophy set the foundations for eugenics. His cousin, Francis Galton was a strong advocate for eugenics and the betterment of society

through selective breeding; the desired and undesired traits, cited earlier, representing respectively the fit and unfit. This notion of 'fit', which is a backbone of eugenics, finds its roots in Darwin's 'survival of the fittest'. Interestingly enough, it is the son of Charles Darwin, Leonard Darwin, who organized the very first international congress of Eugenics, which was held in 1912 in London (Gur-Arie, 2014). The idea of creating an American Eugenics Society (hereafter AES) emerged during the second international congress of eugenics, and materialized in 1926. Its main role was to promote an education program for eugenics in the USA. Some of the core concepts of this education program were racial betterment and eugenic health. The 'Fitter Family' contest was one of the flagship programs of the AES. The following pictures in figures 2 to 6 below, which are from the American Eugenics Society Records, courtesy of the American Philosophy Society, depicts some of the bizarre practices and ideologies of that era. The caption information for the pictures are courtesy of the American Philosophy Society as well, who now holds the AES Records.



Figure 2: View of a "Eugenic and Health Exhibit" with crowd, Kansas Free Fair, 1929. More an advocacy group than a scientific organisation, the American Eugenics Society promoted general ideas to the public. Copyright © American Eugenics Society Records, American Philosophical Society



Figure 3: The winners of the "medium family class" of a "fitter families contest" pose at the 1927 Kansas Free Fair. The American Eugenics Society was founded as a direct result of the Second International Conference on Eugenics, held in New York in 1921. Copyright © American Eugenics Society Records, American Philosophical Society

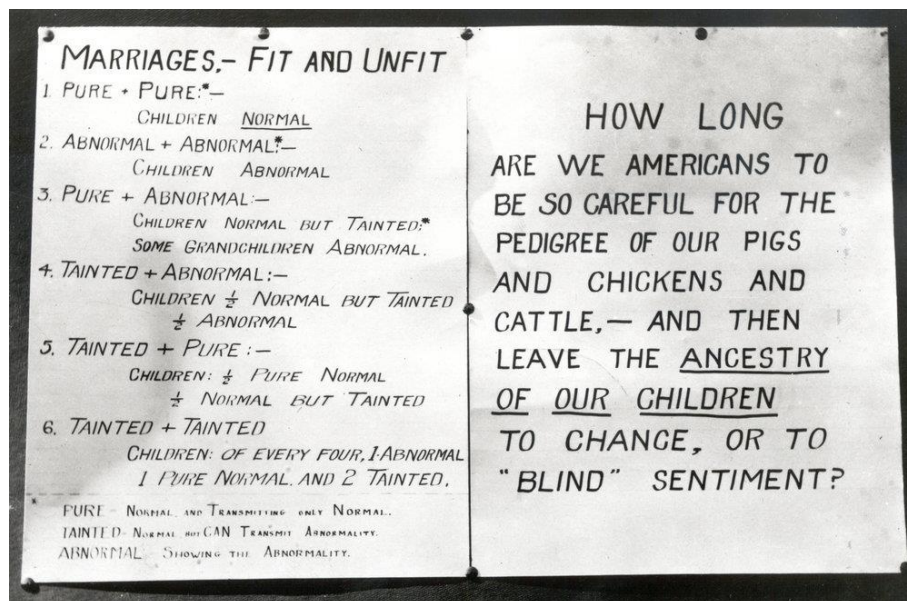


Figure 4: Charts used at a Kansas Free Fair show types of marriage. The American Eugenics Society organized a series of "fitter families contests" in which participants (divided into small, medium and large family classes) were ranked based on the mental, physical and moral health of family members. Copyright © American Eugenics Society Records, American Philosophical Society

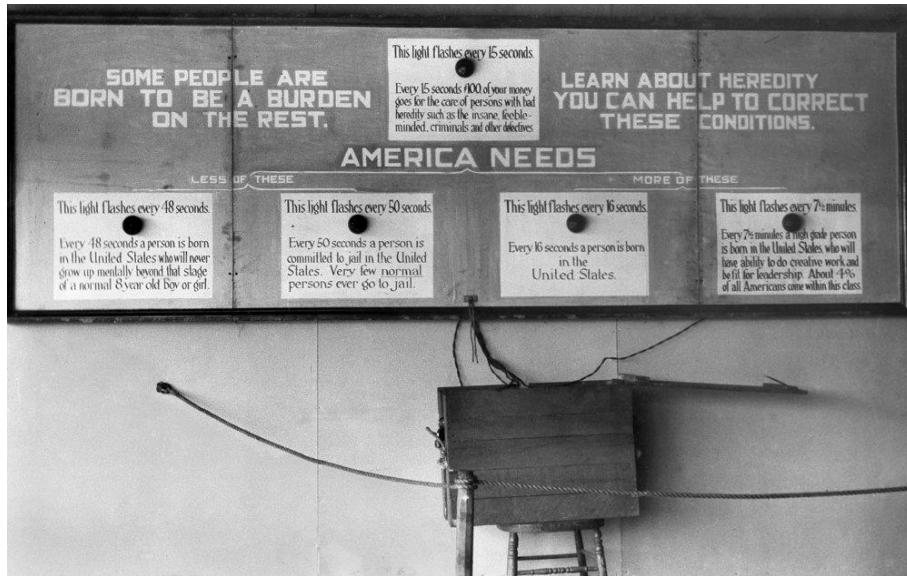


Figure 5: A sign with flashing lights used with the first exhibit at a fitter families contest reads: "Some people are born to be a burden on the rest. Learn about heredity. You can help to correct these conditions". Copyright © American Eugenics Society Records, American Philosophical Society

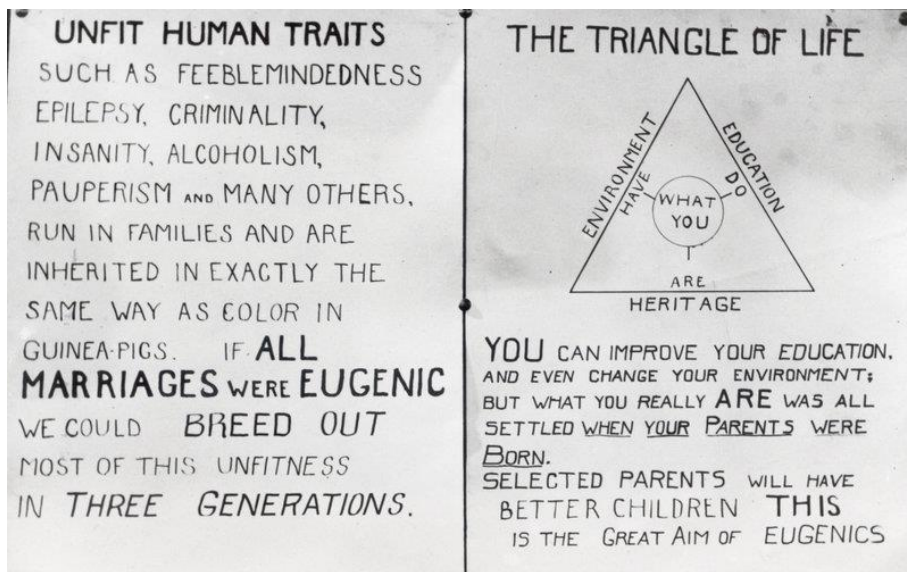


Figure 6: The American Eugenics Society promoted ideas of racial betterment and genetic education through public lectures, conferences, publications and exhibits at county and state fairs — like this chart labeled "The Triangle of Life" from the Kansas Free Fair. Copyright © American Eugenics Society Records, American Philosophical Society

In a Derridean understanding of polarities in text, more breeding of the ‘fittest’ cannot operate without less breeding of the ‘less fit’; or what was labelled ‘genetically defective’. It is therefore not surprising that the focus of British and American eugenics’ programmes was on controlling and reducing the breeding of the unfit, genetically defective, which constituted the ‘scientific’ basis for the emergence and development of the Nazi ideology¹. Hitler viewed Nazism as ‘applied biology’. The Nazi form of applied science had its foundations in the work of the German physician, biologist and eugenicist, Alfred Ploetz, who is known for the German term ‘*Rassenhygiene*’; which can be translated to racial hygiene. This sets the scene to one of the darkest chapters of modern history with the Nazi’ mass sterilisation program.

Following the massacres of the Nazi movement and World War II, the overall support for AES and eugenics in general dropped dramatically. Around the 1960s, the focus of AES turned to the science of genetics and human evolution. Human evolution was then positioned at the intersection of genetics and epidemiology. The society has since had a couple of name changes to reflect its new focus on the biological, social, cultural and medical factors that shape human evolution; but also to distance itself from the events associated with the AES.

Proponents of genetics sought to draw clear boundaries between genetics and eugenics. Genetics is said to be a science that produces objective knowledge freed from the ideology of eugenics. This knowledge is represented as a platform for individual choice. At the core of the rhetoric of individual choice is the freedom to choose – as well as the freedom to be responsible (a topic to which I shall return); therefore contrasting it to the coercive discourse of eugenics. However, critics, within the field of sociology of health and illness, have been vocal about their scepticism towards these distinctions (see for example Rabinow, 1992; Rose, 2007; Tutton, 2012). As Kerr (2004, p. 18) argues, such distinctions are “flexible and contingent upon the social circumstances in which they are drawn”, and the science of genetics has

¹ Although it is important to note that the American eugenics movement was much more aggressive in its ideology, than its British equivalent at the time. While the British eugenic movement was focused on preventing hereditary decline, and supportive of breeding the middle rather than lower classes, its American counterpart was embedded in an openly racist ideology of white supremacy, targeting amongst other ‘issues’ immigration (Allen, 1983). Also, compulsory sterilisation was widely practised in the USA whereas Britain did not adventure in the application of such radical practices.

“both reflected and reinforced a variety of eugenic ideologies about the relationships between the individual, the state, disease and social order”.

As I have discussed earlier, the 1960s marked a shift for the AES' focus and scientists in general started rejecting an understanding of biology as a foundation for social policy. This helped genetics to distance itself from the reductionist discourse of eugenics and its deterministic view privileging nature over nurture. Critics however pointed to an even more powerful form of reductionism to have emerged with genetics, moving from the *'gene as controller'* to the *'genome as book of life'* or *'master code'* (Van Dijk, 1998). The gene is still understood as a strong determinant of the essence of personal identity, particularly with the growth of behavioural biology providing 'scientific' explanations for deviant social behaviour such as criminality, violence, and so on. Even homosexuality has been put under the category of deviant social behaviour, with attempts to unravel the 'gay' gene. Subsequently, critics argued against this reductionist type of thinking, with a strong body of literature flourishing on 'genetic determinism' or 'geneticism' (Lippmann, 1991; Nelkin and Lindee, 1995). What gave even more credence and power to the genetic discourse is its reliance on computing and informational metaphors (Van Dijk, 1998; Brandt, 2005). The 'genome' was conceptualised as the digital inscriptions of the genes that constitute the human body. It represented *'the code of the code'*; code and coding being dominant metaphors in contemporary genetic discourse. The very methodology of the Human Genome Project (hereafter HGP) took inspiration in such references: the 'mapping' of the genome, and reverse genetics that shifted from the primary objectives of this mapping. The focus of the project moved from its initial intent to define the human body through its ideal, healthy version to a definition through diseases and other imperfections. Although this methodological shift appears to be a natural and naïve movement, it had important implications. Indeed, and as Van Dijk (1998) argues, it constructs the human body as a flawed version of a supposedly existent ideal, perfect code. By identifying the problem in such a configuration, it paves the way to a solution materialised in a genetic 'fix'. The influence of the computing and digital discourse has therefore had profound implications on the science of genetics and how we conceive of the human body.

This pushed some critics to view genetics as an individualised and commercial version of eugenics (Beck, 1993; Rifkin, 2001), with the shadow of eugenics very much still present in the genetics discourse and practice. For instance, the genetic research on embryos and stem cells has been for a long time a controversial topic in Germany, and the genetic testing on embryos didn't receive approval (albeit limited) from the German parliament until 2011 (Tuffs, 2011). The scepticism of Germany is understandable provided the Nazi legacy that it carries; with the opponents of genetic research on embryos arguing against the instrumentalisation of life, where, provided access (financial, legal, etc.), parents could be selective of worthy and unworthy embryos. This body of research tends to localise this individualised, commercial form of eugenics as yet another manifestation of the *laissez-faire* ideology (this ideology has been discussed in the previous chapter).

On the other hand, other scholars within the sociology of health and illness adopted a more moderate approach to critique genetics. For instance, Nikolas Rose (2007) draws our attention to the divisions and tensions within genetics and eugenics themselves, as well as the importance of the cultural and historical contexts of the practices associated to them. Focusing on the network of relationships between consumer of genetic products, experts, policy-makers, and biotech companies, Rose views the commercialisation of genetics, and the decentralisation of its governance as fostering liberty, and providing individuals with an opportunity to act upon their future illnesses. This act involves participating in a set of ethical practices. On the other hand, it implies a redefinition of the responsibilities of the at-genetic risk individual with regards to cultivating their own health. This set of practices, rights and responsibilities, and the democratisation of access to genetic information form a basis for a biosocial membership and for staking claims to what has been termed *biological or genetic citizenship* (Rose and Novas, 2005; Petryna, 2004; Kerr et al., 2009). Under this conceptualisation, the at-genetic risk subject becomes: "genetic citizens, fighting for specific rights while shouldering and contesting concomitant duties and obligations . . . [involving] social practices and power relations that cut across online and off-line worlds to co-produce genetic knowledge and genetic citizenship in multiple contexts" (Shaffer et al., 2008, p. 145). A core foundational element that is

necessary to the existence of such a citizenship is the belief in biological and genetic truths.

As Kerr (2004) argued, the spectre of eugenics represents an important discursive resource for both critics and advocates of genetics. The effect of its ideology (or the derived 'lived' ideologies as will be discussed in the methodology section) is key when studying the construction of the role at-genetic risk individuals as market actors as well as the shaping of their consumption practices. In the following sections, I look firstly at the commercialisation of genetics, and then at how the commercial realisation of genetics science combines with the discursive distancing of genetics from eugenics through an elaboration of the notions of individual choice and responsibility. This, I shall argue has important implications for the subjectivities and agentive actions that shape healthcare markets.

3.2. Medicalisation, its developments and performativity:

Medicalisation, pharmaceuticalisation and biomedicalisation represent key processes and concepts that are to a degree linked within the sociology of health and illness, but which have emerged at different historical points (broadly in the 1970s, 1990s and 2000s respectively). The three concepts are briefly introduced in order to highlight their different constructions of subjectivities and how each is enmeshed in differing power structures. In a nutshell, they demonstrate the shifting performativity of markets according to different knowledge claims, and help better locate the genetics discourse within its wider commercial application.

First, medicalisation describes the processes that lead to “defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it” (Conrad, 2005, p. 3). The concept was introduced to medical sociology literature in the 1970s (Bell & Figert, 2012a). Its role was then to understand and critically evaluate “the involvement of medicine in the management of society” (Zola, 1972, p. 488). Since then, medicalisation has been ubiquitously used in both professional and

popular discourses on medicine. Its major topic is the study of medicine as an institution of social control, exercising its power by '*medicalising*' everyday life ie. Constructing the meanings of the labels 'healthy' and 'ill', and emphasising their relevance to humans (Foucault, 1973; Zola, 1972; Conrad and Leiter, 2004). The analytical effort was then very often focused on institutions and professional groups such as the American Medical Association or the American Psychiatric Association as major drivers for the social construction of health and illness. The initial shifts occurred with the focus on the active participation of patients/consumers/users, either as an individual or a collective (Crossley, 2006; Figert, 2011). However, the major shifts happened with the increased attention to the role of pharmaceuticals and the pharmaceutical industry in modern life, as well as the increased involvement of biotechnology in the regulation of the self, which metamorphosed the concept of medicalisation leading to the development of the concepts of pharmaceuticalisation and biomedicalisation.

Pharmaceuticalisation was initially developed in anthropology, first introduced by Mark Nichter in 1989 (Bell & Figert, 2012a); but It is not until the late 2000s that the concept infiltrated the sociology of health and illness, introduced by Williams and colleagues (2008)². Pharmaceuticalisation is the term given to "the process by which social, behavioral or bodily conditions are treated, or deemed to be in need of treatment/intervention, with pharmaceuticals by doctors, patients, or both" (Abraham, 2010, p. 290). While critique of medicalisation lamented the amplification of the power of medicine as a science and a belief system, and underestimated the role of economy, markets and the 'holders of wealth' (Pescosolido, et al., 2000); pharmaceuticalisation appears to address these concerns. The aim of the pharmaceuticalisation scholarship is the broadening of the scope of medicalisation to

² Although the term 'pharmaceuticalisation' is new to the sociology of health and illness, sociologists have engaged with pharmaceuticals and the pharmaceutical industry well before the introduction of the concept (Williams et al., 2012). They have looked at the development of pharmaceuticals (Bell, 1986), their role in development (Gereffi, 1983), in the construction of diseases (Figert, 1996), and the pharmaceutical industry (Abraham, 1995). However, and despite the fact that this scholarship have played an important role in laying the foundations of the concept, these early writings did not relate to wider global economic processes (Bell and Figert, 2012b), which can appreciated in the frequent portrayal of the market as a passive background (which is still frequently the case within this scholarship).

include (1) non-human actors such as drugs and the narrative of their biological effect on the human body (whether it is a treatment or a body enhancement solution such as botox); (2) the interface between consumers, technologies and the understanding of their bodies through those technologies; and (3) the pharmaceutical industry and corporate interest³ (Fox and Ward, 2008).

The final shift, and the one of most interest to the present study, is biomedicalisation that put under scrutiny the transformation of human bodies through technoscientific biomedical interventions. Clarke et al (2003, p. 163) define biomedicalisation as the processes that contribute to the “transformations of bodies to include new properties and the production of new individual and collective technoscientific identities”. Genomics and information technologies enable sophisticated tailored interventions such as biomarkers targeted therapy. They are bound up with the discourse of ‘*personalised medicine*’ that promises to replace the traditional ‘*one size fits all*’ therapy. The biomedicalisation literature is critical of these discourses, and highlights the processes through which they reconfigure human bodies. For instance, Tutton (2012) discusses the discourse of personalised medicine and highlights its reductionist tone by overlooking non-genetic determinants, as well as focusing not on individual unique differences as it claims, but on targeting pharmaceutical developments at shared biomarkers. As he put it: “While 19th century clinicians emphasized their own personal qualities as essential to an individualized medicine, geneticists promoted instead the promise of new technologies and downplayed the role of clinical judgement” (Tutton, 2012, p.1726). The process of biomedicalisation shifts the construction of the human body from universal disease diagnosis and therapy to the level of the sub-population based on genotype and shared biomarkers (Kennedy, 1997). Biomedicalisation captures the complex, global, and multi-sited dynamics that

³ This is another instance where the sociology of health and illness tend to treat economic phenomena quite superficially. The notion of interest (discussed in the previous chapter, with a further discussion in the methodology chapter) is used sometimes without a critical consideration of its configuration. The issue with such narrative shift the exaggerated discourse of dominance of medicalisation from medicine to pharmaceutical companies, without advancing the debate that much further – exception made of certain work that adopted more sophisticated approaches to the question (Eisenberg, 2003; Mirowski, 2007).

shape the technical, organisational and institutional infrastructures of biomedicine that shape the human body (Clarke et al., 2010).

The three concepts discussed above represent excellent manifestations of the performativity of knowledge claims and how they bring into being new entities. The scrutiny to the unravelling the ontological effects of biomedicine is at the heart of this scholarship, and the political commitments are visible across the various works within this body of research. However, and as will be elaborated in further detail in the methodology section, critiques have pointed out the tendency to turn too quickly to grandiose claims about the effects of market ideology on the one hand, and some negligence with regards to human agency and the instances of resistances and their effects (Lupton, 2012). I now look at the rise of biotechnology and the 'biotech' industry.

3.3. (Myth of) The Biotechnology revolution:

The rapid growth of genetic research and technology has important economic, social, ethical and political implications. The field's growth has particularly accelerated with the Human Genome project. HGP was an international, collaborative research project that was initiated in 1990 with the ambitious plan to complete the mapping of the genome. Put simply, the genome is the sum of all the genes together. The project was supposed to map the genetic roots of common diseases such as cancer, Alzheimer and heart diseases. While critics have pointed out that the project has not exactly delivered its promises, proponents stress the breathtaking pace of genetics research, and its benefits for healthcare and society in general. The field continues to thrive, particularly with the rise of 'big data', which has further strengthened the computational and informational basis that lies at the crux of the power of genetics, as previously argued. While the first sequencing of the human genome during HGP took overall 13 years and US \$3 billion, the cost of genetics research has dramatically decreased and has become much more time efficient; thus, sustaining the developments and promises of the field. While the sociology of health and illness has

a wealth of research on the economic, social, ethical and political implications of genetic research and technology, little has been done in market studies, and more broadly in organisation and management studies, on the effects of genetics discourse on shaping market actors and market practices. Therefore, a brief review of the biotech revolution and its critics stands as the background against which this thesis will contribute in scrutinising the performativity of market actors and consumption practices of preventive solutions geared towards genetically redefined diseases.

The global biotechnology market can be divided into four large segments according to its applicability: biopharmacy, bioagriculture, bioservices, and bioindustry. Figures indicate that the biopharmacy market is the largest in terms of revenues (Hexa Research, 2016). The biopharmaceutical market is the branch of biotech that deals with the application of genetics research to human health, and can broadly be defined as “enterprises focused on discovery and development of biopharmaceutical products for human healthcare, based on tools and approaches from modern biotechnology” (European Communities, 2009, p. 1). Despite structural characteristics, such as the capital-intensive, the long time to market, or high risk of failure, that may discourage investors (European Communities, 2009), there has been an increased pace of investment overall. Forecasts predict a growth from a market valued at US \$270.50 billion in 2013, to reach US \$604 billion by 2020 (Market Research Globe, 2016). Despite this financial success, critiques have highlighted a major research productivity crisis, or what have been sometimes called the ‘myth of biotech revolution’ in the healthcare industry (Nightingale and Martin, 2004, Williams et al., 2011).

The biotechnology industry has been the subject of scrutiny within the field of sociology of health and illness, as well as STS amongst other academic fields. An important strand of this scholarship has focused on the discourse of discovery and novelty that is prevalent within genetics, and how it mobilises actors to attract research funding. For instance, Hopkins et al. (2007) describe the claims underpinning the biotechnology revolution to attract funding are “rhetorical devices employed to generate the necessary political, social and financial capital to allow perceived promise to emerge” (Hopkins et al, 2007, p. 21). Other work, such as that conducted

by Pollock (2011), focuses on how biotech companies remain profitable by creating biologics for niche subsets of the population with a high willingness to pay, creating what she termed the ‘drugs for short lives’ phenomenon. ‘Drugs for short lives’ constitute biotech interventions aimed at ‘*end of life care*’. Examples of ‘drugs for short lives’ include drugs targeting specific biomarkers geared at terminal stages of cancer for instance. In the context of the present study, the most relevant example is Herceptin®; a drug that was rapidly and controversially adopted in the UK⁴.

When considering the importance of the commercialisation of genetics discourse in its ‘success’; the scientific, economic and political become intertwined. Defining ‘success’ through the lens of market ideology is a first step in bridging the links between biomedicine, economics and the political. It is part of the broader process of marketisation of healthcare, but also draws on deeper historical elements of genetics (discussed in the previous section). In order to address the politics of performativity within the market for preventive solutions for breast and/or ovarian cancer, I need therefore to attend to the historical components of the technoscientific, economic, social and political discourses that shape markets, market actors and practices. Roscoe’s study (2013) on the ‘organ markets’ is a good example of combining these considerations. Here, Roscoe explores the effects of economics discourse on creating a possibility for a market for transplant organs. Focusing on the rhetorical power of economic reasoning, he scrutinises the various linguistic devices within economic valuation discourse, taking into consideration the risk as well as cost-efficiency calculations, and the construction of economic facts. Roscoe traces the shared intellectual heritage between economics and contemporary bioethics, with their

⁴ Herceptin®, a drug geared towards individuals with a specific biomarker in breast cancer, is an approval story in the UK, and would seem to be a clear case of profitability of biologics for niche. The drug had a rushed approval in the UK, with the National Institute for Health and Care Excellence (NICE) making a decision in a record time. The militating for its approval was done by a joint lobbying for public funding by both patient group and the pharmaceutical company that manufactures the product, Roche Pharmaceuticals (BBC News, 2006a, 2006b). However, it was quickly pointed out that the quick approval of a high-priced biologic such as Herceptin® might result in cost cuts on other ‘established’ treatments to ‘balance the books’ (Abraham, 2009). The story also directed the debate around the NHS payment system’s failure to provide high priced biologics for cancer. Overall, the case of Herceptin® is an example of what has been called the ‘*evidence-based activism*’ movement (Rabeharisoa et al., 2014).

focus on individual choice. In Roscoe's work, these economic facts were deployed to make moral claims (or what he calls moral performativity of economics) and engage in normative debates. In this study, I wish to draw the links between biomedicine, the economic and the political; and to do so focus on the linguistic devices at work in the creation of the market subject.

3.4. Genome, disease and prevention

Several researchers scrutinized the emphasis upon intervention and resources within the genetics research discourse. For instance, Kerr (2004) contends that one major driver for contemporary genetics research is disease and intervention through treatment, putting it at a service of a capitalist system of exchange, constantly aiming at increasing the 'market' for genetic intervention. Kerr suggest to view testing and treatment as a commercial form of applied knowledge. The commercial success is contingent on the apparent objectivity and accuracy of this knowledge. Scrutinising the case of Charcot-Marie-Tooth (CMT) disease and the GARS gene, she highlights how the functions of the gene are put at the front stage, despite its limited involvement to specific types of the condition only. Drawing on STS, she explores the processes of stabilisation of knowledge concerning genes and disease, and their translation into numbers and mutations' types. Kerr draws our attention to two key processes in the making of the GARS gene story: (1) the vanishing of the local context of research processes, and (2) the difficulties of the discovery process that disappear from the storyline when presenting the final form of knowledge narrative. Sitting within the tradition of STS and ANT scholarships, Kerr's study is yet another example of the complex web of relationship between humans and non-human in the process of constructing scientific problems and solutions. However, Kerr takes an additional interesting step in connecting the discovery with the commercial success of its application (although, the term 'market' is sometimes used loosely, almost as a passive background, which is quite often the case within the Sociology of Health and Illness literature). According to Kerr, presenting a form of knowledge as objective, and as a 'success', requires erasing the role of multiple actors involved in the story of

discovery, such as assistant researcher, clinicians, university administrators, research subjects (patients) and their families, as well as certain aspects related to ethics committees, regulators and drug companies. Presenting the story of discovery as 'a success', paves the way to commercial success of its applied forms such as tests and treatments.

It is important to stress that by conducting a social enquiry on at-genetic risk bodies, I do not question the existence of genes as real, natural phenomena, following the tradition of STS and Social Studies of Science. On the other hand, I am not interested in studying behaviours, attitudes or perceptions caused by social factors surrounding genetics. The genes as we know them are not unquestionable objective entities of nature, nor completely a product of a social construction. I see our knowledge of them as intertwined with a network of social and material interactions. I am particularly interested in the attribution of causality between the gene and the disease and its effects on subjectivities and practices. The objective of my study is to scrutinize how knowledge claims about the gene, the body and the disease shape practices of consumption of preventive solutions, and the at-genetic risk subject as market actor.

The repercussions, of the definition of disease through genetics, on the individual are important as well. While the discourse of obligation and coercion of eugenics has shifted to the discourse of individual choice, the notion of control is still dominant as discussed in the previous the section. Whereas the racial and class narrative has been toned down in genetics, the obligation to reform in order to conform to societies' 'norms' through the discourse of genetics is still valid (Kerr, 2004). The main difference is that the definition of the 'deemed misfits' has shifted to illnesses, anti-social behaviours and disabilities that are defined by the gene. The understanding of the processes of social construction of disease is fairly straightforward, and the literature on this topic is abundant. The aim of this scholarship is not to undermine scientific efforts, but rather to place dominant discourses and authorities under scrutiny (Gergen, 1999). Some of the major developments within this field is the concept of medicalisation that I discussed in the previous section. However, the addition of the genetic causality layer complicates the understanding of the process. Most notably, it is the dominance of the discourse of genetics that makes it difficult to be associated

with social processes. Therefore, the concept of biomedicalisation comes in handy for this analysis.

Genetic determinism or 'geneticism' comes into play when a disease is talked about predominantly in terms of genetic causality. The understanding of the disease becomes a matter of identifying 'faulty' genes and developing treatments or preventive solutions geared towards these. This popularisation and oversimplification of the causal links between gene and disease is what Kerr (2004, p. 8) elaborates as: "a parable for popular consumption, promoted by scientists through press releases and popular science". Questioning the causal link between the gene and disease is different from questioning the process of social construction of the disease. This is particularly important in case where the narrative of genetic disease obscure other potential venues for exploring the causality of the disease. In terms of analysing the narratives of women who are at-genetic risk of ovarian and/or breast cancer, I have to scrutinise the dominance of gene as causal factors, rather than simply tracing the progression of the disease and the practices surrounding it. People's articulation of the experience of disease is intertwined with their social and cultural context, but also the historical context. This involves the movement of certain ideologies overtime, and the construction of new common senses, as is the case with genetic explanations of disease and anti-social behaviours for example. The movement of ideologies to commonsensical thinking, or what Billig and colleagues (1988) call 'lived ideologies', will be explored in depth in the methodology chapter.

A key application of genetic knowledge to disease is prevention. Whereas the prevention discourse used to be performed during the eugenics era through sterilisation and other interventions in reproduction, it is articulated now through the rhetoric of genetic disease. Despite this shift, the discourse of prevention still focuses on the control of degeneracy. The definition of degeneracy being very much socially constructed, the narrative of prevention is subsequently in constant mutation. Genetics have also allowed prevention to move in time and space, with the possibility of genetic testing on embryos for instance. Nevertheless, the intervention in reproduction is a matter of individual choice rather than the state, as opposed to

eugenics practices (as explained in the previous section). This intervention is also associated with definition of genetic disease rather than say racial discrimination.

Therefore, prevention is centred on the control of degeneracy. The loss of control over our bodies is one of the factors that create anxiety that constitute the symbolic basis of our uncertainties (Lupton, 1999). It is the responsibility of the at-genetic risk subject to prevent the occurrence of the genetic disease; however this responsibility is bound up with the access (legal, geographical and financial) to genetic information including screening and counselling. The choice of interventions to prevent the genetic disease ranges from surgical procedures to preventive drug therapies. However, it also include consideration of potential side effects of the preventive procedure. For example, one of the effects of the preventive hysterectomy for ovarian cancer is the induced menopause. This implies that the woman will have to take substitutive hormone therapy, which can potentially alter womanhood especially if performed at a young age. It can be considered as a trade-off for avoiding a 'high risk' for contracting the disease. The moral responsibility of the at-genetic risk subject, in the context of hereditary breast and ovarian cancers (hereafter HBOC), will be explored in detail in chapters five and seven.

The lines between prevention and early detection, illness diagnosis and risk diagnosis become blurred in HBOC care. Risk calculations processes do not only shape diagnosis – the at-genetic risk status is constructed as a diagnosis on its own. Definitions and tools of diagnosis play an important role in establishing power relations. As Brown (1995, p.39) puts it: "Diagnosis locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the social control and treatment system (....). For social groups which have been in subservient roles, diagnosis can give credence to conditions which may legitimate their suffering, as well as legitimize themselves". Primary cancer prevention is achieved through the identification and elimination of the 'causes' leading to develop cancer (Fosket, 2010); usually termed in medical practice 'risk factors'. As I will develop in the next sections, breast and ovarian cancers have come to be understood more and more as genetic diseases, primarily associated with genes called BRCA1 and BRCA2. Genetic screening is therefore the routine procedure in case there is a strong family history, or suspicion

of a high risk. On the other hands, dispositive such as mammography and breast-self exams represents methods of 'secondary' prevention of breast cancer. The focus in this case is the reduction of the mortality via the detection of early manifestations of the disease. Slogans such as "early detection is your best prevention" became famous in medical discourse targeting lay population. This genre of health awareness campaigns attracted much criticism from activists and medical sociology scholars, on the basis that it misleads public opinion by blurring the lines between (early) detection and prevention (Fosket, 2010).

This blurring makes the boundary between early detection and prevention porous, allowing discourses to travel more easily across the two arenas. This movement is not only spatial, but also temporal, as primary prevention is geared at a status occurring chronologically before the one targeted by early detection strategies (high risk for HBOC vs. early stage of BOC), which affects the experience of women who are at genetic risk, as they experience pressures to act on their condition that originates from discourses of survivorship. The following sections will offer a detailed account of hereditary breast and ovarian cancer and its relations to genetics and prevention.

Within this study, I explore the practices surrounding the consumption of preventive solutions for hereditary breast and ovarian cancer, with a particular focus on genes associated with an increased risk for HBOC. My commitment on conducting a social enquiry on genes does not mean that I am discrediting any natural dimension of the genes. Nonetheless, I do consider that our knowledges of them are embedded within the social, cultural and historical contexts of their discoveries; and cannot therefore be considered as irrefutable objective entities of nature (Latour, 2000). In other terms, I do not intend to swap a conceptualisation of genes as natural entities for social ones. Instead, the material is intertwined with the social, rather than being determined by social factors, or on the contrary independent of language and discourse. As Kerr (2004, p. 45) put it: "what counts as legitimate knowledge, or truth, is socially

negotiated". Indeed, the social order is shaped by the interactions between human and non-human actors such as genes, diseases, technologies of screening and humans. I will explore this aspect in further detail when discussing sociomateriality in the methodology section of this thesis.

The next chapter bridges the concerns articulated in chapter two and three, and locates the framework of power as used in this thesis.

Chapter 4: Foucault, Responsibilisation, and Neoliberalism

The previous chapter side-tracked from the market studies literatures, and engaged with sociological perspectives on genetics and genetic interventions. In it, I highlighted the emancipation of genetics as a distinct area from eugenics, or more so the historical construction of such distinction. I thoroughly discussed how the narratives surrounding genetics delineate and attempt to distinguish the field from its roots in eugenics. They hold the flag of science and objectivity, and distance genetics from the ideologically driven movement that is eugenics. I also emphasized the causal attributions between genetics, disease and prevention, and hinted to considerations of attribution of responsibility.

One of the biggest distinctions between eugenics and genetics that I discussed in the previous chapter, is the emphasis within genetics' narratives on the notion of individual choice, which contrasts with the coercive values of eugenics. It marks also a leap from an understanding of issues surrounding genes as a matter of state decisions to a matter of individual choice, under the protection of neoliberalist ideology. Another notable aspect is that the focus of genetics narrative is not geared towards attributing causality to social deviance (disability, homosexuality, etc. as was the case with eugenics), but disease. But how do these two contrast? These distinctions have important implications in shifting responsibility from the state to the individual, with the rhetoric of freedom of choice and freedom of responsibility. What about the location of blame? Has it moved? And how is the responsibility attributed to people, under the umbrella of individual choice, negotiated by them? And how does it translate in their experiences of disease and preventive practices? These constitute some of the practical questions I address in this chapter and throughout the remainder of this thesis.

In order to do so, and before moving to the methodological sections of this thesis, this chapter presents the main theories of power that I draw on; and more specifically locates this work within a Foucauldian framework of responsabilisation under neoliberalism (notions which will be discussed in depth in this chapter). By doing so, this chapter bridges the concerns articulated in chapter two and three, and locates the framework of power as used in this thesis.

This chapter proceeds as follows. Firstly, I focus on the discourses of risk and control and how they shape the applicability and commercialisation of genetics knowledge. The possibility of the commercial application of genetics knowledge enrol various human and non-human actors, and shape the creation of potential markets surrounding the prevention of genetic diseases. Moreover importantly, these discourses are bound up with the rhetoric of individual choice that distinguishes genetics from early eugenics, but also reinforce neoliberal processes of responsabilisation by the same token. This section will provide the initial linkages between the main literatures discussed in the previous chapters. This discussion naturally directs us towards considerations on power. I then move to a brief review of traditional conceptualisations of power within STS-influenced market studies, before moving to Foucauldian power and a review of market studies and organisation studies literature that engaged with Foucault's governmentality. Finally, I articulate the specific way I use Foucauldian power within this thesis, and how I combine these theories with the other elements of my theoretical framework.

4.1. Risk, control and responsabilisation:

"Societies develop a system of strategies and beliefs in the attempt to deal with, contain and prevent danger" (Lupton, 1999, p.3).

Belief systems by which dangers are dealt with conceptually and behaviourally have always existed, as they give some sense of *control* to people over their world. The scientification of risk through the incorporation of statistics and mathematics and

scientific constructs has given rise to new forms of 'risk'. The concept of risk has become an increasingly pervasive concept in modern societies, as it aims at developing techniques to reduce uncertainty and increase control. On the other hand, critiques have pointed out how the process of scientification made the concept of risk become: "a central cultural and political concept by which individuals, social groups and institutions are organised, monitored and regulated" (Lupton, 1999, p.25). This scholarship has developed an understanding of 'risks' as constantly constructed and negotiated phenomena that form part of "assemblages of meanings, logics and beliefs cohering around material phenomena, giving the phenomena form and substance" (Lupton, 1999, p.30). Mary Douglas' work, for instance, has focused on the practices surrounding risk (for example the risk level grid classifications) and the interplay between these practices and dominant discourses of the context of her study (Douglas and Wildavsky, 1982). Her work emphasizes the political use of the concept of risk, particularly in relations to accountability, responsibility and blame (Douglas, 1992). This body of research on the sociocultural dimensions of risk has demonstrated how the management of risk is bound up with the rhetoric of individual choice, particularly in the context of biomedicine. Hilgartner (1992) used the term 'risk object' to qualify entities that has been identified as the cause of harm or danger. This qualification process is performed either in experts or public speech (talk and text). In the context of genetics, attaching the causality of a disease or medical condition to a gene constructs the later as the risk object; attributing the responsibility of control of the risk to the individual, *carrier* of this gene.

The 'logic of control' is a dominant discourse in what Beck labels 'risk society' (1992); a society obsessed with future safety, thereby constructing definitions of risk and organising strategies to respond to it. As Rose (2001) observes, this logic of control is pervasive in applied genetics: from genetic counselling sessions to biobanks, tracking of family histories for genetic 'mutation' to preventive procedures for at-genetic risk subjects. Individual choice can be located at the core of this logic. This includes the reinterpretation and decision making based on genetic information, as well as the possibility of choice of a genetic 'future'. The conduct of these ethical practices implies both the ability and responsibility of the individual, rather than say, simply following

and executing doctor's orders. The elevation of individual choice enables what Giddens (1990) labels 'dialogic democracy', which challenge experts' authority and destabilizes the power relations between experts and lay populations. The main assumption here is that individuals, when receiving genetic counselling and seeking the right information, would follow the appropriate ethical procedures and take the rational course of action (Kerr, 2004). However, stopping the analysis here would be somewhat naïve; as neglecting the work of neoliberalist forces in shaping subjectivities and practices would miss the point of the critique. Indeed, the rise of the concept of individual choice can be traced to its developments within a neoliberalist ideology. In neoliberal ideology, the notion of individual choice translates the understanding of society to "collections of choice-making individuals whose actions imply trade-offs between alternative ends and the various means to attain them" (Çalışkan and Callon, 2009, p. 373). However, the rhetoric of this discourse has important implications on constructing market actors and shaping their practices. In their study on new human genetics, Kerr and Cunningham-Burley (2000) argue that genetic knowledge and testing technologies, while offering new choices to individuals, construct new risks, and by the same token create more uncertainty in the decision process. They also demonstrate how science organisations manage threats to their authority by adding a democratic gloss to the genetic testing and consultation practices.

While the power balance is redistributed between the lay population and the experts under the umbrella of neoliberalist' individual choice, the 'scientific' knowledge occupies an even more dominant position as the availability of information will form the basis of choice (Kerr, 2004). This does not mean, however, that expert voices are shut down or minimized. On the contrary, certain experts' voices, who are involved in producing 'successful' forms of research, construct the scientific narrative within their network of knowledge production. The authority of this narrative is often positioned by the pronouns 'we' and 'they'. While referring back to those expert voices, this formulation attains to an unnamed authority, giving even more sense of objectivity and credence to these voices. I return to this aspect in detail in the methodology and analysis chapters when discussing pronouns. The key point here is that the coercion

and control that were previously exercised through state regulation and institutionalisation, find a different voice to articulate them, materialized in the processes of medicalisation, pharmaceuticalisation and biomedicalisation (Kerr, 2004).

Neoliberalism claims are that the freedom of choice of the individual is protected by free markets (the *laissez-faire*). It represents a freedom to choose but also a freedom (or obligation) to be responsible, and therefore the empowerment of individuals through their engagement with consumption practices. I will quote here Uncle Ben from '*the Amazing Spiderman*': "with great power comes great responsibility"⁵. I am not using a quote from Spiderman just to add a funny twist to my narrative. This quote is an excellent exposé of an apparently naïve mode of transfer of responsibility from the state to the individual under the neoliberalist ideology. The freedom of choice is formulated as contingent on the acceptance of the responsibility that it entails.

However, for such claims to freedom to be plausible, the entities, market, rational individual and freedom, need to be pre-existent, ie. Ontologically prior to social structures. Foucault is highly critical of this 'freedom' of choice, and argues that under neoliberalism, norms and incentives, operating in the shadow of the law, regulate and govern both the individual and the collective (Mayes, 2016). This is what Foucault developed later as 'technologies of the self' (Foucault, 1988). According to him, the very construction of the individual as the neoliberal subject (*homo oeconomicus*) enables its governance through market ideologies, as rational and responsible choices are constituted within the process of subjectification. Developments within behavioural economics and marketing, such as nudge theory and the famous choice architecture, are straightforward examples of such means of governance. This

⁵ Other scholars attribute this quote to Voltaire (France Convention Nationale, May 1793). In this collection of decrees, Voltaire says: "**Ils doivent envisager qu'une grande responsabilité est la suite inséparable d'un grand pouvoir**" (p. 72) which can be translated to "They should consider that a great responsibility is the inseparable succession of a great power" (**source: own translation from original**). It is indeed very close to the quote by Spiderman's Uncle. Obviously, Voltaire was a huge literal and philosophical figure of the age of enlightenment, and his ideas influence the development of liberalism and subsequently the authors of '*the Amazing Spiderman*'.

construction has important implications for the concept of choice within neoliberalism: not only the choice is individual and has to be rational, but is also understood in terms of efficiency and effectiveness; a choice of a healthcare preventive procedure becomes understood as investment in the self, in order to improve the human capital (Foucault, 2008).

This self-governance, under the banner of the discourse of individual choice, is contingent on the access to specific technologies; whether the restrictions to this access are legal, financial or geographical. The effect of such a discourse is the exclusion of poor people, as well as people living in under-developed countries or countries with tight regulations with regards to genetics. For instance, in Roscoe's study of organ markets (2013), the exclusion or exploitation of poor people was deemed morally acceptable by proponents of organ markets, and neoliberally infused accounts were frequently used to defend the legitimacy of such a market. Another key aspect to self-governance is the responsibility that is associated with it. The transfer of the responsibility from the state to the individual under the banner of freedom of choice has been called '*responsibilisation*' (Garland, 1996; Shamir, 2008). The term finds its roots within developments in the governmentality literature that can be traced to Michel Foucault's '*Birth of Biopolitics*'. Central to the analysis of Foucault is the metamorphosis of the relationship between the state, the economy and the individual.

In a deconstructionist fashion, I can appreciate that defining responsibility and responsible acts creates a meaning for irresponsibility and irresponsible acts. Not following the ethical set of practices and the rational course of action for genetic diseases will define the practice as irresponsible. This contributes into shaping the experience of illness of the individual including the anxiety and guilt associated with such practices and the pressure to take the rational choice. The main danger of the discourse of freedom is the loss of protection of individuals when they perform 'irresponsible' choice. The protection is lost for individuals with limited or no choice that can be due to problems of access (legal, financial, geographical). This process, therefore, participates in reproducing and reinforcing inequalities (Léonard, 2003). This is particularly important when considering the marketisation of the different

areas of life, including healthcare, where collective public policies are reframed through the lens of individual choice and responsibility (Mayes, 2016). Neoliberalist ideology redistributes welfare under the banner of freedom of choice and responsibility. Failing to conform to the frame of the rational responsible choice results in an exclusion from the protection by the system. The individual's insufficient welfare is interpreted as their own moral failure (Garland, 2014; Rawlinson and Ward, 2017). This leads to consider how neoliberalist governance frames morality through "the foundational epistemology that dissolves the distinction between market and society and, furthermore, encodes the 'social' as a specific instance of the 'economy' (...) The moralisation process thus entails a set of practices that contribute to a constantly evolving and adapting neo-liberal imagination and, moreover, to the further economization of the political" (Shamir, 2008, p. 14). The reframing of morality makes responsabilisation an important concept when studying the politics of performativity, particularly in the context of genetics and prevention where the rhetoric of individual is dominant. This is because a framework of responsabilisation under neoliberalism allows us to critically engage with the power relations involved in the economization of the political, and its resulting effects in the bringing into being of new market and market actors.

As the discussion is shifting towards power and politics, it is important at this stage to clearly locate the theories of power used within this thesis. The following section clarifies this aspect by discussing the traditional approaches to power within STS-inspired market studies, and contrasts them within Foucauldian power. It also locates the present study within a Foucauldian framework of responsabilisation under neoliberalism.

4.2. Power:

Within a Callonian framework of performativity, power is best approached through an analysis of Socio-Technical Agencements (m-STAs discussed in chapter 2). Within this approach, a good starting point for studying power struggles is the controversies on calculating tools, and how they shape the development of calculative agencies. As

Çalışkan and Callon (2010, p. 13) put it: “Inequalities derive from the unequal power of calculating agencies that loop back to reinforce themselves. Due to these asymmetries, the most powerful agencies are able to impose their valuations on others and consequently to impact strongly on the distribution of value”. In other terms, power asymmetries result from the work of calculative agencies and modes of calculation, and are therefore represented as a calculative ability (Callon and Muniesa, 2005; Araujo, 2007; Cochoy, 2002). However, and as discussed in depth in chapter 2, this approach does not fit with my overall theoretical framework, primarily due to its overall descriptive analysis as well as its departure from the core of political economy analyses of categories such as class, gender and capital. Therefore, I turn to a Foucauldian theorising of power as it sits more comfortably with the discussions above on individual choice and responsabilisation. I particularly draw on his later work on governmentality and technologies of self.

It is clear from the discussion in the previous section that a Foucauldian theorisation of power appears to be more suitable for the case under study; taking a particular inspiration from his work on ‘technologies of self’. However, how does it fit within the overall theoretical framework? This is the central topic of the following sections. First, I discuss Foucauldian power and its foundations, before moving the focus onto his later work on ‘governmentality’ and ‘care of the self’. Second, I present a review of the recent development of Foucault’s ‘governmentality’ within market studies and organisation studies. Finally, I elaborate on the specifics on the way I am approaching Foucauldian power within this present work.

4.2.1. Foucauldian Power:

From a Foucauldian perspective, power is not what is exercising domination on the subject from the outside; it is rather understood as constituting the subject within as well. As Butler (1997, p.2) put it: “power is not simply what we oppose but also, in a strong sense, what depend on for our existence and what harbour and preserve in the beings that we are”. The interplay between performative knowledge and power plays

an important role in the construction of subject positions (the notion of 'subject positions' will be explored in depth in the methodology chapter).

Within a Foucauldian lens, power delineates the realm of the knowable. Thus, power does not emanate from somewhere or something, but is constitutive of the social fabric as well as subject positions. In other terms, power "traverses and produces things, it induces pleasure, form knowledge, produces discourse" (Foucault, 1980, p. 119). According to Foucault, power manifests itself beyond the obvious threats and constraints, and operates within discourses and language structures. Various forms of power are embodied within knowledge systems. Thus, power is best understood in relational terms within this perspective.

Power is dynamic and pervades the social fabric. From an analytical point of view, this implies that power cannot be analysed as something localised, held by a specific entity or traveling from an entity to another⁶. Instead, power should be analysed from a dialogical perspective, exercised in interaction (Foucault, 1973). Power-knowledge relations are heterogeneous, involving discursive and non-discursive entities, and exist in circulation. 'Heterogeneity', in this context, does not only imply coexistence, but also connection and co-constitution. Thus, a Foucauldian perspective proves to be helpful in scrutinising how certain discourses and practices access privileged positions, where they can shape various forms of social domination and control; thereby positioning the political as forming an intrinsic part of discourses and practices (Deetz, 1996).

Foucault's journey to studying power took him through a variety of contexts such as madness, criminology, sexuality, disease, and governance; sketching a history of what he calls 'regimes of veridiction' (Foucault, 2008). His later work focuses on the 'technologies of government' which constitute and condition subjects, but also allow room for interaction, negotiation, and resistance. This conceptualisation marks a step away from his initial understanding of subject as a 'docile body' (which dominated Foucault's early work) to integrate individual agency, and the possibility of resistance

⁶ The notion of power travelling from an entity to another shapes other definitions such as certain ways of talking of 'empowerment'. This constitute a key aspect that will be discussed in further depth in the analysis and discussion chapters.

(Munro, 2012). Freedom of choice is not to be understood here as depending on the absence of threats or constraints. It is rather defined as a set of ‘technologies of self’, which co-exist alongside technologies of domination. However, this freedom is packaged with a set of duties and obligations, including the notion of self-responsibility discussed at the beginning of this chapter. As Rose et al (2006, p.91) put it, freedom (within Foucault’s governmentality) constitutes the “choice, autonomy, self-responsibility and the obligation to maximize one’s life as a kind of enterprise”⁷. Domination, control, resistance, and freedom all exist within power relations.

Foucault’s governmentality shifts the focus from external discipline, to an understanding of a disciplined subject. The disciplining is performed through knowledge claims, and the construction of norms and standards. It takes effects through iterative practices, where knowledge claims produce norms and standards. Foucault describes the knowledge systems, which produces the disciplining claims, as totalising techniques (Foucault, 1983). By totalising, he refers to their pervasiveness within everyday practices; as they are inscribed within commonsensical notions of health (medicine, pharmacy, and biotechnology), trade (economics), governance (politics), and even knowledge itself (education system). The totalising character of knowledge systems renders power omnipresent – power is everywhere (Foucault, 1984). Thus, the definitions of rational and responsible behaviours are delineated within knowledge systems, and inscribed in the social fabric, hence constructing a disciplined subject. This mode of disciplining constitutes the backbone of Foucault’s *governmentality*, which is a neologism derived from the French word ‘gouvernemental’, which means ‘concerning government’ (Lemke, 2010), and represents “necessary critique of the common conceptions of ‘power’” (Foucault, 1997, p. 88). Governmentality bridges between the technologies of domination and the technologies of the self; therefore, shaping ways of self-government.

Within Foucault’s governmentality, neoliberalism has an effect of limiting the exercise of government power internally (Foucault, 2008). Public authorities can and should only exercise their power where it is positively and rationally useful. And what

⁷ Entreprenure and individual entrepreneur are key Foucauldian concepts for the present study. I engage with these in depth in the analysis and discussion chapters.

determines this rationality and definition of utility? The answer lies within the 'market'. The market becomes a site of formation of truth(s), rather than simply a domain of jurisdiction of exchange (Foucault, 2008). This approach proposes to scrutinise the conditions under what these truths are exercised, as well as their effects. Rather than a focus on falsification of truth claims, the effort here is on dissecting the 'regimes of veridiction' that enabled a discourse on genetics or prevention to be held, as well as their wider effects. This attention to the historical conditions of constitution as well as effects makes this theorising power compatible with a Butlerian/Derridean approach to performativity, as well as the political commitments of this thesis. As Foucault (2008, p.37) puts it: "this is the point (in fact) where historical analysis may have a political significance".

Throughout his development of the governmentality thesis, the shift from the early conceptualisations of docile bodies to integrate individual agency becomes clear. This shift brought with it an emphasis on resistance, conceptualised as omnipresent as power (Foucault, 1978). His description of the '*technologies of self*' addressed the relation between the government and the governed, particularly through the practices of freedom. Freedom is intrinsically connected to resistance, as any act of resistance is contingent on the freedom to do so (Rabinow, 1997). For Foucault, whenever there is power, there is also freedom and resistance (Foucault, 1990), where freedom is "constructed through the operation of power" (Hodgson, 2001, p.125). However, Foucault distinguishes between two heterogeneous conceptions of freedom: the freedom to exercise human rights, and the independence or autonomy of the governed. Both concepts have different historical origins, and while the former is concerned with the juridical and moral question of rights, the latter is of particular interest to the present study. The independence of the governed is intimately connected to the processes of responsabilisation discussed at the beginning of this chapter. Hence why autonomisation of individuals is sometimes translated into 'liberating responsabilisation' (responsabilisation libératrice) within governmentality studies (Hache, 2007).

4.2.2. Foucault's governmentality and 'care of self' within market studies and organisation studies:

In this section I provide a review of the literature within market studies and organisation and management studies that incorporated Foucauldian power with their framework. This review has an emphasis on the scholarship that drew on Foucault's governmentality in order to keep a focus on work connected to the presented study (for extensive review of Organisation and Management Studies literature that draws on various Foucauldian concepts, please refer to Raffnsøe et al (2017)). I identify the various approaches adopted, their contributions, before discussing the specific way I integrate Foucauldian power within my theoretical framework.

Randall and Munro (2010) draw on Foucault's concept 'the care of the self', and utilise it to re-evaluate the concept of mental health care. They explore how mental health workers make sense of their work, with a particular attention to their practice vis-à-vis victims of sexual abuse. The study scrutinises the reflections of these workers on the concept of care on the one hand, and on the various forms of knowledge as applied in practice on the other hand.

Randall and Munro discuss the processes of normalisation of the human body through medical science as elaborated by Michel Foucault, and how it coexists with other concepts that sit within 'opposite' moral arenas. They contrast the 'care of the self' and the 'normalising techniques' of medical practice as two heterogeneous organising concepts, independent yet co-existing, within mental health work. They explore the tensions and conflict that arise from the coexistence of these discourses within the arena of medical and psychiatric practices. Randall and Munro take a narrative approach to exploring identity and provide a thorough critique of the processes of normalisation within the mental healthcare sector, and a neat re-evaluation of the approaches to engage with the psychiatric institution clients in light of Foucault's 'care of the self'. By doing so, they propose a move of mental health care as solely a science

of healing, to engage with the “day-to-day practice of living, both as a pragmatic and aesthetic project” (Randall and Munro, 2010, p. 1502). Randall and Munro’s work provides great insights on the tension between the care of the self and normalising techniques as organising principles.

Drawing on Foucault’s concept ‘the care of the self’ as well, Skinner (2011, 2012) explores the various modes of subjectification and objectification in a self-managing non-commercial organic farming community. She dissects the organic/non-organic binary, and deconstructs the historical and cultural distinction between the two categories in retail.

The central topics in Skinner’s work are the notion of ‘organic’ and the construction of subjectivities around it. She scrutinises the discourses around what constitutes a ‘good organic consumer’, and the struggles in sustaining the category membership. Drawing on Butler, she considers the fragility and fragmentation of subjectivities, and the on-going tensions inhabiting an apparently stable category.

Skinner’s argument is that the construction of subjectivities is not an entirely social process, and should consider individuals’ own interactions of the social world; therefore shifting away from an over-grandiose notion of subjugation that characterises some of OMS that draws on early Foucault’s work. By doing so, she draws our attention to the tensions in subject construction, as well as instances of resistance and negotiation with the ‘organic’. These tensions occur with the various (and sometimes contradictory) narratives of ‘organic’ products, but also other macro practices such as those of certification organisms, associations’ rules, and so on, and how they can push for particular ways of doing ‘organic’.

Locating his framework within Foucault’s writing on governance under neoliberalism, Roscoe (2015) examines lay-investment in financial markets, and suggest viewing lay investors as self-entrepreneurs. The lay-investor becomes a docile body of neoliberalism, and self-discipline is conceptualised as a normalising technology

through which they rationalise their belonging to financial markets despite the difficulties and the losses. To do so, he connects Foucault's governmentality and performativity, through a focus on marketing knowledge-power. Thus, Roscoe proposes to strengthen the notion of power as calculative ability through Foucault's governmentality.

The analytical focus of Roscoe's study is the entrepreneurial self as a mode of subjectification, and the technologies of self-discipline. He brings back our attention to important considerations of rights and duties, mostly with regards to the responsibility of consumers under neoliberalism – which is consuming. Then, he connects these notions to Foucault (2008) and Rose (1996) writings of life as an entrepreneurial project of ourselves. Ultimately, this leads him to analyse the lay investor as “self-entrepreneur, producer of his/her own satisfaction, manager of his/her own capital, and foundational member of the social contract under neoliberalism” (Roscoe, 2015, p. 212).

Roscoe's study offers a useful way to theorise the attachment of lay investors to the financial markets, their service providers. This illuminates in particular the power relations at play in the bringing into being of market actors, in a way that allows a more critical account than a view of power as a calculative ability. However, it pays less attention to discussions of resistance, and how tensions and instability inhabit the 'self-entrepreneur'. There is an interesting critical discussion of conceptions of freedom under neoliberalism, but the overall focus was more geared towards 'coping' technologies and self-discipline, rather than tension and conflict. Thus, the study opens important questions about the tensions and conflict inhabiting the entrepreneurial self, the processes facilitating his bringing into being, as well as the instances of resistance to the rights and duties attached to this entity. These questions take a more central role in the current work.

Carrying a relatively similar objective as Roscoe but through a different approach, Leclercq-Vandelannoitte (2011) proposes a Foucauldian-based process model as a way to strengthen discourse-focused organisation studies scholarship. She explores

the power-knowledge relationships through which communication constitutes organisations. Her argument centres around balancing the focus between the symbolic and material, through a theory of power that considers the discursive and non-discursive practices that constrain and enable everyday life. She criticises the way Foucault's work is deployed within to organisation studies, and proposes to go beyond a narrow focus on dominant discourses to one that considers both the discursive and the material.

To do so, she draws on Foucault's governmentality, and takes on the issue of the agency-structure binary. Following Foucault, she suggests adopting "a dialogic, relational, contextualized conception of social reality" (Leclercq-Vandelannoitte, 2011, p. 21), and scrutinising the interactions at the symbolic-material intersection.

Exploring a different approach to implementing Foucault with their framework, Giamporcaro and Gond (2016) connect Foucauldian power to calculative agencies. To do so, they draw on Lukes' (2005) 'radical view of power' and his critical engagement with Foucault's analysis of power. They explore the French socially responsible investment market, and suggest viewing organisations as sites of power through calculability.

Giamporcaro and Gond's paper consider the political work of calculative agencies in market making. Their approach aims to shed the light on the interactions between micro and macro-level politics of market making. At the heart of this view is the interface between power and calculability. They unravel the creation of new 'power sites' at the micro level (or what they also call 'calculative lobbying'), and highlight the interaction of these with macro actors' practices (or what they also call 'government of calculability'). They argue that these interactions are mediated through calculative agencies.

Paralleling Luke's (2005) argument in viewing Foucauldian's power as subjectification as 'ultra-radical', they engage with Fleming and Spicer (2014) framing of power when studying organisations. Therefore, their framework shifts from a focus on Foucault's subjectification to scrutinise the forms of power "*constituted by* but also exercised

through, over and against calculative agencies” (Giamporcaro and Gond, 2016, p. 466, emphasis in original). They contribute into framing calculability as politics when studying market shaping. By doing so, they provide another interesting route to explore the political and critical potential of Callon’s performativity. They explore both the stabilising work of calculative agencies, as well as misfires. Thus, there are some parallels with the present study in highlighting process, as well as instances of failure. Nevertheless, the quasi-focus on calculability, calculative asymmetries and the materialisation of calculative devices, differs from the attention this study gives to discourse and discursive practices. The view of calculative agencies as ‘sites’ of power does not sit comfortably either with the epistemological commitments of this thesis.

4.2.3. The framework of power adopted in this thesis:

My starting point in discussing power is, therefore, a Foucauldian framework of responsabilisation under neoliberalism. The connection that I am making between Foucault’s governmentality and market studies bears some similarities, but also a few differences from the papers cited above. The most obvious one is that I am integrating Foucault’s writing of governance and responsabilisation with Butler’s performativity, whereas most of the studies reviewed incorporated it with Callon’s performativity and a focus on calculative agencies (exception made of Skinner’s work, which however does not engage directly with notions of performativity).

Overall, I align with Butler with regards to her readings and interpretation of Foucauldian power, and integrate notions from governmentality, particularly those related to responsabilisation, within her version of performativity (Butler, 1990, 1993, 1997). Similarly to Butler, I use Foucault as a starting point to studying power (McKinlay, 2010), and review its notions to ensure an overall cohesion within my framework, and an alignment with the objectives of my study. Accordingly, there are a couple of aspects that I reconsider below.

The first aspect concerns the process of normalisation (which is central to the discussion of Randall and Munro’s work (2010) discussed above). Butler extends Foucault’s understanding, and elaborate on the process of materialisation of these

norms through processes of repetitive citation (Butler, 1990). Whilst seeking to distance her stance from some notion of magical ontological effects through her insistence upon the sedimentation of performative acts (as explained in chapter 2), Butler keeps the materialisation process as central to her approach to performativity but draws on a different 'version' of discourse. For Butler (1990), juridical power is consolidated and materialised through reiteration processes. Yet, studying repetition also means examining the inherent instability of the materialised categories, as they shed the light on instable relationship between the signifiers and signified, as well as the possibility of resignification.

This discussion on repetition bring us back to Derrida's 'iterability', which I have discussed previously in chapter 2, and therefore the need to clarify my stance on discourse. The view of discourse that I use is largely inspired by Jacques Derrida's work. Within Derrida's deconstruction, the possibility of destabilisation is always present within the analysis. While reiteration is essential to the success of performatives, its analysis always hints to a domain of instability inhabiting the structure. The influence of Derrida's discourse is also highly visible in Butler's work in general, including her conception of performativity. One of the major focuses of her version of performativity is to the importance of studying instances of failure in subject formation, as well as resistance. Although Foucault's later work addresses the possibility of resistance (through a discussion of autonomy, freedom and resistance), a Butlerian/Derridean framework offers more fine-tuned tools to scrutinise instances and possibilities of resistance as well as the inherent instability and fragmentation of subjectivities. Moreover, this approach allows a more detailed inspection of the effects of normalisation processes, as well as consolidates the historical analysis of their coming into being.

Thus, by combining a Foucauldian framework of responsabilisation under neoliberalism and Butlerian performativity, this study deploys a Foucauldian view of power in conjunction with a Derridean conception of discourse. Having clearly set the theoretical framework, the next chapter will discuss the methodology adopted for the present study.

Chapter 5: Methodology

This chapter presents a detailed account of the methodology adopted for the present study. First, I present the research questions, and explain the grounding of this thesis within a social constructionist approach. The second part of the chapter discusses Discourse Analysis, with a particular focus on the challenges of a too narrow focus on the local-situated context, in contrast with the over-grandiose approaches that avoid looking beneath the macro-system context. This leads me to discuss the analytical framework that I have developed, which connects three concepts within Discursive Psychology, a 'branch' of Discourse Analysis. The three key concepts are: the discourse action model of description and attribution, ideological dilemmas, and positioning theory. Finally, I discuss how this analytical framework helps bridge between the 'micro' and 'macro' context, by locating subject positions in interaction with the 'other', as well as wider ideological domains.

5.1. Research questions:

From the discussions in the previous chapters, the present thesis poses one general research question (RQ1):

RQ1: How does scientific knowledge participate in performing new subjectivities and forms of consumption of prevention? And what are the effects of this performativity?

and two specific research questions (RQ2 & RQ3):

RQ2: How are the responsibilities of the at-genetic-risk subject negotiated in everyday practice?

RQ3: How does the translation of genetics and risk knowledges by lay population shape their practices? And how does this knowledge interact with other moral domains throughout the decision making process?

This thesis sits broadly, as will be discussed in depth across this chapter, within discursive research. My epistemological commitments (elaborated in the next sections) have very much shaped the formulation and the wording of these research questions. Another aspect that shaped the formulation of these research questions is the working with a set of ‘naturalistic’ research material, which will be detailed at the end of this chapter. An advantage of working with naturalistic data is that it regularly features unexpected events, which challenge traditional repertoires of explanatory concepts (Potter, 2012). This meant that the research questions alongside the literature review were continually refined throughout the course of this study and the engagement with analytical work.

The next section exposes in detail my epistemological commitments.

5.2. Locating this social enquiry:

5.2.1. Epistemological commitments:

The aim of this section is to present my epistemological commitments within the present research. I do not intend to present a detailed review of the so-called paradigm war within social sciences, nor advocate a specific stance towards the status of knowledge over others. My objective here is to discuss my various influences and how they lead to the choice of my epistemological stance within this research, and most importantly demonstrate how these commitments can help answer the research questions, as well as the kind of knowledge I produce subsequently.

I adopt a broadly constructionist approach. Within a social constructionist approach, what is asserted to be ‘truth’ should be considered as the product of power relations. Before delving deeper into social constructionism, let me scrutinise this last statement

first; where I have just made a reference to few key notions such as truth, product, power, and relations. By *'truth'*, I refer here to knowledge claims considered as accurate reflections of the world. Within modern theory, knowledge claims are traditionally viewed as candidates for universal truth; generalisation being a key foundation of its research philosophy, alongside the 'objectivity' of the researcher. As Alway asserts, modern theory depicted "the figure of the value-free, impartial, dispassionate observer, occupying a point external to any particular position in society" (Alway, 1995, p.223). The establishment of this position would be the backbone for the development of an objective knowledge about the world. This initial separation is part of a collection of dualisms: subject from object, fact from value, nature from culture, reason from emotion, and so on. The researcher or scientist becomes a *'truth teller'*; accurately observing, analysing phenomena and reporting their findings. These principles sit traditionally within positivism and empiricism.

On the other hand, social constructionism considers human experiences as historically, culturally and linguistically mediated (Willig, 2008). One of the main commitments is the deconstruction of the dualisms that are prominent with the positivist position. Therefore, concepts such as perception are not completely distinct from experience, as social constructionism refutes the mind-body dualism: perceptions are considered mediated as well. In other terms, what we experience and perceive is performed from one's vantage point, and represent a specific interpretation or reading of the world; rather than a direct reflection of the world as understood within a positivist stance. Thus, there are knowledges rather than a universal knowledge, varying from the vantage point where the knowledge claim has been produced (Gergen, 1999). To sum up, the epistemological claims made within a social constructionist tradition are that the knowledge produced through research is partial, situated and relative. That is, truth is a *'product'* as referred to earlier in this section. As Bakhtin put it: "we do not address inquiries to nature and she does not answer us. We put questions to ourselves and we organise observation or experiment in such a way as to obtain an answer". M.M. Bakhtin, *the problem of the text* (1986 – cited in Gardiner, 2002, p. 106).

Social constructionism is, therefore, a commitment to adopting a critical stance towards taken for granted forms of knowledge. This includes the categories that we utilise as humans to apprehend the world, and might consider as referring to real divisions. I am going to illustrate this latter point with few examples. For instance, I have an interest in dance, more specifically street dance. When I started training in the various styles within street dance, I was overwhelmed with the terminologies and associated technicalities. Nonetheless, I tried to learn about the foundations of my favourite styles and perfect my technique. However, during a class in 'waacking' (one of my preferred dance styles) in London, the teacher, who has a world-class reputation in this style, explained how the labels are not invented by the '*gods of dance*', and that she will take the liberty to categorise the movements in a way that she felt was easier to grasp. This was an eye opener for me, as it reminded me of my epistemological commitments and their application in everyday life. I started researching the culture and history of the style, and discovered my own way of categorising the foundational movements and perfecting my craft. Another example, which is certainly more 'radical' than dance styles, is the concept of gender performativity as informed by Butler (for a detailed review please refer back to Chapter two). While it might appear at first difficult to question the categories of man and woman, 'simple' practices of gender reassignment surgeries disrupt this model. Further manifestations are all the gender stereotypes around masculinity and femininity. For instance in the context of breast cancer, patients are bombarded with the colour pink in 'positive' campaigns around breast cancer survivorship. Pink is used as a symbol associated to femininity, representing hope for women who are affected by a disease attacking symbols of their femininity; the breasts being an organ strongly attached to the category *woman* as well as notions of femininity in contemporary culture (a detailed discussion on the colour pink in context of survivorship is available in the next chapter).

Within the present study, the research subjects have access to a number of categories such as survivors, BRCA positive/negative, uninformative and so on. The categories are made available to them through their discussion with experts (oncologists, surgeons, and geneticists), interactions with their peers in the online forums or in the various 'physical' support groups, as well as through the various informational

resources, and other forms of social interactions. As I explore in detail in the analysis chapter, these categories carry with them a set of subjectivities, rights, duties and play a major a role in the attributions of responsibility, blame and causality. Through their definitions, they outline a set of ethical practices for the prevention of the occurrence of breast and ovarian cancer, and thereby the preservation of the body. Individuals interact reflexively with these categories to draw subject positions for themselves, as well as their interlocutors. Thus, social constructionism is useful in deconstructing the apparent '*out-there-ness*' and self-evidence that attend the institutionalisation and conventionalization of such categories and practices (Shapin, 1984). I delve in detail in the topic of categories and subject positions in the context of previvorship in the analysis chapter.

Burr (2015) summarises the foundational principles of a social constructionist epistemology, presented in figure 7 below.

Anti-essentialism

- There cannot be any given, determined nature to the world or people. Social constructionism rejects essentialist dualisms such as individual/society and mind/body

Questioning realism

- Social constructionism denies that our knowledge is a direct perception of reality. Instead, knowledges are historical, cultural and linguistic constructions

Historical and cultural specificity of knowledge

- Theories and explanations are time and culture-bound and cannot be taken as final descriptions of the nature of a phenomenon

Language as a pre-condition for thought

- Concepts and categories are acquired by each person as they develop the use of language and are thus reproduced in social interactions. This means that the way a person thinks, the very categories and concepts that provide a framework of meaning for them, are provided by the language they use. Language therefore is a necessary precondition for thought, and constitutes one of the principal means by which we construct our social and psychological worlds.

Language as a form of social action

- By placing centre stage the everyday interactions between people in the production of knowledge, it follows that language is a form of social action. This is one of the foundational principles of the performativity thesis.

A focus on processes

- The aim of the social enquiry is removed from questions about the nature of people or society towards a consideration of how certain phenomena or forms of knowledge are achieved by people in interaction.

*Figure 7: Foundational principles of social constructionism
Adapted from Burr (2015)*

5.2.2. Poststructuralist influences on the present study:

The 1980s saw an increased interest in interpretive research within management studies. One of the manifestation of this interest was the turn to a focus on language as a result of the influence of poststructuralism, particularly within the critical circles (Jones, 2009). Some of the pioneer works within this so-called *linguistic turn* in management studies include Weick's seminal work on the social psychology of organising (1979), as well as his work on sensemaking (1995), which set strong foundations for the importance of studying language in organisation studies. Other scholars drew on specific poststructuralist writers, in order to outline explicit outputs for the critical scholarship within management studies. Utilising Wittgenstein's 'language games', Astley and Zammuto (1992) depict organisational science language as a resource for managers' speech, and more specifically a form of symbolic language accruing power relations; which contrasts with its traditional view as a form of 'scientific' technical prescription for managers. As a strong advocate of the work of Jacques Derrida, Cooper (1989) highlights the importance of studying organisation theories' function to legitimise the structures they represent, and to this end, borrows three core concepts: *deconstruction*, *writing*, and *différance*. Following Derrida, Cooper draw the focus on the importance of analysing process, rather than structure, in social systems. Another key work is Knights and Morgan's paper (1991) on corporate strategy that took inspiration from the work of Michel Foucault. Using a historical analysis, they highlighted how the reproduction of strategy discourse constitutes a '*mechanism of power*' that constructs subjectivities, and how the engagement and acceptance of subjects in strategic practices secures a sense of well-being. They demonstrated how this construction of subjectivities relates to wider instances of inequality and privilege in organisations.

These are some examples of early work that introduced poststructuralist thinkers to management studies. This scholarship paved the way for the birth of a new sub-discipline of management studies early 1990s. The so-called 'critical management studies' (hereafter CMS) emerged after the publication of the highly influential collection of Alvesson and Willmott (1992). CMS constitutes a broad church now, and

has given to sub-disciplines such as Critical Marketing Studies. Critical Marketing Studies' scholarship has drawn on a number of perspectives including neo-marxism, humanism, post-structuralism, literary criticism, feminism, environmentalism, social psychology, cultural studies, queer theory, and numerous others (Brownlie et al., 1999; Ellis et al., 2011; Firat et al., 1987; Fournier, 1998; Hopkinson, 2003; Morgan, 1992; Saren, 2015; Stern, 1996; Tadjewski, 2010). This study broadly sits within Critical Management Studies endeavours.

Before moving forward with the discussion on Discourse Analysis and the specific methods of analysis I am using in this research, I would like to draw the focus on what it actually means to 'analyse' text and talk. The 'linguistic' turn has been wrongly conceptualised as solely focusing on language, which is a very reductionist conception of the term and the associated set of principles (for an example of critique of the linguistic turn in management studies, see Reed, 2000). The aim of the rest of this section is to address these critiques, and develop my position with regards to the debates between discourse and materiality in market studies. The Derridean/Butlerian influences on this study has certainly shaped my positioning with regards to this aspect.

The linguistic turn is part of the effort to deconstruct the subject-object dualism that was overwhelmingly dominant in social sciences (and still is in a wide range of disciplines). This binary opposition suggests that other distinctions are possible: the researcher (the knower) and the object of research (what is known), the subject experiencing the world (human behaviour) and the external world of 'things' (the world in which it operates), the subjective (discursive) and objective (material), the word and the world, and so on. Rejecting this dualism, and by the same token this way of seeing the world, means problematizing the methods of investigation that come with this epistemological stance (Deetz, 2003, Mumby, 2011).

Through various conceptual and analytical resources, which I expose in detail in the following sections, the focus is drawn onto the linguistic character of experiences and knowledge claims, as well as the dialectic relationship between those experiences and objects. Thus, this view draws the focus onto examining and problematizing "the ways

in which the subject-world relationship is produced” (Mumby, 2011, p. 1149). The linguistic turn has shed the light on the interconnectedness between power and discourse, and how they are constitutively connected in the construction of social realities. The latter makes the linguistic turn vital for critical research, for it enables to explore how particular identities, meanings, institutions and object acquire a privileged status over others, and by the same token helps scrutinise the contested character of constitutive processes (Mumby, 2011). Disciplinary regimes are founded on systems of thoughts, and as I have discussed earlier language is a perquisite for thought. Thus, disciplinary regimes constitute themselves a specific interpretation of the world through language. For instance, Fox (1993) argues that in the context of biomedical sciences, healthcare professionals’ relationship with patient bodies follows a two stage process. First, they de-territorialise patient bodies following ‘*evidence-based*’ models of health and illness. Afterwards, they re-territorialise those bodies within the framework that match their conventional systems of thought. The aim of critical research is to deconstruct and challenge these conventional systems of thought. Thus, challenging the ‘natural’ and the taken-for-granted paves the way for alternative approaches of reconfiguring and reorganising processes and practices.

In conclusion, the linguistic turn is not a way of privileging the discursive over the material. At its core foundations is a commitment to decipher their mediated relationship. By acknowledging the linguistic character of the experiential and interactional, the distinctions between subjective and objective, discursive and the realist concepts, become obsolete. Indeed, language forms the objects of which we speak (Foucault, 1979), and therefore offers endless possibilities for interpreting the world (Fox, 2002). My focus on language is not an end but a starting point for a critique. As Kristeva puts it “semiotics can only exist as a *critique of semiotics*, a critique which opens on to something other than semiotics, namely *ideology*” (Kristeva, 1986, p.78, emphasis in original).

Before moving forward with the discussion on my analytical framework, I want to present two excellent examples of the practical potential of the application of a linguistically focused analysis. First, Potter and Wetherell (1987) provide a case, within social psychology, of the practical use of analysing discourse in the context of

healthcare, and more specifically the UK National Health Service. This example highlights the entwinement of the discursive and the material, yet they cannot be isomorphic or reducible to each other. When presenting their case on the NHS, Potter and Wetherell state:

“None of us has actually ‘seen’ the National Health Service – it is not the kind of entity that could be seen: it is geographically highly disparate and largely abstract. Yet we have conversations about ‘it’, read newspaper articles about ‘it’, and express opinions about ‘its’ future. One of the positive fruits of discourse analysis is to promote an informed critical attitude to discourse of this kind; to be more aware of its constructive nature and the close connection between the way textual versions of the world are put together and specific policies and evaluations are pushed.” (Potter and Wetherell, 1987, p. 175).

The second example is from Holt and Mueller’ research (2011), within organisation studies. They highlight problematic features of practices of attribution, within the context of tobacco industry. They draw the focus onto attributions of causality between smoking and health hazards such as cancer and blindness. Subsequently, they question practices of attribution of responsibility of the harm. As they put it:

“Scientists, for example, have established that smoking causes cancer, out of which knowledgeable awareness we are redefining things like responsibility (for example, at what points do tobacco firm managers’ responsibilities for harm dovetail with the responsibilities of smokers to themselves?) as well as investigating further material relations between things (for example, in which instances or at what point can we claim smoking induces blindness?). There is no end to such negotiation between established science and science in action, and over the equipmental norms and habits brought into relief by such negotiations. Neither language nor material conditions act as a final court of appeal, as things and the relations between them are always being discovered and reappraised” (Holt and Mueller, 2011, p.77).

In the next part of this chapter, I discuss foundations of Discourse Analysis, before delving in depth into one of its 'branches' – Discursive Psychology. Finally, I will present the key concepts, within discursive psychology, which I draw upon to map my analytical framework.

5.3. Discourse Analysis:

Within a constructionist stance, talk (what we say) and text (what we write) are considered central mediums of our relation to the world. Discourse analysis (hereafter DA) has been growing in popularity as an approach to scrutinise speech and writing. However, it is quite difficult to find an agreed upon definition of the word 'discourse', as it has been used in a variety of ways (Alvesson and Kärreman, 2000). Discourse Analysis has become such a wide church for analysing speech (written and oral) that Potter and Wetherell describe it as a field where "it is perfectly possible to have two books on discourse analysis with no overlap in content at all" (Potter & Wetherell, 1987, p. 6).

DA broadly refers to a style, approach or method of analysing talk and text. I mostly refer to speech and writing (or talk and text) as 'accounts', following Scott and Lyman (1968). Within DA, accounts are considered active participants in the process of the (social, cultural or historical) construction of reality, rather than a window to reality. Whereas some other methods for analysing language treat it as a neutral medium through which the researcher can access reality, DA is concerned with interpreting accounts as a form of action (Alvesson and Kärreman, 2000). There are different ways of 'doing' discourse analysis, which manifest in the variety of versions of discourse analysis. The differences usually lay in terms of (1) methods of analysis: some school of DA draw their methods from applied linguistics, while other take inspiration from conversation analysis, or patterns of language related to broader themes of social structure and ideological critique; (2) the way core theoretical constructs, such as 'ideology', 'power' and 'interests' are conceptualised; and (3) the way 'context' is conceptualised; from close-range (local-situational or 'micro') to long-range (historical, cultural or 'macro') approaches (Edwards, 2005).

Alvesson and Kärreman (2000) mapped the different versions of discourse analysis using two key dimensions: the meaning of context, and connection between discourse and meaning. The first dimension, 'the meaning of context', refers to the formative range of discourse and the assumptions about its scope and scale - from the localised to the historical. The second dimension, 'the connection between discourse and meaning', marks a distinction between a transient meaning on the one hand (which emerges from specific interactions), and a 'durable' meaning on the other hand (which transcends the specific interactional level, and proves to be more or less stable). Figure 8 below presents the details of this mapping.

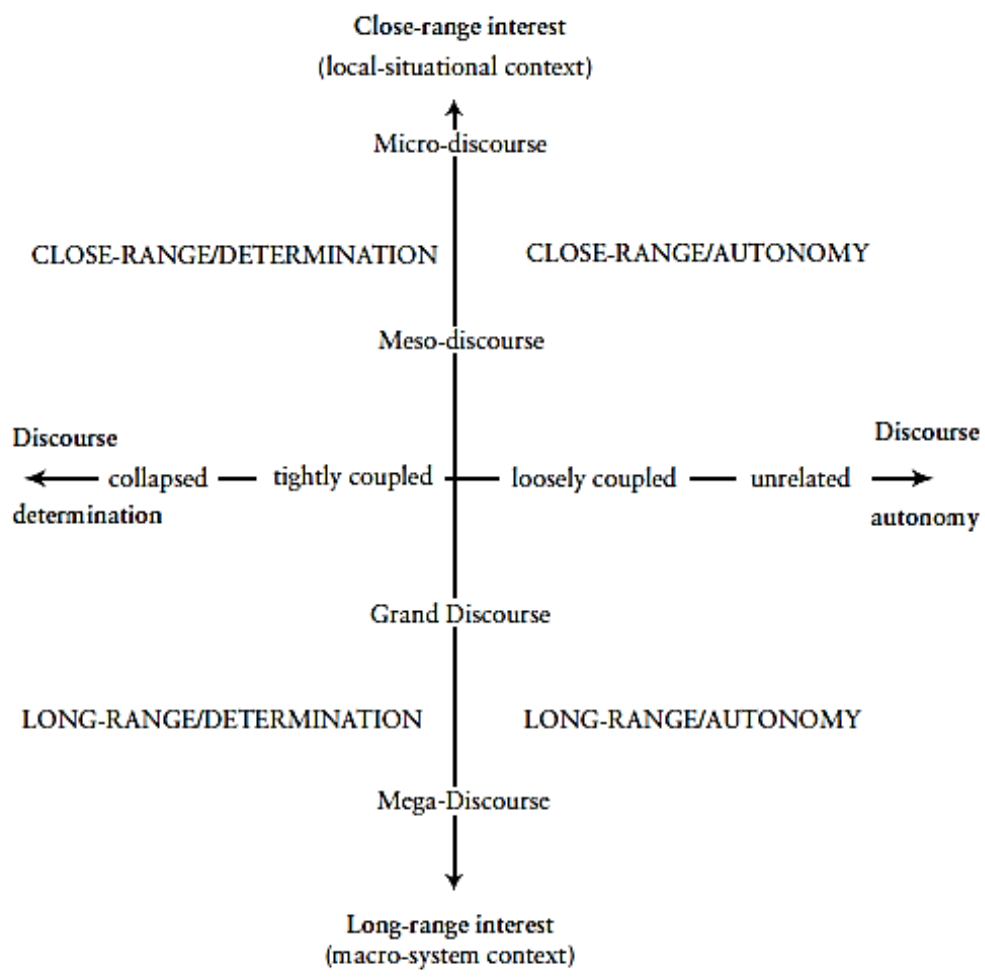


Figure 8: Elaboration of core dimensions and summary of positions in discourse analysis
Source: Alvesson and Kärreman (2000)

Alvesson and Kärreman (2000) problematise the process of ‘climbing’ the ‘*discursive ladder*’, from the localised to the historical contexts. They draw the focus onto the methodological difficulties related to the gradual progression from locally-situated ‘discourses’, to grandiose ‘Discourses’:

“How does one in empirical work proceed from encounters with texts (documents, interview talk, observed talk) to make summaries and interpretations of wider sets of discourses including aggregations of a variety of elements, an integrated framework of vocabularies, ideas, cognition and, interrelated with these, practices of various kinds? In short: To what extent – and if so, when and how – can we move from discourses to Discourse(s)?” (Alvesson and Kärreman, 2000, p.1146)

It is a question that I struggled a lot with through my research, particularly when approaching the data analysis. Nevertheless, I believe the analytical framework that I built is effective to *connect* (rather than ‘gradually travel’) what Alvesson and Kärreman called discourses and Discourses. I have combined three key concepts from Discursive Psychology for my analytical framework. Before moving to the analytical framework, I start by outlining the foundational principles of DP.

5.4. Discursive Psychology:

As I have mentioned in the previous section, Discourse Analysis is a broad church for approaches to analyse discourse. At first glance, one could think of Discursive Psychology (hereafter DP) as one of the separate strands of DA, which is simply concerned with the application of discourse theory and analytical methods to the field of psychology. However, DP constitutes itself a broad umbrella of discursive work within psychology. Its growth meant the development of different, and sometimes contradictory, stances and orientations (Wetherell, 2007). But before diving into the different branches, and the specific concepts I draw on for my analytical framework, I start by outlining the foundations of DP.

The starting point for Discursive Psychology is taking language as a 'topic', broadly exploring the ways in which people construct things within the psychological realm such as emotions, attitudes, memories and attributions. This aspect is the core foundational principle that distinguishes discursive psychology from traditional cognitive psychology, where language is viewed as a 'resource' revealing what is going on inside the mind or brain, thereby constructing concepts such as emotions, attitudes, memories and attributions as explanatory systems of the various psychological phenomena under study. By challenging this positivist view, DP is yet another expression of the linguistic turn across social sciences and humanities (Edley, 2001; Edwards and Potter, 1992; Harré and Gillet, 1994; Parker, 1992, Potter, 1996; Potter and Wetherell, 1987; Wetherell, 1998).

Discursive Psychology draws on a range of theories and intellectual resources. The most frequently associated with DP are: speech act theory and the work of Austin, Wittgenstein's philosophy, the work of Bakhtin and Voloshinov, Deconstructionism and the work of Derrida, ethnomethodology and conversation analysis, narrative analysis as well as post-structuralist discourse theories (with feminist post-structuralism having a rather large influence). Within DP, there is commitment to a view of discourse as *action oriented*. Discourse is analysed for what it constructs or achieves in the contexts of interactions: the focus is drawn onto what people '*do*' with language, and how various representations are constructed and oriented to action (Wiggins and Potter, 2008; Horton-Salway, 2001). The production of descriptions or accounts is considered as an activity itself, rather than a neutral reflection of other activities. Another unifying aspect of DP approaches is an anti-cognitivist stance (Edwards, 1997; Edwards and Potter, 1992). By unravelling the dialogical and distributed nature of everyday mundane interaction and collective sense-making, DP challenges cognitivism and its view of the nature of psychological phenomena (Billig, 1997).

In their seminal book 'Discourse and Social Psychology: Beyond Attitudes and Behaviour' that laid the foundations of DP as a distinct program of research, Potter and Wetherell (1987) outline ten stages in the analysis of discourse, which have influenced my research design. These stages are summarised in figure 9 below.

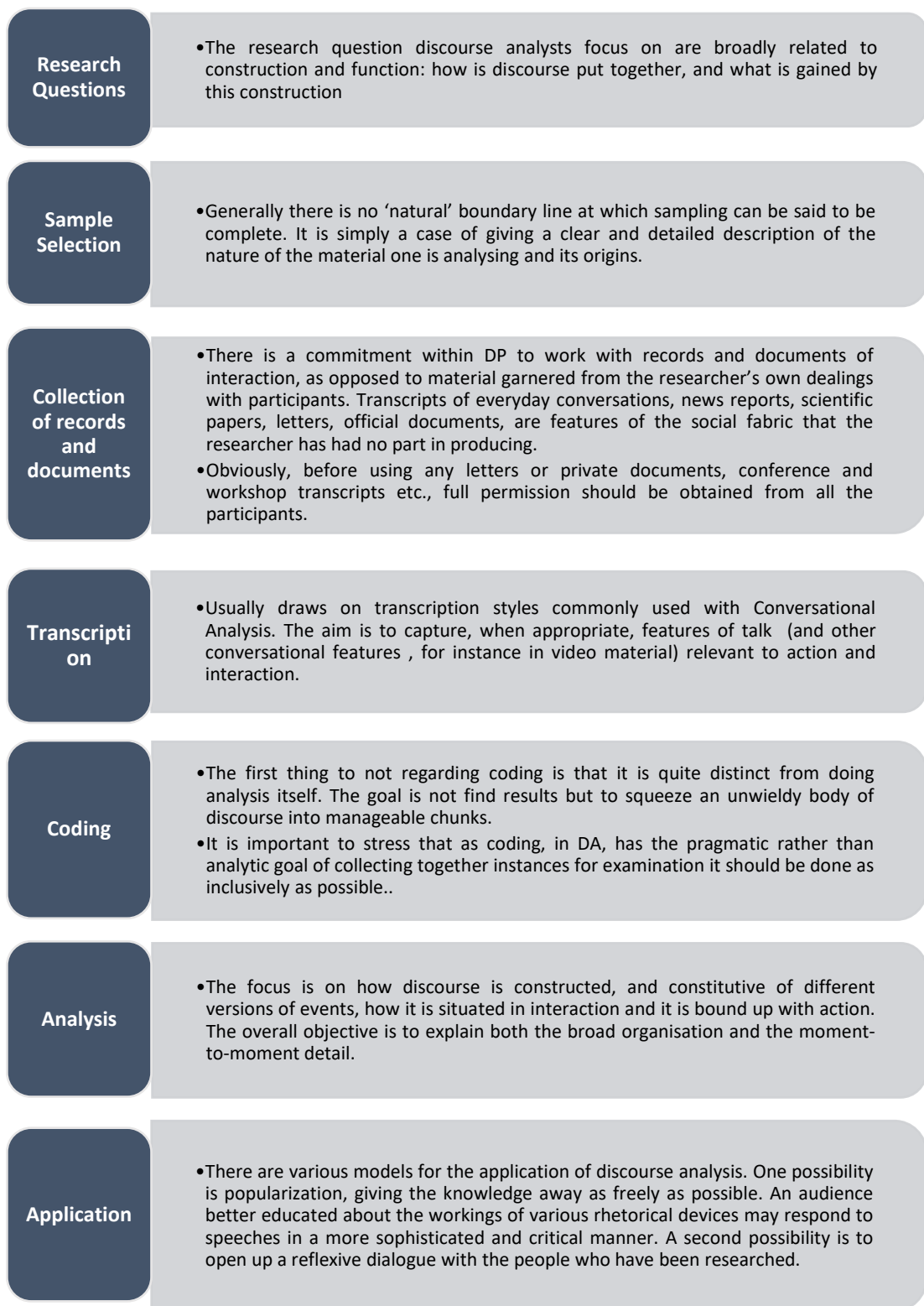


Figure 9: The different stages in the analysis of discourse

Developed from Potter and Wetherell (1987) and Wiggins and Potter (2008)

5.4.1. The various strands within Discursive Psychology:

As stated above, far from constituting a homogenous group of researchers representing a discrete strand of discourse analysis, discursive psychologists have taken up various stances and directions that have sometimes been contradictory. The main differences are located within the understanding of the meaning of context on the one hand, and the engagement with the fine-grain details of discourse versus a concern with wider instances of ideology on the other hand. While the meaning of context is fairly similar to the first dimension of mapping of Alvesson and Kärreman (2000) discussed earlier; the second dimension of their model, 'connection between discourse and meaning', has a different understanding here. This difference is mainly due the fact that the conceptualisation of ideology within DP differs from those of the so-called 'muscular' approaches such as Critical Discourse Analysis. The distinction between autonomous and deterministic discourse, as depicted in Alvesson and Kärreman model, is therefore obsolete in this case. I further elaborate on the topic of ideology in the next section.

Within Discursive Psychology, there is a strand that is rigorously engaged with the fine grain details of discourse in everyday conversation. Research within this 'branch' of DP draws heavily on conversation analysis and ethnomethodology (Potter, 2003b; Edwards and Potter, 1993; Wooffitt, 2005; Edwards, 2005), with a focus on analysing 'naturally' occurring interactions. Advocates of this branch conceptualise the 'social context' as a situated, interactive and local matter (Horton-Salway, 2001), relating this to a commitment to a fined-grained analysis of discourse. At first, this approach appears to be the answer to what Deborah Lupton (2012) considers being the main weakness of social constructionist' approaches to the social studies of health and illness. Lupton warns against the dangers of climbing too hastily the discursive ladder when analysing critical issues in contemporary medicine. According to her, the major concerns with such approaches are:

“Concentrating upon medical discourse at the macro-level; [for] making broad generalizations and avoiding a detailed examination of the micro-context in which discursive processes take place (such as the everyday experiences of people); [for] their insistence that discourses have general social effects,

regardless of social class, gender or ethnicity; and [for] not recognizing human agency and the opportunity for resistance” (Lutpon, 2012, p. 10).

By the same token, this focus on the interactional would make this strand of DP a perfect fit, when considering the methodological issues associated with “a too grandiose and too muscular view on discourse” (Alvesson and Kärreman, 2000, p. 1145), and engage in a further contemplation at the level of talk and text.

However, by setting boundaries around the situated and interactional, this branch of DP has been criticised for its lack of concern with issues of ideology, and for overlooking the wider cultural and historical contexts. Some proponents of this strand of DP defend this aspect by drawing attention to the fact that a search for ‘wider social context’ would lead to “the analysis of yet more situated reality construction” (Horton-Salway, 2001, p.183). Nevertheless, this limitation makes this branch of DP, if used on its own, ill equipped for developing a critical approach. Therefore, I draw on concepts from the Discourse Action Model within this strand, as developed by Edwards and Potter (1993), and combine it with two other concepts within Discursive Psychology: Ideological Dilemmas as conceptualised by Billig et al (1988), and Positioning Theory as developed by Davies and Harré (1990). I demonstrate in the next section how these three concepts fit as an ensemble, and constitute a very suitable approach to link analysis of micro processes of social interaction to the broader historical context and consideration of ideologies and subject positions within these.

Other strands within the broad church of Discursive Psychology provide analytical tools that are useful in identifying the complex, historically developed organisation of ideas, and yet emphasise the flexible requirements of situated practices. The advantages of theorising flexibility can be appreciated, for instance, in the reworking of ideology in the domain of practice by Billig and colleagues (1988). The researchers, within this strand, have stepped outside the boundaries placed by conversation analysis, through considering interactional sequences as embedded with some sort of historical context (Billig, 1995; Dixon and Wetherell, 2004; Edley, 2001; Edley and Wetherell, 2001, 2014). This loose grouping, has sometimes been labelled as *critical discursive psychology* (Edley, 2001, Wetherell, 2007). Some of its proponents have continued pushing the use of certain original concepts of discursive psychology such

as 'interpretative repertoire' (Gilbert and Mulkay 1984), and combine it with more 'macro' discourse approaches including narrative analysis (Wetherell, 1998; Edley and Wetherell, 2001).

In the following section, I provide a brief overview of the timid literature, within organisation and management studies, that draws on concepts from DP. I identify some of the specific stands they have drawn, as well as the methodological gaps; before moving onto elaborating on the analytical framework that I developed for this study.

5.4.2. Discursive Psychology in Management Studies:

Symon (2005) called for a need to focus, within organisation and management studies, on the importance of scrutinising how various discourses are drawn upon so as to legitimise practices, accounts or win arguments. Paralleling Symon's argument, Whittle and Mueller, who have been strong advocates of Discursive Psychology within organisation studies, argue for its contribution in studying practices within a wider institutional context. As they put it: "DP does not view discourse as a purely individual phenomenon: it is intimately linked to the performance of wider roles, identities and institutions" (Whittle and Mueller, 2010, p. 428). Whittle and Mueller call for further research deploying Discursive Psychology methods in order to realise its full contribution to organisation and management studies, considering the multitude of themes addressed within DP that can be of interest to this scholarship. In a sense, this research is methodologically speaking an answer to the above-mentioned calls.

There has been a modest interest in Discursive Psychology within organisation and management studies in the past few years. This work has drawn on various concepts and strands of DP, and has deployed these in a variety of context. For instance, there has been a growing scholarship focusing on the notions of interest and rhetoric at an interactional situated level, drawing on analytical concepts informed by the Discourse Action Model (as developed by Edwards and Potter, 1993). Examples for this research are the work of Whittle and Mueller (2010) in exploring the role of interest-talk in reproducing, or in certain cases questioning the legitimacy of, institutional structures at the interactional level in the context of a UK public-private partnership. Other

research has focused on the concept of interest-talk within the context of management research (Whittle et al., 2014). They explored issues related to practical aspects of 'doing' research, such as gaining access, building 'trust' with the research participants. In another study, Whittle, Mueller and Mangan (2009) have argued for a focus on contradiction at an interactional situated rather than institutional level. Drawing on notions of rhetoric within DP, they explored how the different actors draw on different interpretative repertoires to depict themselves and their actions in such a way so they can win arguments.

The work of Samra-Fredericks (2003, 2004, and 2005) is another example of a focus on the fine-grain detail of discourse in management studies. Although not referring to her framework as sitting directly within discursive psychology, Samra-Fredericks uses tools that are very close to those used within a more Edwards and Potter' (1992) style of DP, even making several references to the work of Potter in some of her papers (see for example Samra-Fredericks, 2004). She uses a combination of ethnographic and ethnomethodological/conversation analytic tradition to study strategy-as-a-discourse. Her analysis highlights the power effects of strategy discourse in shaping participants accounts in mundane interactions.

Other scholarship within organisation and management studies have combined concepts within Discourse Psychology with those from 'Foucauldian' Discourse Analysis. This scholarship tends to draw on the work of Wetherell and colleagues; mainly those interested in the Foucauldian approach in studying issues of power and subjectivity. Dick and Collings (2014) study of strategy-as-discourse is a good example of such scholarship. They explored the relationship between discourse and power, by incorporating a more discrete and localised view of power. This framework allowed Dick and Collings to extend the initial work of Samra-Fredericks cited earlier. Effectively, by borrowing the notion of '*hindrance and stumbling block*' from Foucault (1978), they uncovered the presence of '*points of instability*' within the strategic discourse itself, which in turn constitute rhetorical resources for resistant voices. Another pioneer work within organisation studies that explored the combination of DP and Foucauldian analysis is the work of Dick (2005). She uses an interesting framework mainly drawing from Critical Discourse Analysis as informed by Fairclough

(1992), and combining it with Foucauldian notions of power, as well as concepts from DP (particularly those related to identity localisation in social settings). Dick explores the concept of '*dirty work*' to problematize the concept of 'role' in studying 'identity', and reveals the different social and moral orders that shape occupational identity within specific interactional contexts. Nevertheless, the epistemological cohesion of this work could be questioned. Critical Discourse Analysis traditionally views ideologies as dominant systems having a discursive effect in mind (hence the critical realist epistemological stance), and it appears to be a rather un-cohesive mix and match with the anti-cognitive stance of discursive psychology. Dick calls for further research exploring disruption and resistance to ideologies in various interactional contexts, which confirms the limitations of this framework in studying situated accounts. Nevertheless, this study was one of the pioneer works to explicitly implement concepts from Discursive Psychology in an organisation studies research. The latter work of Dick (Dick, 2013, 2014; Dick and Collings, 2014) integrated notions from DP in a more cohesive way, borrowing for instance notions from Critical Discursive Psychology (Dick, 2013).

Other researchers, in management and organisation studies, have taken a narrative approach in combination with Discursive Psychology. An example of this strand is the work of Brown, which has given a particular attention to narratology, combining it explicitly or implicitly with notions from DP. For instance, his paper with Thompson (Brown and Thompson, 2013) advocated for a study of strategy-as-practice with a greater attention to narratological concerns. By studying storytelling as a key tool for strategists, they present the perspectives through which narratology can assist the strategy-as-practice research agenda.

Some recent work of Dick combines concepts from DP with those of narrative analysis. Drawing on concepts from the so-called *Critical Discursive Psychology*, she develops an understanding of what constitutes experiences and practices as sexist, by exploring the reproduction and resilience of sexism as a social fact (Dick, 2013). She scrutinises the interpretive duality within the sexism discourse (sexism as an objective fact versus sexism as a subjective experience). Dick's work takes a narrative turn, and draws on concepts from critical discursive psychology, as she argues that the researcher, within

'traditional' discursive psychology that focused on the situated context only, have missed the point of connecting the role of their own discursive practices, as an actor within the research process, to the construction of sexism as a category. She stresses how narrative construction depends on the interactional context of storytelling, as well as its power asymmetries. Other work by Dick that took a narrative approach, has explored the professional part-time work with a focus on 'micro-political' resistance (Dick, 2014). She explores how part-time work transgresses the traditional dominant workplace norms, and how resistance can be manifested through the refusal of peripheral work for instance. Dick's analytical framework brings to the fore the notion of subject positions. She draws on feminist poststructuralist Weedon and her argument on the '*decentering of the subject*'; where identity is best understood as temporary positions made available to individuals to occupy, within a wide network of discourses (Weedon, 1987). Advocated by Rom Harré, positioning theory has gained increasing popularity within some strands of Discursive Psychology. Despite the strong parallels between the use of the notions of subject-position and positioning within feminist poststructuralist theory and DP, Dick does not make any reference to DP in this paper, neither the work of Harré and colleagues. I explain in detail in the next section how the concept of position and positioning is central to my analytical framework, and how it perfectly bridges between the 'micro' and 'macro' perspectives within Discursive Psychology.

Finally, Hopkinson (2015) combines various concepts within DP, and presents the *metaphor of graffiti* as an alternative to the metaphor of network-as-picture that has traditionally been used to conceptualise sense making within business networks. Hopkinson draws on the conceptualisation of *ideologies as prevailing truths or conventions* (as informed by Harré (2002) cited by Hopkinson (2015)). This conceptualisation of ideology as a resource for constructing accounts, highlights the potential for ideologies to be reproduced but also negotiated and resisted in interaction. This approach blends perfectly with the ideological content of graffiti; particularly when considering the analytical themes that the metaphor of graffiti brings to sensemaking such as ephemerality and ideological struggles. Hopkinson's study draws attention to the importance of scrutinising the content of the 'say', the

right to 'say', as well as the political nature of the construction of a relevant contributor/contribution. This approach is probably the closest to the analytical framework that I utilise for this research. However, the linkages between ideologies as conventions, and how individuals actually draw up patterns of these conventions, to locate themselves within the discourses, was not always evident. While there were hints to attributions of obligations or duties, as portrayed in the example of the shift from the use of the pronouns 'I' to 'you' in some key accounts, the fine-mechanics of these attributions in connection to the wider ideological and historical context were not always clearly articulated. I argue that the concept of positioning (particularly through the focus on the linguistic device of indexicality) as used by Dick (2014) is helpful to have a neater bridge between micro-discursive practices and wider Discourses.

In the next section, I present my analytical framework, which connects three core DP concepts: Discourse Action Model, Ideological Dilemmas and positioning theory.

5.5. Analytical Framework:

In this section, I present the analytical framework for this study. First, I map and discuss the framework, before dissecting each part of it, and the three key concepts that I bridge to build it, namely: Discourse Action Model by Edwards and Potter (1993), Ideological Dilemmas as conceptualised by Billig and colleagues (1988), and Positioning Theory as developed by Davies and Harré (1990). The analytical framework is mapped in figure 10 below.

At the centre of my analytical framework is the notion of subject positions and positioning. I study identity as temporary positions made available to individuals to occupy, within a wide range of discourses. These subject positions represent temporo-spatial, as well as moral locations, hence the tri-dimensional plotting. They represent the vantage point from which people see the world, and make sense of the story lines, visuals and concepts. These positions are made available within the discursive

practices of the individual as well as the 'other', and emerge through social interaction as a constantly work-in-progress product.

The function of *indexicality* is key to the process through which individuals draw-up from the temporo-spatial and moral locations that constitute certain subject positions. It represents a linguistic property of pronouns, which I explore in detail in the part on positioning theory later in this section. What I would like to stress for now is the role of indexication in bridging between the micro-detailed analysis of the discourse action model on the one hand, and the study of ideology as ideological dilemmas on the other hand. Subject positions are made available by various discourses, with a focus in this study on genetic and neoliberal discourses. The subject-position is drawn from a temporo-spatial as well as moral locations. Individuals draw up subject positions and *indexicate* patterns of lived ideologies from what they are told by experts or by their peers from their support groups (physical and virtual), read online, make sense of within the range of information available, as well as commonsensical notions, and so on.

Heading bottom-right of the diagram (figure 10 below), the indexication happens in interaction, with the positioning of the other within a specific location; thereby attributing a specific set of rights and duties. Factual discourse, management of stake or interest, accountability in reported events represent discursive strategies (amongst others) that individual use in interaction to attribute blame, causality and responsibility to the other (the following parts of this section will dissect the discourse action model and its various elements). The function of indexicality locates the individuals within these interactions, and help locate matters of accountability within the moral order.

Heading top-left of the diagram (figure 10 below), the indexication happens in interaction with 'lived ideologies' (which represent a set of beliefs, values and practices that are dominant within a society or culture – a concept which I will explain in detail later in this section). Lived ideologies provide individuals with resources for speech, which can be contradictory sometimes, and constitute what Billig (1992) calls the '*kaleidoscope of common-sense*'. They are adopted, rejected and negotiated in everyday speech, and through thinking. This means that the process of thinking, and

the holding of opinions, is not only located at the interactional and local level, but also in its wider social context. In 'arguing' with ideology, individuals indexicate specific patterns which shape the locations of their subject positions. Finally, the lived ideologies feed into the intellectual ideologies (which represent integrated, coherent and dominant sets of ideology – again, I shall explore this in detail later in this section), and vice-versa.

This framework also allows me to study how subjects locate each other, as well as the fine grain of their interactions. Indeed, within the choice of available subject positions comes a range of right and duties, and subsequently the associated responsibility and accountability. The interactional (as informed by the discourse action model) is very much entwined with the historical and cultural positioning. It is the function of indexicality that allows positioning theory to bridge between the micro detailed analysis of the DAM and the study of ideology, by drawing the focus on individuals experiencing themselves as contradictory. Finally, the 'positioning' is the process of the discursive construction of personal narratives, and comes as result of all the aforementioned processes. It happens in interaction, and functions as a device to construct actions in a way that is intelligible to both the speaker and the audience (Tirado and Gálvez, 2007). By jointly producing storylines, selves are located in conversations through the discursive process of positioning. This resulting personal narrative is an ephemeral construction and competes with other narratives (personal, collective, and institutional).

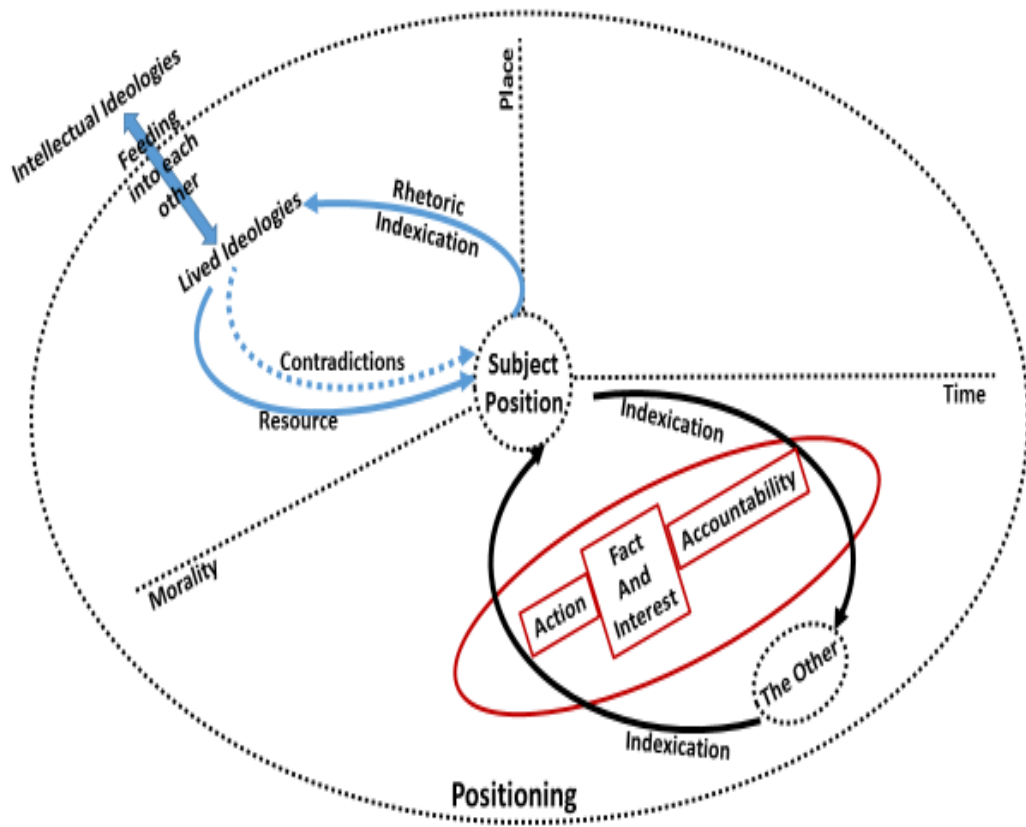


Figure 10: Analytical framework
 Source: Own development

5.5.1. The Discursive Action Model of description and attribution:

In this section I dissect a specific part of the analytical framework as displayed in figure 11 below.

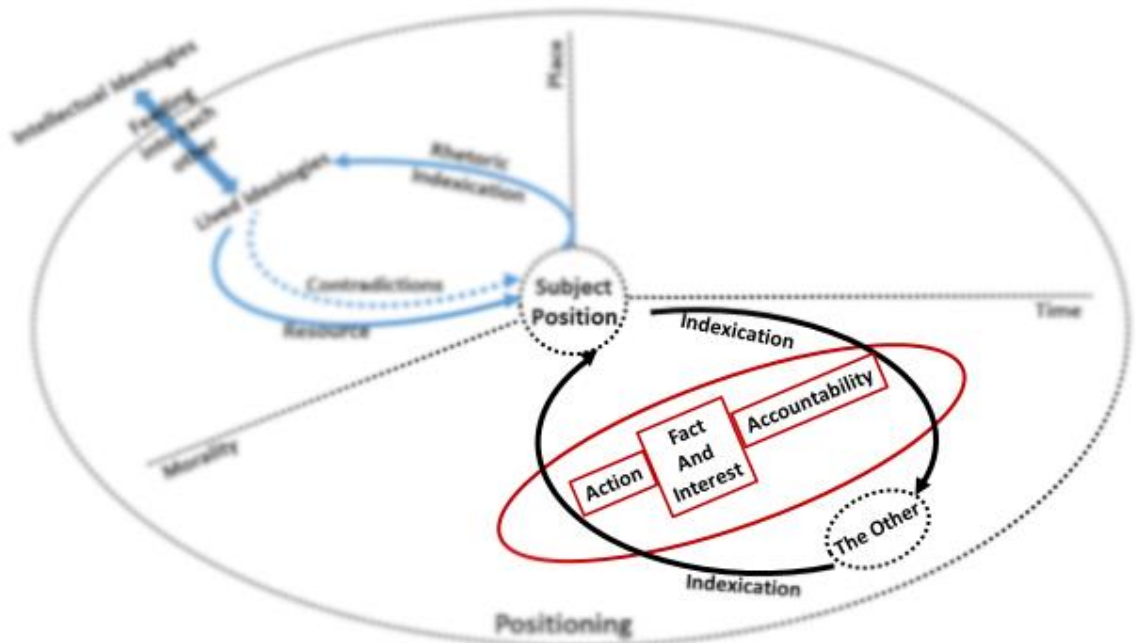


Figure 11: Analytical framework – Focus on Discourse Action Model
Source: Own development

Edwards and Potter (1993) developed the discursive action model (hereafter DAM) to link various features of individuals' discourses together in a systematic manner, with a focus on action ie. how these features 'work' in everyday social interaction. With that being said, DAM considers elements such as mind, identity and reality as matters of representation, not 'things' in themselves (Edwards and Potter, 1993). The focus of DAM is on action, not cognition (which is, as discussed earlier, one of the foundational principles of Discursive Psychology).

One of the core concerns of DAM is the way reports are constructed in such a way that prevents accounts from being perceived as biased, or motivated by particular ideological discourses. Blaming is performed through descriptions of the 'world-as-it-is' (Potter and Edwards, 1993) and the straightforwardness and apparent 'out-there-ness' of the speakers' accounts; rather than only overt blame attributions (Sneijder

and Molder, 2005). The attributions of blame and accountability are linked, and performed through seemingly 'factual' descriptions. As Potter and Edwards put it: "people *do* descriptions and *thereby do* attributions" (Edwards and Potter, 1992, p.103, emphasis in original). Concepts such as causality, agency and accountability are analysed in the way that they are managed, and made relevant in talk and text through factual descriptions (Potter, 1996; Tileagă, 2006), rather than as an explanatory resource.

The DAM is divided in three main themes: action, fact and interest, and accountability. Each theme is again divided in three parts each. The model is outlined in figure 12 below.

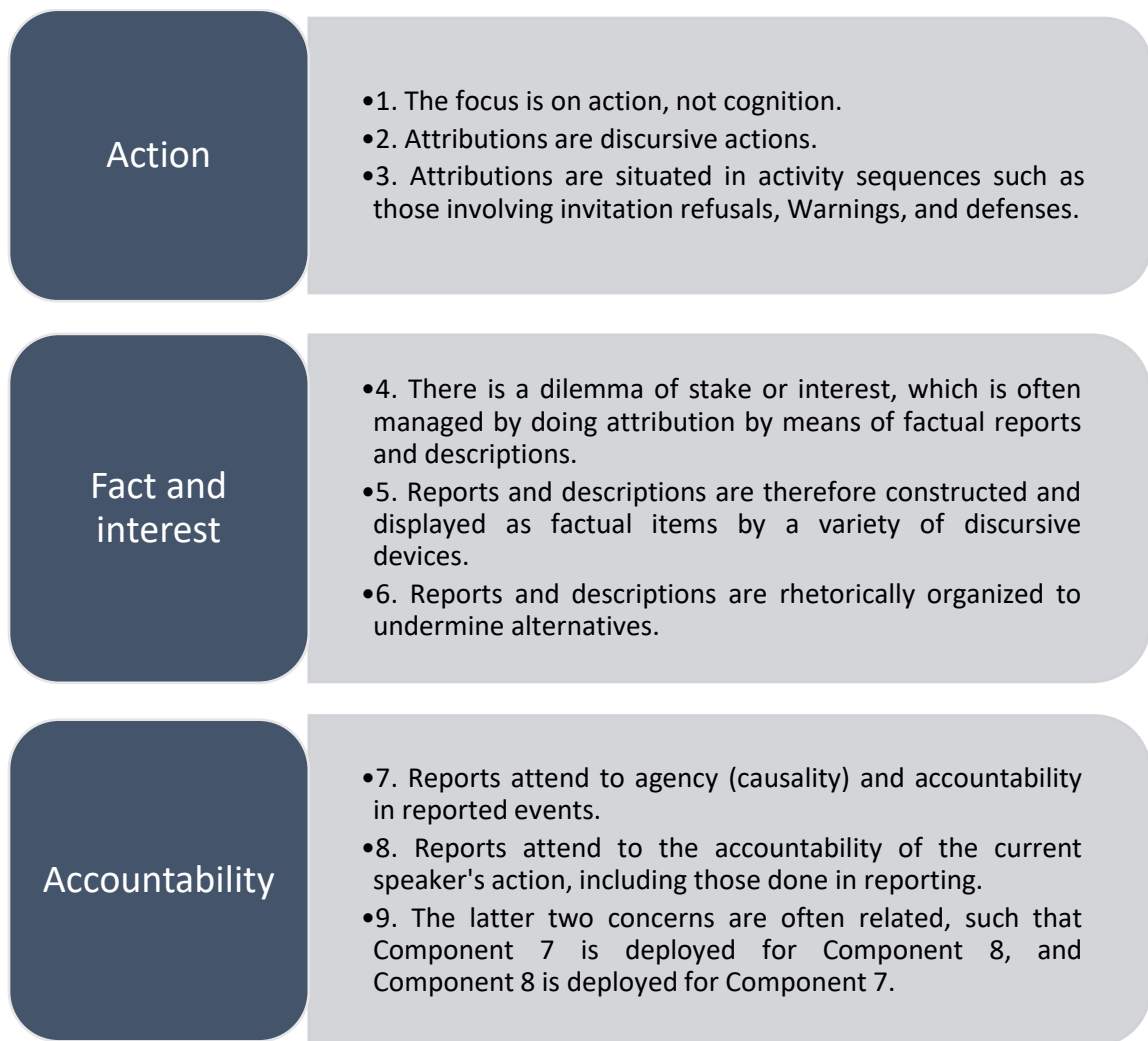


Figure 12: Discursive Action Model of description and attribution

Adapted from Edwards and Potter (1993)

5.5.1.1. Action:

The DAM focus on action performed through discourse. DAM treats talk and texts as forms of action. While traditional cognitive psychology focuses on how mental processes shape individual's perception and understanding of the world, therefore influencing subsequent action, DP focuses on how representations are constructed within, and constitutive of, social practices. DP is "concerned with what people *do* with their talk and writing (*discourse practices*) and also with the sorts of *resources* that people draw on in the course of those practices (the devices, category systems, narrative characters and interpretative repertoires which provide a machinery for social life)" (Potter and Wetherell 1995, p. 81). In other terms, within DAM, language

is analysed as a social practice, and not as a tool for description emerging from general cognitive abilities. Attributions are reconstructed in terms of discursive practices with a focus on the allocation of responsibility, causality and blame; rather than the traditional attributional ontology of mental heuristics and processes. Therefore, I analyse talk and texts as discursive practices and constructions, rather than mirrors of emotion and cognition. As informed by the DAM, my analytical focus is the way discourse is constructed, within the interactions amongst the BRCA gene mutation' community, to perform a specific social action.

5.5.1.2. Fact and interest:

The second theme of the DAM is concerned with how specific descriptions of a phenomenon can be established as factual and independent of the speaker's personal interests. Edwards and Potter (1993) have coined term '*dilemma of stake or interest*' to describe the rhetorical strategies surrounding these descriptions. The focus of the analysis is the way individuals use reports, descriptions or versions to manage any form of interest that could undermine the credibility of their claim on the one hand, and increase their personal accountability on the other hand. Therefore, the focus within this theme is the process through which factual accounts are given a sense of '*out-there-ness*' (Woolgar, 1988).

The movement within the analytical focus here is from attitudes as mentally encoded, to practices through which (1) evaluation is performed and (2) evaluative positions are attributed in the process (Potter et al, 1993; Potter and Wetherell, 1988, Pomerantz, 1984). One way to successfully manage the dilemma of stake and interest is through factual descriptions, and the rhetorical organisation and production of versions that can be accepted as factual. Successful constructions of a version of a narrative as 'factual' makes the claims harder to undermine, and by the same token destabilises alternative versions (Billig, 1991).

I elaborate on rhetorical strategies further when discussing the two other concepts that constitute my analytical framework alongside DAM. Particularly Billig and colleagues' conceptualisation of ideological dilemmas and its linkage to rhetorical thinking (Billig et al., 1988).

5.5.1.3. Accountability:

The final theme in the DAM is accountability. The DAM highlights how the construction of a particular version of an event is formulated to imply responsibility. Edwards and Potter (1993) distinguish two levels of accountability: The reported event itself, and the current speaker who is performing the report. The latter includes the speaker's own actions in the performance of their speech, the credibility of their accounts, as well as the interactional sequences within the talk's occurrence. As Edwards (1997) puts it "(...) when people describe events, they attend to accountability. That is to say, they attend to events in terms of what is normal, expectable, and proper; they attend to their own responsibility in events and in the reporting of events" (Edwards, 1997, p. 7).

When formulating their accounts, individuals are managing issues of stake or interest as I have explained in the previous theme; and by doing so they are routinely dealing with matters of agency, accountability and responsibility (Potter and Edwards, 1992). This can be performed through the formulation of hesitations and doubts for instance. As I will demonstrate in the analysis chapter, the legitimisation of these (hesitations and doubts) can function as a device for reducing the accountability of the individual in a decision making situation. My analytical focus is, therefore, on the way accountability is constructed and negotiated in social interactions. Accountability can also be managed through the discursive construction of subjectivities and the positioning of the self and the other within a moral order. Moral accountability will be discussed in further detail in the section dedicated to the third concept of my analytical framework – positioning theory.

5.5.2. Ideological Dilemmas:

In this section I dissect a specific part of the analytical framework as displayed in figure 13 below.

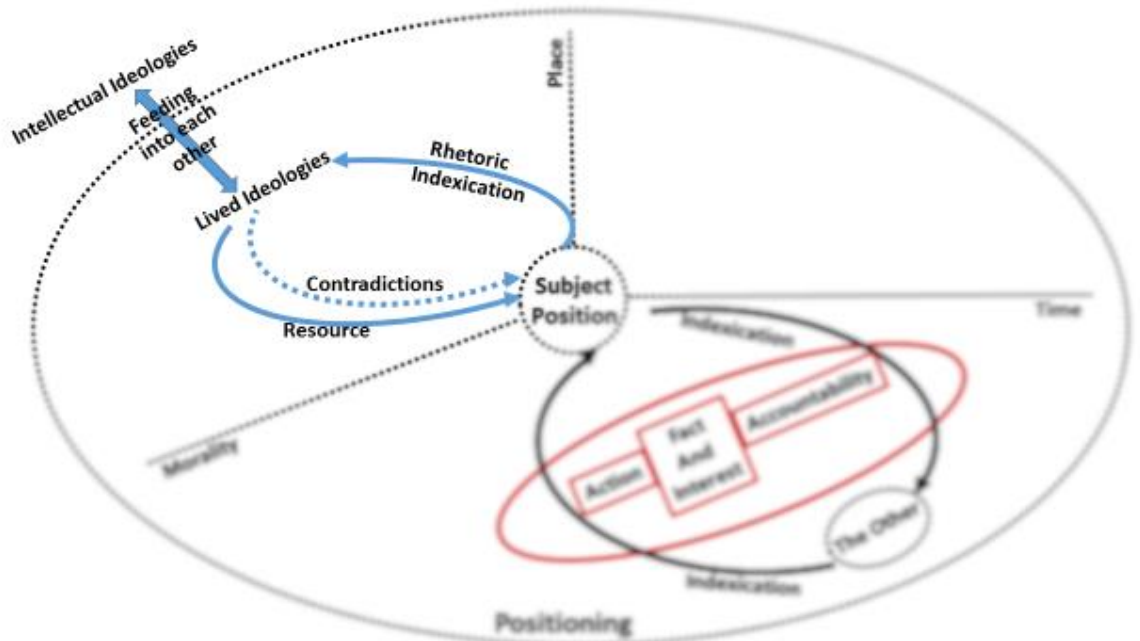


Figure 13: Analytical framework – Focus on Ideological Dilemmas
Source: Own development

As a result of its influences by ethnomethodology and conversation analysis (CA), the Discourse Action Model is extremely useful at magnifying the details at the interactional level, and drawing attention to minutiae that can be overlooked by other methods. In this fine-grained analysis of discourse, the 'social context' is conceptualised as situated, interactive and local matter (Horton-Salway, 2001). However, the DAM has been critiqued for its lack of concern with critical issues of ideology, and overlooking the wider cultural and historical context (see for example Edley, 2001; Wetherell, 1998, 2007; Korobov, 2001). Indeed, individuals have history that they bring into everyday conversation, and even the words, that they utter, have their own history as well, which stresses the moral dimension of language in use. As

Billig and colleagues put it: "many words are not mere labels which neutrally package up the world. They also express moral evaluations and such terms frequently come in antithetical opposites which enable opposing moral judgements to be made" (Billig et al., 1988, p. 16).

Developing a critical approach requires more than focusing solely on an interactional analysis of speech acts; these need to be linked to wider instances of ideologies. To investigate the ideological implications of practices of attributions of blame and responsibility requires going deeper than simply documenting their existence. There is a need to explore how an explanation of a social event fits into wider patterns of ideology (Billig et al., 1988). In order to stay consistent with my epistemological stance, I decided to avoid 'top-down' approaches such as Critical Discourse Analysis (hereafter CDA), as it conceptualises the context as a yet more situated reality construction, with ideological systems having a discursive effect 'in' mind (Korobov, 2001; Bamberg, 1997). Billig's conceptualisation of ideological dilemmas appeared to be more appropriate, and a perfect fit for my analytical framework.

Billig (1991) looks at the interplay between ideology and rhetoric. He argues that thinking is both rhetorical and ideological. The individual, who Billig calls the '*subject of ideology*', is not a docile body imprinted by ideologies and incapable to react (as it can be sometimes depicted in CDA research). Instead, the 'subject' of ideology is "a rhetorical being who thinks and argues with ideology" (Billig, 1991, p.2). This means that the process of thinking, and the holding of opinions, is not only located at the interactional and local level, but also in its wider social context (I have established earlier that I do not, in this present research, consider thinking as occurring 'in the mind'). Thus, notions of time and place, but also morality, take a further importance within the study of interactions when considering the wider context.

Rather than conceptualising ideologies as entities, existing independently, and exerting effects on individuals, Billig et al. (1988) suggest to view them as '*lived ideologies*' when analysing everyday talk. They coined the term '*lived ideologies*' in contrast to '*intellectual ideologies*', which represent a more traditional view of ideology as represented in the prevailing Marxist conceptualisation of ideology. Within the '*Intellectual*' view, ideologies appear to be integrated and coherent sets;

this cohesion being a determinant factor for the success of their domination (Edley, 2001). While not refuting these forms of ideology, Billig and his colleagues suggest that there is another type of ideology, and drew a conceptual distinction between *'intellectual'* and *'lived'* ideologies. *Lived ideologies* are constituted of a set of beliefs, values and practices that are dominant within a society or culture. Billig (1991) argue that they represent cultural products themselves. In everyday speech, they are traditionally labelled *'common sense'*, and are composed of the maxims, values, idioms, commonly held opinions, and so on. Thus, common sense does not only have a history, but also possesses functions which are related to the present. Provided common sense is conceptualised as a form of ideology within this view, its functions are, therefore, intertwined with patterns of domination and power. Unlike the *'intellectual'* branch, *'lived'* ideologies do not represent integrated and coherent sets. On the contrary, Billig and colleagues describe them as characterised by inconsistency, fragmentation and contradiction. Provided their nature, lived ideologies provide speakers with resources for speech that can be contradictory, or what Billig (1992) calls the *'kaleidoscope of common-sense'*. *'Lived'* ideologies are adopted, rejected and negotiated in everyday speech.

Billig and colleagues have coined the term ideological dilemmas in order to explain how speakers struggle, make sense of, and deploy commonsensical thinking in order to construct rhetorically robust claims, or win arguments. Rhetorical formulations are created by and within ideology. By the same token, the rhetorical reproductions of commonsensical thinking contributes to the continuing history of dominant ideologies. However, these reproductions are not mere repetition; they shape ideology. As Billig (1991, p.22) puts it:

“Yet, the traditions of ideology are not constant, for that they are the sum of such ideological moments, each one stretching back into the past as it opens out into a rhetorically uncertain future. Thus, the past does not control the present to the point of insisting upon its own exact reproduction. Each echo is itself a distortion, for none can be a perfect repetition of what was already a series of repetitions. No two contexts are exactly identical, and, therefore, no

two utterances can have precisely the same meaning. Each repetition will be a creation, bringing the past towards its future”.

The concept of ideological dilemmas have been applied in various contexts such as: the use of metaphors in political discourse (Billig and Macmillan, 2005), prejudice and moral exclusion (Tileagă, 2014), conspiracy theories as a form of ideological explanation (Byford, 2014), and ‘banal nationalism’ and what constitutes nationhood (Billig, 1995), just to name a few. Within this perspective, ideology and rhetoric are interconnected. This proves to be helpful in linking the details of micro processes of social interaction, as elucidated by the DAM, to the broader historical context and movements of ideology.

The linkages between rhetoric and ideology, as informed by Billig’s ideological dilemmas, makes it a highly compatible method in combination with the DAM, in order to escalate the analytical ladder from the fine details of everyday social interaction to a wider cultural and historical dimension (or in other terms from micro to macro context) . There is also an epistemological compatibility that wouldn’t have been really possible with other approaches to study ideology, such as CDA. As stated earlier, the conceptualisation of ideology within CDA makes the domination of the governing bodies of the society as almost natural or inevitable, with ideological systems having a discursive effect in mind (Korobov, 2001; Bamberg, 1997).

Nonetheless, I am still missing at this stage robust analytical tools to conceptualise subjectivity, to complete my analytical frameworks. While Billig’s ideological dilemma helps bridging the interactional and cultural historical, it does not say much about how individuals position themselves within the ideological fields, and the construction of subjectivities. The only positioning available is the individual as a subject of ideology (as conceptualised by Billig), which is a result of their own rhetorical thinking and argument with ideology. In order to have a robust framework, I need an analytical method that helps demonstrating the fine mechanics of the construction of subjectivities, while still being epistemologically compatible with the concepts of DAM and ideological dilemmas. This final piece of my theoretical framework is positioning theory, which has been introduced in discursive psychology by Rom Harré.

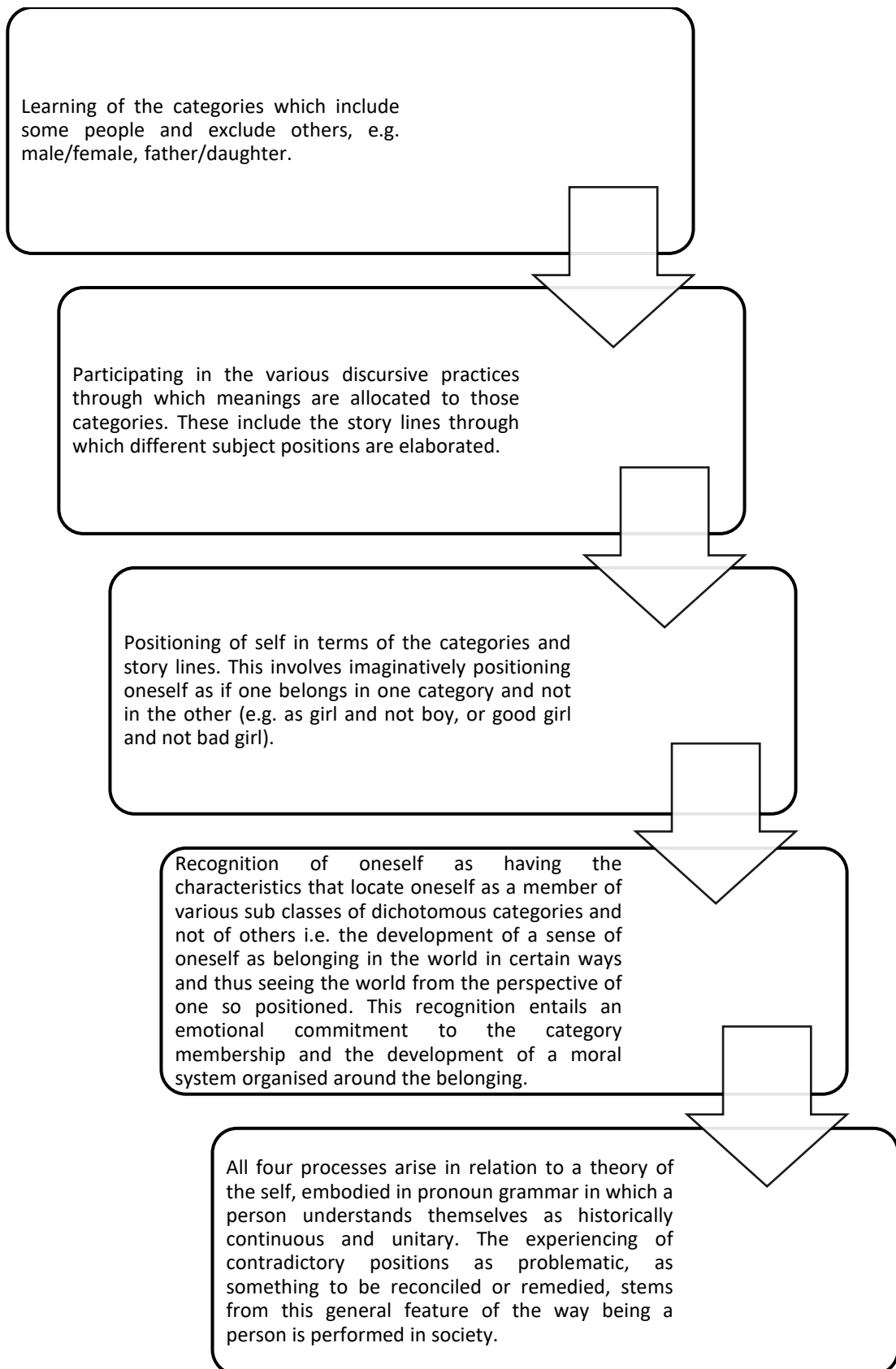
5.5.3. Positioning Theory:

An important step to study the practices surrounding the consumption of preventive solutions for breast and ovarian cancer, is to first understand how the at-genetic-risk subjectivity is constructed; or what it means to be at-genetic-risk for the individual as well as the *'other'*. In order to understand the concept of selfhood, Harré and Harris propose to replace the problematic question of *'what is the self?'* with "What is the sense of the self; the sense of personal identity, and how is it expressed?" (Harré and Harris, 1993, p. 111). This reformulation of the question shifts the focus from a conceptualisation of selfhood that focuses on static, formal and ritualistic aspects (which is common within the concept of *'role'* in the study of selfhood), to one that emphasises the dynamic aspects of interactions. The movement from a conceptualisation of self as a substance (that can be unravelled through research) to an investigation of a sense of self, appears therefore to be more appropriate to the present research, and I explain how it fits within my framework in detail in this section. As Harré and Harris put it: "(to) have a sense of self is have a sense of place, of time and of responsibility of one's actions" (Harré and Harris, 1993, p.113).

The concept of position and positioning has been introduced in Discursive Psychology by Davies and Harré (1990) to study selfhood. Within positioning theory, a subject means "the series or conglomerate of positions, subject-positions, provisional and not necessarily infeasible, in which a person is momentarily called by the discourses and the world he/she inhabits" (Smith, 1988). Thus, a *'subject-position'* represents a temporo-spatial, as well as a moral, location. It represents the vantage point from which the person sees the world, and makes sense of the story lines, visuals and concepts. *'Positioning'* represents the discursive construction of personal narratives. This positioning happens in interaction, and functions as a device to construct actions in a way that is intelligible to both the speaker and the audience (Tirado and Gálvez, 2007). By jointly producing storylines, selves are located in conversations through the discursive process of positioning. Put differently, subjectivities, within positioning theory, emerge through social interactions, as a constantly work-in-progress product (or construction) of the various discursive practices in which individuals take part.

Harré (2015, p. 2) defines positioning theory as “an approach to the analysis of the patterns of interpersonal actions created by the individuals engaged in the unfolding of a social episode in which rights and duties are created and maintained ad hoc through discursive interactions between the actors present and engaged in the episode”. The concepts of ‘rights’ and ‘duties’ play a major function in the study of morality in everyday life. While distinct, these concepts are strongly related, as they bridge between vulnerabilities on the one hand, and capacities and power on the other hand (Harré, 2015). Rights and duties appear, therefore, to be strongly linked to accountability and responsibility. Through the actors’ engagement in discursive practices, rights and duties are constructed in everyday interaction. Positioning theory views rights and duties, accountability and responsibility as ephemeral products of the temporary stabilisation of the acceptance (full or partial) of a certain role. The moral position is located within the structure of rights and duties associated with a specific interpretive repertoire (Davies and Harré, 1990). There are several implications to matters of responsibility and accountability, particularly for stabilised roles (or what I prefer to label here, following positioning theory, as subject positions). For example, there can be instances of questioning failure to act, especially if there are specific expectations from a collective. This is particularly valid for the case of the discourse of survivorship in breast cancer (which I will discuss in depth in the next chapter). Survivorship in breast cancer represents an instance where rights and duties merge: on the one hand, individuals affected with breast cancer believe that they have the right to access to appropriate treatment and care related to their illness. On the other hand, it also becomes their duty to ‘fight’, ‘battle’ and ‘not give up’ as part of their category membership on the other hand. Not following a certain set of ethical practices to battle the condition becomes a sign of failure. I shall expand this analysis to the context of genetic disease and ‘previvorship’ in chapters five and seven.

Subject positions are made available within the discursive practices of the individual as well as the ‘*other*’, and emerge through social interaction as a constantly work-in-progress product. Davies and Harré (1990) propose the following steps (presented in figure 14 below) in order to explain the processes of acquisition and development of the sense of self, and the interpretation of the world from that vantage point.



*Figure 14: The Multiplicities of 'Self'
Adapted from Davies and Harré (1990)*

Positioning theory proposes to scrutinise the expression of accounting. For the sake of intelligibility, accounts are tied to an array of relevant individuals. They are tied through the use of pronoun systems, which represent an effective device to link accounts to both the utterer and the audience. They represent '*indexical*' expressions as they signal a relationship between the speech act and the individual; in terms of the time and place of their utterance, as well as their moral location (Harré and Harris, 1993). This linguistic property of pronouns is called *indexicality*. Korobov (2001, emphasis in original) defines indexicality as "a micro-discursive way of demonstrating how the interactive use of language forms *index* (or draw-up into a kind of communicative space) versions or perspectives that *in turn* index certain subject positions, or social acts / social identities".

It is the function of indexicality that allows positioning theory to bridge between the micro detailed analysis of the DAM and the study of ideology, by drawing the focus on individuals experiencing themselves as contradictory, rather than focusing on the experience of contradictions, when exploring the sites for sensemaking of one's identity (Haug, 1987). As I have explained in the previous section, approaches with a conversational analysis orientation (such as DAM), while providing valuable insights on the functions of the discursive purposes (attributing blame, managing interest, etc. – I have elaborated this aspect in the previous section), tend to overlook the historical, cultural and ideological context (or the syndrome of '*myopic technicalities*' as called by Korobov (2001)). On the other hand, approaches with a CDA orientation, while unravelling historical constructions and ideology at work, tend to have a 'top-down' emphasis, with subjectivities and other interpretive repertoires being conceptualised as ideologically managed. On the other hand, a discussion of indexicality helps unravel how speakers' choices of specific linguistic forms indicate claims to particular memberships. It can also signal stances toward a particular category (Bamberg, 1997). It is, however, important to stress that these choices are not indicative of knowledge or ideological systems having a discursive effect in-mind (as advocated by Critical Discourse Analysts), nor are these choices constructed anew during each interaction (as it tends to be the case in conversational analysis). Instead, they are, as Davies and Harré (1990, p.49) put it, part of the "cumulative fragments of a lived autobiography".

These cumulative fragments or residues of language practices (Bamberg, 1997) are locally instantiated, in interaction, to claim positions regarding the category membership. The effects of these residual language practices come about through the iterability of utterances (Derrida, 1972 – notion discussed in detail in chapter two), and their establishment as ‘common sense’. The historical and ideological can be unravelled through the indexicality within the course of language use. As I shall demonstrate in the analysis chapter, indexicality is a key concept when analysing the discursive production of selves, as well as the fine details of the moral management of everyday life. This makes Positioning Theory a central concept to my theoretical framework.

Another feature that makes positioning theory a great fit for the present research is the interrelationship between ‘position’ and ‘illocutionary force’. As Harré and Harris (1993, p.113) contend, the speaker’s position “stands in a triadic relation with the storyline to which the utterance in question contributes and to its illocutionary force”. The social meaning of the utterance depends upon the positioning of the individuals involved in the social interaction, which is itself a product of discursive practices (Davies and Harré, 1990). Depending on the multiplicity of story lines (organised around events, characters and moral dilemmas), the cultural stereotypes and labels as resource for conversation, and the illocutionary forces of each speaker’s contributions; the conversation can be highly multivocal and complex. A pure univocality is impossible, as the only scenario favouring its occurrence would be where the speakers adopt subject positions that are perfectly complementary, and organised their conversational locations around a shared interpretation. In spite of this perfect scenario, the conversation is still occurring from the vantage point of two different positions, no matter how complementary they are. Positioning theory is therefore very helpful in deciphering the multivocality of everyday conversation.

All in all, positioning theory offers useful tools to bridge the micro-linguistic level to the ideological and historical contexts, as it scrutinises: “the fine-mechanics of how participants are actually—linguistically and sequentially— drawing up subject positions or indexing (from the ground up) patterns of lived ideology” (Korobov, 2001). Ideological discourses are linguistically adopted, resisted, or re-worked. Within

positioning theory, the speakers and their audience are constructed by discursive practices, while using these same practices as a resource to negotiate new subject positions. As they engage in conversations, speakers and their audience take one or several positions, while interpreting multiple (and sometimes contradictory) discursive practices. 'Identity' becomes an active, interactional accomplishment that is constantly work-in-progress (Bamberg, 1997).

5.6. Research methods:

Within this study, I scrutinise market performativity and its effects in the context of an online interactions of individuals with a genetic predisposition to breast and ovarian cancers, with an emphasis on the BRCA genes mutation. This chapter presents the research methods deployed for the data collection, refinement and analysis of this online forum, as well as a discussion of the ethical process.

The data I am using for the current study has been copied from a multitude of public online sources primarily newspaper articles, online support groups and activist websites – primarily U.S. based. The U.S. healthcare system is quite unique. Most of its services are delivered privately, even if publicly financed. Far from having a uniform health system, it relies strongly on private funds. The Centre for Medicare and Medicaid services (CMS, 2018) estimates that, in 2014, 48 percent of U.S. health care spending originated from private funds, while 28 percent came from the federal government and 17 percent from state and local governments. It represents in a sense a highly privatised hybrid healthcare system. Although the overall health insurance covered has been increasing over the past few years, there was still a percentage of 8.8 percent of people without any form of health insurance in the USA in 2016. Private health insurance coverage is largely more prevalent with 67.5 percent versus 37.3 percent for government health insurance coverage (Barnett and Berchick, 2017). In addition to that, there is a rise of health insurance premium with an increase by 83

percent for workers contributions between 2005 and 2015 (Kaiser Family Foundation, 2015).

With regards to genetic testing, there are also several particularities to the U.S. healthcare system as well. In the case of the BRCA gene specifically, four different BRCA testing systems were initially introduced in the market. However, Myriad Genetics, a biotechnology company, secured the patent of the BRCA gene, and became the sole provider for testing for the BRCA gene. Myriad Genetics made the BRCA testing available to anyone through any physician. The only issues being their pricing strategy often described as outrageous. Through this configuration, the patient is very much positioned as a consumer who could access a range of services available, provided they can pay the price (or have access to the adequate insurance system). The only aspect where the consumer cannot have any control is the testing system, as they were monopolised by Myriad Genetics (Parthasarathy, 2005). However, several legal suits resulted of the debates surrounding the controversial question of the possibility of patenting human genes, which eventually led to Myriad Genetics losing the patent dispute on the BRCA gene in 2015 (Pollack, 2015). I discuss the Myriad Genetics case in more depth in the next chapter. Nevertheless, the women that were part of my dataset had to go through Myriad Genetics and were not affected by the events following the loss of patent, as the patent dispute did not end until 2015.

Before diving into presenting the data and the techniques of data sampling and refinement, I briefly introduce linguistically focused Computer-Mediated Communication (hereafter CMC) research, in order to locate the 'home' of the research methods I use. Following that, I present the first part of my data, which focuses on a single newspaper article. For the second part of my data, I discuss the use of internet forums as a source for research material, and focus on the 'biosocial' community FORCE. Next, I discuss some aspects of data sampling and refinement, and present an overview of the linguistic devices that were recurrent in my dataset. Finally, I conclude this chapter with a discussion on the ethics process for this study.

5.6.1. What is a linguistically focused CMC research?

The study of social interaction within virtual spaces has been growing since the early 1990s. Due to the rapid technological progress and the growth of digital media, the amount of data available for research keeps increasing. Not only has it offered an increasingly wider range of material to use, but also paved the way for the development of new research methods such as digital ethnography or corpus linguistics. Interactional virtual spaces range from digital spaces such as chatrooms, instant messaging, emails, online forums, and comment sections of online newspaper articles, to 'social' media spaces such as Facebook, Twitter, Instagram, YouTube, and so on.

This data is characterised by its textual nature, as well as a naturalistic aspect. These characteristics have led to a growing popularity in the disciplines of linguistics (eg. discourse analysis, literary studies, sociolinguistics, corpus linguistics), and sociology (with a particular interest within sociology of health and illness, but also research on sensitive topics such as racism, radical groups, etc.), to name a few. There has been recently a modest interest within the market studies area. Examples of such scholarship include Pettinger's (2013) analysis of a website collecting customers' reviews of commercial sex encounters, '*Punternet*'; and Hopkinson's (2017) study of the market for male dairy calves, using Newspapers available online as a dataset.

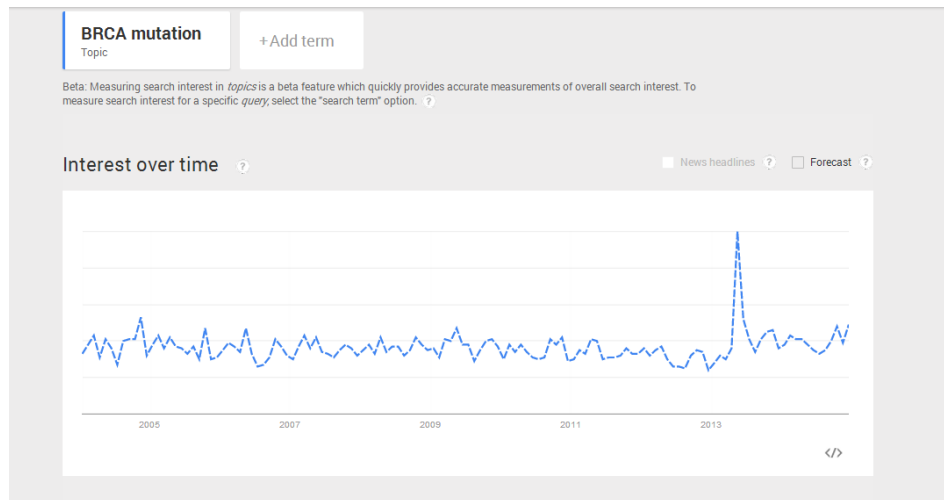
According to Georgakopoulou and Spilioti (2016), linguistically focused CMC research is unified by (1) a commitment to interdisciplinary research, (2) the view of language as locally situated in digital environments, as well rooted in a socio-cultural and historical context, and finally (3) a commitment to considering multimodality when studying CMC. The next section will introduce the biosocial community FORCE.

5.6.2. Hereditary breast and ovarian cancers in the news:

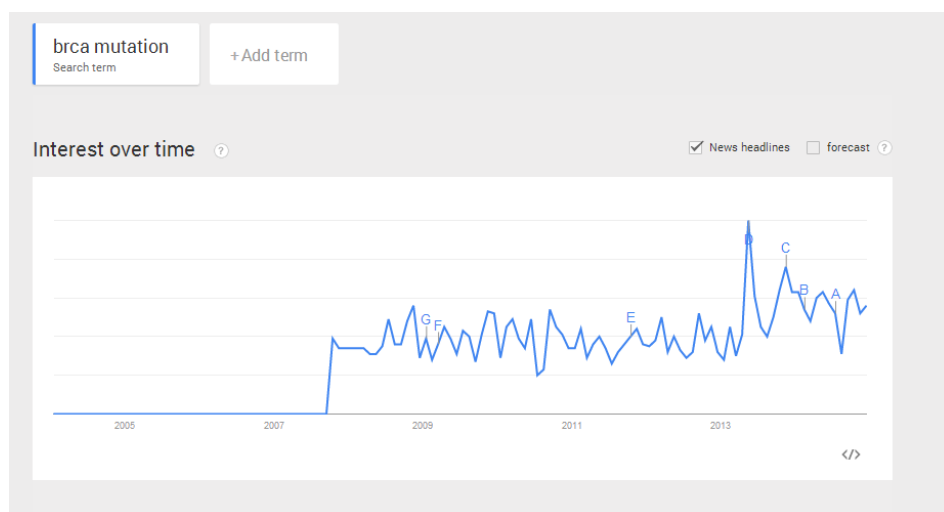
The first part of my dataset traces breast and ovarian cancers in the news, with a particular focus on narratives surrounding a particular gene – the BRCA gene (I will be introducing the disease and the gene in further depth in the analysis chapter).

The final in-depth analysis focuses on a single piece published in the New York Times. I follow a framework informed by Billig (1988) regarding single-text analysis. The framework suggests reading thoroughly around the piece and the topic before, during and after the analysis. The other supporting pieces (I have already discussed some of those above) were collected in a snowballing fashion. As Billig (1988, p. 207) put it: “In one way, the original text is a starting point for a search, rather than being the object of a methodological examination in itself. In another way, the text is not the starting point: the analyst will already have built up a knowledge of the topic before starting the search required for understanding the particular text”. In the next chapter 6, I discuss the readings surrounding the piece, as well as the cultural and historical contexts of breast and ovarian cancers and their redefinition as genetic diseases.

The headline I chose to discuss regarding the BRCA narrative in popular news is an op-ed by the American actress, film director, screenwriter, and author Angelina Jolie, published in *The New York Times* on May 14th, 2013. In her piece entitled ‘*my medical choice*’, Angelina Jolie revealed to the public her decision to undertake a double mastectomy following her diagnosis as a faulty gene carrier. There have been several popular figures who went public, in the past decade, about their mastectomies (whether curative or preventive). Just to name a few: Christina Applegate, Olivia Newton John, Lynn Redgrave, Katy Bates, and Sharon Osbourne all announced their medical choices to public. Sharon Osbourne, for instance, revealed to *Hello! Magazine* that she undertook a preventive double mastectomy after discovering that she had ‘the breast-cancer gene’ few months before Angelina Jolie’s letter, back in November, 2012 (Hellomagazine.com, 2012). ‘*My medical choice*’, by Angelina Jolie, has however sparked an enormous interest, both in terms of media coverage and reaction, as well as public interest. The public interest went beyond the revelation of Angelina Jolie, onto knowing more about the faulty gene. Figures 15 and 16 below show a significant peak in Google searches of the term ‘BRCA mutation’, in May 2013 directly after the publication of the story in the New York Times.



*Figure 15: Evolution of interest overtime for the key word ‘BRCA mutation’ – Worldwide
Source: Google Trends – Collected 18/12/2014*



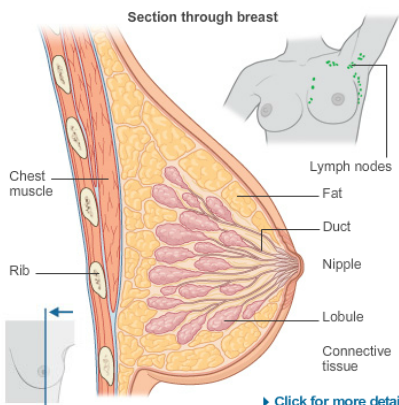
*Figure 16: Evolution of the number of popular News headlines covering the topic of
‘BRCA mutation’
Source: Google Trends – Collected 18/12/2014*

The reactions of the media to Angelina Jolie’s letter were very diverse. Some pointed out the overly positive faith in medical science advances, discarding other factors that are more commonly associated with breast cancer, as well as creating some sort of paranoia around genetic diseases, and risks of over-testing (Caldwell, 2013;

Vidyasagar, 2013). Whilst other praised her courage about going public about her decision, appointed her as a figurehead for owning one's medical journey, and even compared her act to the first lady of the USA, Betty Ford, who spoke openly about her mastectomy in 1974 (Grady et al., 2013).

The discussion around Angelina Jolie story moved beyond BRCA carriage, onto breast cancer narratives more broadly. For instance, a link to an article discussing her prophylactic surgery featured on the UK National Health Service webpage for the definition of breast cancer. The link was positioned just under a sketch for the anatomy of the breast at the beginning of the article (figure 17), for around two years at least.

Introduction



Section through breast


Labels: Chest muscle, Rib, Lymph nodes, Fat, Duct, Nipple, Lobule, Connective tissue

▶ Click for more detail

Media last reviewed: [unclear]
Next review due: [unclear]

Angelina Jolie's breast cancer surgery

Actress Angelina Jolie has had a double mastectomy to reduce her high genetic risk of breast cancer. We explain the cancer behind



Breast cancer is the most common cancer in the UK. About 48,000 women get breast cancer in Britain each year. Most (8 out of 10) are over 50, but younger women, and in rare cases, men, can also get breast cancer.

A woman's breasts are made up of fat, connective tissue and thousands of tiny glands, known as lobules, which produce milk. If a woman has a baby, the milk is delivered to the nipple through tiny tubes called ducts, which allow her to breastfeed.

Our bodies are made up of billions of tiny cells. Normally, cells grow and multiply in an orderly way. New cells are only made when and where they are needed. In cancer, this orderly process goes wrong and cells begin to grow and multiply uncontrollably.

Learn more about [the causes of breast cancer](#).

Breast cancer can have a number of symptoms, but usually shows as a lump or thickening in the breast tissue (although most breast lumps are not cancerous). If cancer is detected at an early stage, it can be treated before it spreads to nearby parts of the body.

Learn more about [symptoms of breast cancer](#).

If you notice any of these symptoms, see your GP as soon as possible. After an examination, they may feel it necessary to refer you to a specialist breast cancer clinic for further tests.

Read more information about [how breast cancer is diagnosed](#).

Types of breast cancer

Figure 17: Screenshot taken from the breast cancer informational page by NHS Choices
Screenshot taken on 04/2015

The most notable headline that followed Angelina Jolie's 'my medical choice' was the 'The Angelina Effect', which was the cover of the *Time*, on May 27th, 2013. The term was initially used to describe the 'cultural and medical earthquake' caused by the star's revelation. A study appearing in the journal *Breast Cancer Research* in 2014,

revealed that *'the Angelina effect'* more than doubled the frequency of testing for the BRCA gene in the UK following the publication of the letter (Evans et al., 2014). Similar studies were conducted in other western countries such as Australia and Canada, revealing a similar tendency to increased screening (Hagan, 2013; CBC News, 2013). Another study published in the British Medical Journal in 2016 revealed that *'the Angelina effect'* has indeed *'caused'* a significant increase in testing, but not in mastectomy rates arguing that the information might not have reached the population that is *'really'* at risk, and just participated in increasing the paranoia surrounding genetic diseases (Desai and Jena, 2016).

5.6.3. Conducting research within internet forums:

The second (and the largest) part of my data focus on internet forums. There are several internet forums in the USA and the UK dedicated to individuals diagnosed as BRCA positive. I present few examples in figure 18 below. It is interesting to note that all the forums bolster a vivid pink colour, and very colourful imagery throughout. While this is evidently connected to the symbolism of mainstream breast cancer activism, it still represents an interesting feature – one that *'does things'* indeed. The colour pink is constructed in our contemporary culture as girly, pretty, and healthy, which makes it an odd choice for a disease such as breast cancer that is characterised by a loss of womanhood (King, 2006). However, this colour works in perfect symbiosis with the overly optimistic and positive tone of the survivorship discourse. I discuss the survivorship discourse and breast cancer mainstream activism in depth in the next chapters. What matters for now, is that these online forums reproduce these discourses through the usage of *'branded'* breast cancer colours.

I focused on the biosocial community FORCE, which I introduce at the end of this section. The selection of FORCE as the main forum to analyse was based on the fact that it caters the largest community, and also its activities that go beyond the online discussion. FORCE is a national non-profit organisation in the USA devoted to hereditary breast and ovarian cancer created in 1999. The organisation is involved in support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. It even holds its own annual conference that gathers healthcare

practitioners, genetics and cancer researchers, patient advocacy groups and patients. From a methodological point of view, FORCE constitutes an online assemblage as it operates at “the interface of geographical, regional, temporal, linguistic and other boundaries and create the context within which users interact with multiple audiences” (Georgakopoulo and Spilioti, 2016, p. 323). Before introducing FORCE in further depth, I discuss internet forums as research data, and the technical consideration for their usage as such.

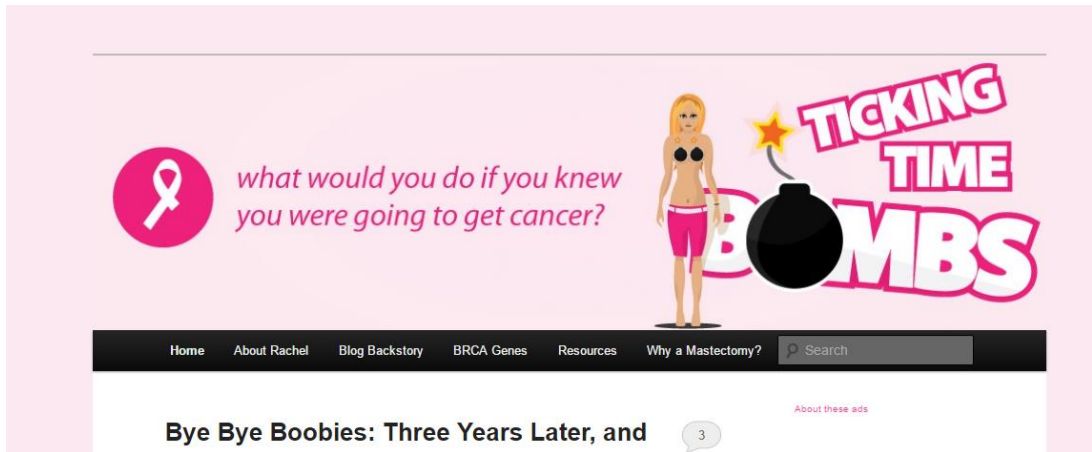


Figure 18: Examples of biosocial communities, which have the BRCA gene at the centre of their discussions. Websites from top to bottom: Fight like a girl' club, Ticking time bombs (USA), and Breast cancer care (UK). Screenshots taken in 06/2016.

5.6.3.1. Pros and cons of using internet forums as research data:

Internet forums (or message boards as labelled in FORCE) constitute a useful resource for sensitive topics such as the present case under study. Other examples of use of internet forums to study other sensitive topics include hate, crime, and racism (Glaser et al. 2002), German neo-Nazi discussion groups, or the radicalisation of young German muslims (Holtz et al. 2012).

Particularly in the case of chronic and severe illnesses, and personal accounts related to health and illness more broadly, people tend to express themselves more 'freely' on the internet (Seale et al. 2009; Robinson, 2001). For instance, Internet forums have been used to analyse narratives of childbirth experiences (Bylund, 2005), prostate cancer (Seale et al., 2009), weight loss (Manikonda et al., 2014; Trainer et al., 2016), pro-anorexia and weight loss drugs (Fox et al. 2005), stroke (De Simoni et al., 2014), youth sexual health (Harvey et al., 2007), veganism (Sneijder and Molder, 2005), just to name a few. In Figure 19 below, I outline some of the pros and cons of analysing internet forums, as informed by Holtz et. (2012), Seale et al. (2009) and De Simoni et al. (2014).

Benefits of analysing internet forums

Abundant Material	Natural Data with Few Social Constraints	Public Data
<ul style="list-style-type: none"> • Multiplicity of topics, interests and point of views. • Gravitates around a community for discussing matters of concern of the respective interest group, fostering a discussion between members that usually do not know each other in real life. • Almost unlimited amount of material for analysis that can be collected in a short space of time. • Because the material exists already in digital format, labor-intensive procedures like the transcription of audio material is usually not necessary. 	<ul style="list-style-type: none"> • Data stems for participants' agenda without being prompted by pre-structured research questions or the interference of the researcher during the construction of the narrative. • Participants are more prone to disclose personal and intimate information, with a great level of detail in their narratives. • The relative anonymity of internet forums stimulates contributors to greater openness, which is highly relevant in the case of sensitive topics. • Participants reveal their day-to-day concerns by actively documenting their experiences in a given thread, which gives a longitudinal aspect to the data. 	<ul style="list-style-type: none"> • More transparency of the research process as it is relatively easy to retrace the sampling of the analysis material. • The structure of internet forums makes it relatively easy to find, select and sample segments of the forum relevant to the research question.

Potential issues with analysing internet forums

Anonymity	Privacy	Representativeness
<ul style="list-style-type: none"> • Little sociodemographic information available about the users. • Potential difficulty to trace back the posts to the source, which could be an issue in case follow up interviews are required. • It is however possible to characterise the social group organising and moderating the forum by taking into account the background information such as mission statements or introductory pages of the forum. 	<ul style="list-style-type: none"> • Blurred boundary between the realms of the private and the public, which characterises internet forums' data. • The terms and conditions of the website usually clarify this aspect. However, and particularly in the case of sensitive topics, forums are designed to create a sense of private or semi-private communication sphere. 	<ul style="list-style-type: none"> • The first and main sampling bias is the access and usage of internet as an inclusion criteria. • On the other hand, this implies the possibility to access people, who are socially isolated or geographically dispersed, more easily; as long as they have access to internet, and have been socialised into the process of sharing personal stories on internet forums. • In case where the aim of the research is a generalisation of the findings, triangulation strategies can be used to compare the analysis of internet forums with other material available on the internet, as well as traditional qualitative and quantitative data.

Figure 19: Benefits and potential issues of analysing internet forums
Source: Adapted primarily from Holtz et al. (2012), with additional notes from Seale et al. (2009) and De Simoni et al. (2014)

5.6.3.2. Technical aspects regarding the analysis of internet forums:

5.6.3.2.1. Asynchronicity:

Internet forums constitute an *'asynchronous'* mode of communication. An asynchronous mode of communication is the opposite of a synchronous one. A synchronous mode of communication implies real-time, online interaction. It requires participants to be both available at exactly the same time and (virtual) space for the interaction to happen. In the case of a synchronous mode of communication, the genre is a conversational-like written discourse, with non-verbal clues of everyday conversation being substituted by paralinguistic clues, embedded within the writing (Montero-Fleta et al. 2009). Examples of platforms utilising this mode of communication include chatrooms, messenger, or online conferences. The mode of interest to the present study is asynchronous communication. It involves a non-real-time, online interaction. Similar to the case of FORCE message boards explained above, discussions or threads starts with a post from a forum contributor, and other participants interact and contribute to the thread at their own pace. The virtual space is the same for all participants but there is no constraints for being there at the same time. This makes the genre of writing different from the one of synchronous communication, as the contributions are crafted more carefully, with usually a higher level of detail than say a chatroom (Montero-Fleta et al. 2009). Messages are traditionally stored within the website domain. Examples of platforms utilising this mode of communication are e-mails, internet forums or messages boards, and massive open online courses or *'MOOC'* (in the context of education). Social media platforms often blur this dichotomy, and provide modes of communication that are hybrid. For instance, Facebook instant messaging functions both in synchronous and asynchronous modes (Tagg and Seargeant, 2016). However, it is important to stress that both modes requires the socialization of the participants into their specific genre of writing.

Other common features of internet forums' genre of writing, in comparison to traditional written texts, include more frequent humour, as well as a tendency toward a greater level of intimate personal disclosure and emotional expression. The

electronically mediated text is very often sent unedited, with a lot of typing mistakes and words' contractions, which accentuates the informal dimension of this genre (Baron, 1998). Fairclough (1995) defines this genre of writing as characterised by the processes of informalisation and technologisation of discourse. He describes modern discursive practices as a blending of "formal and informal styles, technical and non-technical vocabularies, markers of authority and familiarity, more typically written and more typically spoken syntactic forms" (Fairclough 1995, p. 79).

5.6.3.2.2. Observation versus Engagement:

In order to ensure a cohesion within my methodology, and particularly with regards to my commitment to use naturalistic data, non-participant observation appeared to be the appropriate approach for this study. Thus, I have collected the data unobstructively.

Seale et al (2009) argue that the abundance and ease of access of archived internet materials makes internet forums an excellent candidate for direct observation of illness experiences. This is particularly relevant when contrasted with the traditional laborious off-line observational research methods. My data is derived from messages archived over time, and constitute a day-to-day narrative (or interactional diary) of past events. This is different from a dataset constituted of narratives of what participants 'would say they did', which is the case of interviews for instance. The problem of *reactivity of participants* as described by Hammersley and Atkinson (2007) was not an issue here either, as there was no participation of my part in the internet forums.

Observational research contrasts with other forms of online research that blur the boundaries of the private and public in a similar context, such as digital ethnography (see for example Iorio et al. 2016) or netnography (Kozinets, 2002). While these methods do have certain benefits, the sensitive nature of the topic, and the overall 'safe space' atmosphere of the forum, meant that any form of participation or probing, from my side, would have yielded less richer and detailed accounts. FORCE message boards leave participants free to start a thread on any topic to discuss

(subject to moderation), and while this might not have always aligned with my initial research questions, it provided rich and detailed, naturalistic accounts.

5.6.3.3. *The Biosocial community FORCE:*

The data I use in this research has been copied from the website FORCE. FORCE can be defined as a '*biosocial community*', rather than a medical support group, as it caters to the 'pre-ill': individuals who have been diagnosed with a higher susceptibility to a disease they do not have, yet. Already in 1992, Rabinow anticipated the emergence of such collectives, describing them as '*biosocial communities*'. He predicted that such groups would form around 'new truths' produced by the Human Genome Project. For these movements to materialise, a key requirement is the organisation of efforts around specific DNA mutations; mobilising genetic experts, medical specialists, laboratories, diagnosis technologies, narratives, and support groups to help 'understand' and deal with their almost determined fate to develop the disease caused by that mutation (Pender, 2012).

FORCE is yet another manifestation of those efforts to enrol actors around a genetic mutation. FORCE is a national non-profit organisation in the USA devoted to hereditary breast and ovarian cancer created in 1999. The organisation is involved in support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. There appears to be a focus on genetic screening and mainly BRCA mutation as the website states: "Our programs serve anyone with a BRCA mutation or a family history of cancer" (Copyright © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved). The website is organised around informational resources, and community platforms for engagement, support, and advocacy.

There is a rich section dedicated to providing up-to-date information for the members. The information is organised in sections revolving around HBOC. One noteworthy aspect is the wording of the titles of the main and subsections. While the main sections are labelled in quite a generic way, the subheading display a more explicit focus on genetics. For instance, the main section '*Understanding HBOC*' is subdivided

into several sections ranging from Hereditary cancer to cancer risk and risk management as well as treatment options, insurance and genetic privacy laws, and so on as displayed in figure 20. However, when clicking on the main section, *'Understanding HBOC'* becomes *'Understanding BRCA & HBOC'*, with the conjunction *'and'* functioning as a device for both association and ordering in this case. Moreover, the subsections are detailed in a way that relates directly to genetics conceptualisations of the disease, as highlighted in figure 21. The aim of the present study is not to analyse the content of the website and its structure; nevertheless, these elements provide some contextual hints on the ideological patterns that are pervasive within this biosocial community. Although the website caters to individuals at risk of both breast and ovarian cancers, the *'branding'* of breast cancer is dominant. This is visible through the omnipresence of the vivid pink colour, as well as the pink ribbon. The *'breast cancerisation'* of cancer will be discussed in further depth in the next chapter.

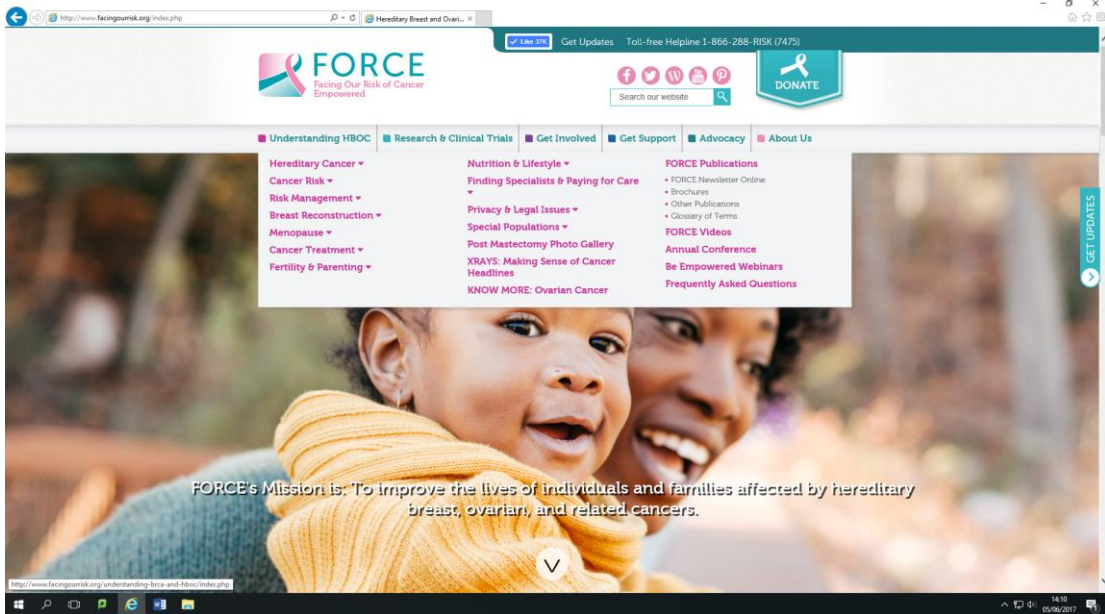


Figure 20: screenshot from the home page of force website – Source: FORCE (Copyright © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved) screenshot taken on 04/06/2017

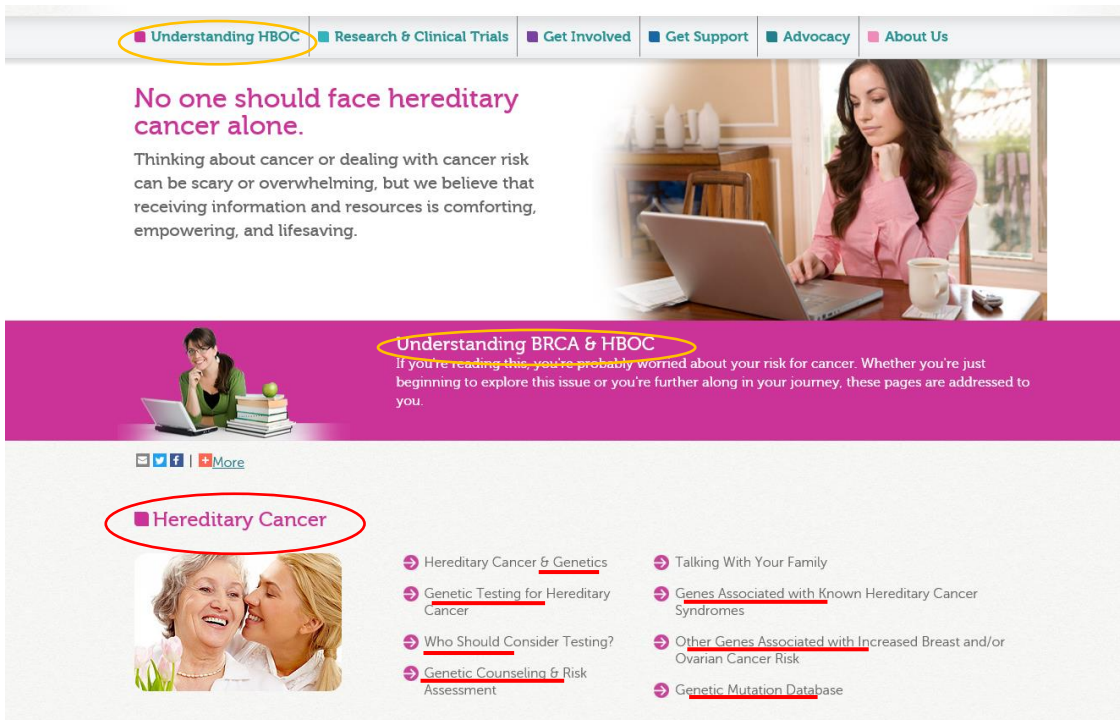


Figure 21: screenshot from the 'Understanding HBOC' tab – Emphasis added Source: FORCE (Copyright © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved) screenshot taken on 04/06/2017

Another section, Research & Clinical trials, provides the reader with information on the latest clinical trials, as well as advertisements for studies enrolling patients, where members of FORCE can subscribe to participate in research trials. Members have also options to get more involved in the community through various ways such as donations, volunteering, advocacy or blogging. FORCE organises an annual conference as well. This international conference is targeted primarily at people affected by genetic mutations, which are associated with an increased risk of developing cancer (with a strong emphasis on BRCA mutation and breast and/or ovarian cancer), as well as their family members; and provide them with information on recent research as well as the opportunity to network with fellow previvors, survivors, patient advocates, researchers as well as healthcare providers.

Finally, there is a section dedicated to support the members. The section comprises of a chat room and several message boards. The message board section is the main section of interest to the present study. This section is organised in a traditional way, as far as internet forums are concerned, with a 'tree-like' structure (Holtz et al., 2012). There is a variety of topics discussed within different sections grouped around umbrella themes. Larger sections are sometimes subdivided into subsections.

The message board section contains a '*main*' forum and several other specific forums including a '*surveillance*' forum, a '*diet and lifestyle*' forum, a '*articles, journals and reports*' forum, a '*men's*' forum, a '*spouse and partner*' forum, and so on. There are overall twenty forums in addition to the main forum. The data was retrieved from the '*young previvors*' forum. FORCE defines the label '*previvor*' as follow:

"'Cancer previvors' are individuals who are **survivors** of a **predisposition to cancer** but who haven't had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. The cancer previvor term evolved from a challenge on the FORCE main message board by Jordan, a website regular, who posted, "I need a label!" As a result, the term *cancer previvor* was chosen to identify those living with risk. The term specifically applies to the portion of our community which has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer.

The medical community uses the term ‘unaffected carrier’ to describe those who have not had cancer but have a BRCA or other cancer-predisposing mutation. The term applies from a medical perspective, but doesn't capture the experience of those who face an increased risk for cancer and the need to make medical management decisions. Although cancer previvors face some of the same fears as cancer survivors, undergoing similar tests and confronting similar medical management issues, they face a unique set of emotional, medical, and privacy concerns.” (FORCE, Copyright © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved)

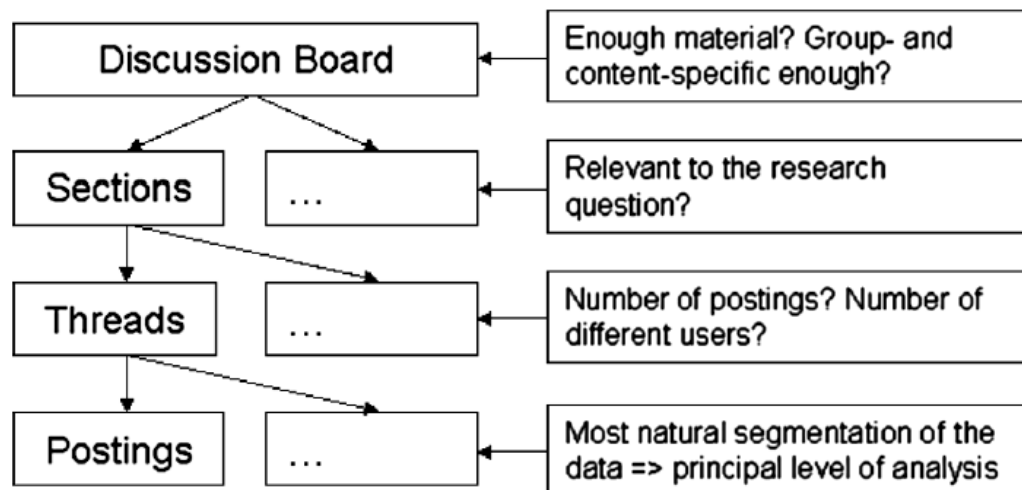
This forum is a space where people can communicate with each other on a range of topics including surveillance procedures, genetic screening, preventive procedures, post-surgery aesthetics, hormonotherapy, family issues, and so on. Anyone can start a discussion (or what is commonly called in internet jargon as a ‘*thread*’) by introducing the topic of concern. There is no mandatory requirement to register or provide any personal information to use the message board, although participants can do so if they wish, and choose their own username. In case the individual does not want to register, they are identified as *anonymous*. Although it adds a layer of confidentiality to the research subjects, it proved to be an additional difficulty on a methodological level. Indeed, keeping track of the different conversations was sometimes challenging, especially when individuals were switching between their username and anonymous in case they forgot to login. In most cases, they were referring back to their posts as anonymous, which helped connecting the different elements of the narrative. On the other hand, the open access nature of the forum also means that any internet user could read the threads and postings. Finally, the number of participants varies from a thread to another.

5.6.3.4. Data sampling and refinement:

The data was retrieved mainly from the ‘*young previvors*’ forum. There were several reasons for this choice: first, the ‘*young previvors*’ forum was the most popular forum after the ‘*main*’ forum in terms of number of topics, and also in terms of the number of posts and replies, which was a sign of a good level of interaction between the

participants. Second, the title of the forum reserved it to the category that I am interested in for the present research, ie. previvors.

I copied the data from the archives of the forum, starting the selection from the beginning of the ‘young previvors’ forum, September 2008; and finishing February 2015, excluding the threads within the last six months prior to the data collection, in order to have well advanced narratives with sufficient interactions. I initially excluded all the posts that had less than 20 replies in order to focus on rich conversation with an adequate level of interaction, which narrowed down the selection to an initial corpus of 49 threads from the forum. Overall, the data sampling followed a method that is very similar to that elaborated by Holtz et al (2012), which is presented in figure 22 below.



*Figure 22: Sampling strategies in view of the hierarchical structure of internet forums
Source: Holtz et al (2012)*

I initially used the computer-assisted qualitative analysis software, Atlas.ti, for data reduction and refinement. For this purpose, I exported the content of the threads into a format that was compatible with the software, which was PDF in this case. There is a function within the website to extract the forums directly into a PDF format. Apart from the use of emoticons and quotes, there were no other elements that disrupted

the uniform text format. Every single thread was assigned as a primary document in itself, in order to be able to analyse the accounts and themes within the context of their narratives.

The initial data refinement consisted of a thematic content analysis. It involved traditional coding techniques, and delineating content categories. This allowed me to delineate the major narratives discussed within the forum, which were surveillance procedures, genetic screening, preventive procedures, post-surgery aesthetics, hormonotherapy, and family issues. After this process, the data was reduced to 16 threads. The main criteria for selection were the level of detail of the conversation, the way participants treated certain issues of concern as controversial in one way or another, as well as the time span covered by the thread. Following this step, I performed further coding, and started identifying the predominant linguistic categories within the discourse. Most importantly, this step helped me identify five polarities: fear and hope; knowledge and uncertainty; control and anxiety; family, children and individual; time and death. The identification of these categories mostly drew on the concept of polar opposites from Derrida's deconstruction (Derrida, 1981, but also see Wood, 1979; and Parker, 1988). I summarise the steps I followed in figure 23 below.

Step 1

- Identify conceptual oppositions, or polarities in the text, and the way one pole is privileged over the other.

Step 2

- Demonstrate that the privileged pole of the opposition is dependent on/ could not operate without the other.

Step 3

- A reinterpretation of the opposition, and the production of new concepts

Figure 22: The three steps of deconstruction
Source: Adapted from Parker (1988)

The polar opposites identified within FORCE extended those analysed in the Angelina Jolie letter. The following step for me was identifying the way one pole was privileged over the other. For instance, in the case of the framing of previvorship, one of the key dichotomies was between fear and hope. The fear of the occurrence of cancer, evidence by the calculated score of its high risk, shaped the subject position previvor and the constitution of prevention as part of the at-genetic risk subjectivity, rather than it being only an outcome of diagnosis. These oppositions serve as devices that construct subjectivities as well as the practices surrounding these. However, the oppositions themselves were reinforced and constructed through various discursive devices. I did another thematic analysis; this time scrutinising the discursive devices, involved with the construction of these conceptual oppositions, that were frequent within the dataset. The identification of these discursive devices was guided by the analytical framework described earlier in this chapter.

Next, I scrutinised the relation between the two poles, and how the privileged pole was not only connected, but also dependent to its polar opposite. Thus, in the case of the dichotomy between control and anxiety, whereas the control narrative was essential to establish radical practices on healthy bodies as essential to reduce genetic risk, it could not operate without the messiness of our knowledge of the human body and the necessity to organise it through certain forms of categorising, as well as the anxiety that this messiness induces. This interconnectedness could also be also explored through the study of discursive devices that enable or shape these relations, and the connection with the wider social, cultural and historical contexts. Again here, I did an additional thematic analysis to explore the more frequent discursive devices involved in/narrating ways of connecting these polar opposites. And evidently, the identification of these discursive devices was guided by the analytical framework described earlier in this chapter. I summarise these discursive devices in the next sections.

The final step was more concerned with the analysis of possibilities of failure in the initial process of the doing, as well as things-could-have-been-otherwise alternative narratives. This step involved more of my own assumptions about the nature of

meanings, and my own moral/political inclinations. There was an iterative process where I was connecting the data back to the literature, as well as the wider social, cultural and historical contexts.

Following these steps and the series of repeated thematic analysis of the 16 threads, I organised (and reorganised few times) my data analysis around groupings of discursive devices and what they do. I did a final narrowing down of the forum data to 4 threads in order to have manageable chunks of data. In line with Potter and Wetherell's (1987) staging of discourse analysis, I distinguish between coding and analysis, in a sense that the emergent themes and codes do not represent findings, but simply help to squeeze unwieldy bodies of discourse into more practical portions for an in-depth analysis of performativity at work. Thus, those themes had more of a pragmatic, rather than analytical, value. The final threads I picked for the extensive analysis of the discursive devices and what they do, was based on the level of interactions (number of posts, follow-up, multiplicity of interactants and voices), the diversity of topics discussed and diagnosis outcomes, and the diversity of discursive devices included. This was to ensure a rich dataset, which was as inclusive as possible of the frequently used discursive devices that were identified earlier. The aim of the analysis was the search of the linguistic evidence for the functions and effects of speech acts.

5.6.4. Frequent discursive devices within the dataset:

In terms of the technical aspects of the analysis, I scrutinised the functions of linguistic categories within their context of use, and connected these to the wider cultural and historical context (as outlined in the previous section). With this in mind, I was constantly referring back to the general guidelines of discourse analysis as informed by my analytical framework, described earlier in this chapter (Potter and Wetherell, 1987; Billg et.al, 1988; Davies and Harré, 1990; Edwards and Potter, 1993; Wetherell, 1998). Thus, when identifying the discursive devices that were the most frequent within my dataset, particular attention was given to instances of attribution of blame,

causality and responsibility, as well as pronoun systems and indexication. Whenever applicable, I attempted to bridge between the interactional and the ideological, by exploring the social, cultural and historical contexts of the use of these devices. It was an iterative process between the data, the social cultural and historical contexts, and linguistics foundations. I provide a summary of the discursive devices that emerged within the dataset in table 1. These are the discursive devices that were the most frequent in my dataset, and therefore these definitions could help familiarising with these notions before delving into the analysis chapters, as I will be frequently referring to them. However, it is important to clarify that the definitions I present in this table are merely indicative; it is the functions of discursive devices in use, and their effects, that matter.

Discursive Device	Definition	Key Sources
Extreme Case Formulations	Specific formulations such as 'brand new', 'completely innocent', 'he didn't say a word', 'I really don't know', 'no time', 'forever', 'everyone', which can be deployed to warrant the 'rightness' or 'wrongness' of certain practices. These formulations can be used in the business of complaining, accusing, justifying, and defining; through the use of the extreme of the dimensions available to perform evaluations.	<i>Pomerantz (1986); Edwards (2000)</i>
Script Formulations	Conditional formulations (such as 'if', and sometimes 'when'), which function as scripting devices providing inferences. Within these inferences, accountability, causality and sequencing of events have a co-constitutive relationship. Script formulations are often combined with the use of modal verbs.	<i>Edwards (1994, 1995)</i>
Modality	Modal verbs such as 'might', 'can', 'should', 'must', locate the moral responsibility of actors. They can refer to the degree of necessity or rightfulness of the actions performed by morally responsible actors.	<i>Halliday (1970), Lyons (1977), Snejder and Molder (2005).</i>
Discourse markers	Discourse markers such as discourse connectives 'and', 'but', and 'or' can have different functions depending on the context of use. Beyond the obvious functions such as connection and contrast, they can operate as devices for moral ordering, causality attribution as well as the legitimisation of the specific actions.	<i>Schiffrin (1982)</i>

Discursive Device	Definition	Key Sources
Externalisation or 'out-there-ness'	Presenting a description in such a way that it appears objective and unbiased. This can be performed by the use of factual evidence and/or the construction of the speaker as independent from the claim.	<i>Potter (1996)</i>
Performulations	Performulation is the act of formulating, within the same utterance, an argument as well as an expected counter-argument	<i>Potter et al. (1991)</i>
Passivisation and nominalisation	The passivisation of specific utterances, which functions as a device to delete agency and reify processes.	<i>Fowler et al. (1979), van Leeuwen (2008), Billig (2008).</i>
Pronouns	The use of pronouns is intertwined with relations of power; representation and the localisation of subject position (please refer back to positioning theory in chapter four).	<i>Davies and Harré (1990), Harré and Harris (1993), Pennycook (1994).</i>
Stake inoculation	The practice of downplaying or even denying the vested interest a speaker might have in a particular rhetorical stance.	<i>Potter (1996)</i>

Discursive Device	Definition	Key Sources
Amplifiers	Sometimes also called intensifiers, such as ‘very’, ‘so’, ‘absolutely’ and ‘totally’. They can be used to amplify expressions of emotions, in order to legitimise certain claims, such as expressions of doubt, hesitation, and so on.	<i>(Labov, 1984)</i>
Numerical and non-numerical quantifiers	Divided into non-numerical quantifiers (such as <i>some, big, small</i>) and numerical quantifiers (such as percentages, ratios, absolute numbers). Each formulations perform specific functions, which are context dependent.	<i>Potter et al. (1991)</i>
Plural quantification	The distinguishing between the functions of first-order and second-order quantifiers; particularly with regards to their ontological commitments. This is particularly the case when scrutinising the evaluations of ‘sets’. For further detail, please refer to the seminal analysis of a ‘set of cheerios’ in <i>Boolos (1984)</i> .	<i>Boolos (1984)</i>

*Table 1: The discursive devices scrutinised within the analysis
Source: Own development*

5.6.5. Ethics:

Ethical issues surrounding internet-mediated research, and particularly internet forums, have been subject to heated debates. On the one hand, some approaches regard ethical approval or informed consent from research participants as unnecessary, considering internet posts as material available in the public domain. The argument is that the quasi or total open access of internet forums positions them as available in the public domain, and therefore not requiring informed consent or ethical review (Seale et al. 2009, Harvey et al. 2007), unless stated otherwise in the terms and conditions of the forum. On the other hand, other perspectives on research ethics contend that online forum participants may preconceive their communications within those virtual spaces as 'private'. Even when disclaimers clearly outline the visible, traceable and permanent character of the participants' posts (such as FORCE's message board disclaimer), the ethical implications of the free use of such data for research purposes remain ambiguous (British Psychological Society, 2017). This is particularly problematic when dealing with highly sensitive cases such as individuals suffering from cancer or with a high pre-disposition for developing the disease.

The blurring of boundaries between the public and the private, within digital environments, constitute an ethical challenge for present and future CMC research (Paolillo, 2016). One of the major risks is the transformation of online data collection into a form of surveillance, which would represent a threat to individuals' safety (Georgakopoulou and Spilioti, 2016). This is particularly relevant for sensitive topics, such as political activism web groups for instance. There is, therefore, a need for the development of an ethical agenda for CMC research, which would include "the politics and implications of circulation and circulatability of specific communication genres and practices" (Georgakopoulou and Spilioti, 2016, p. 6); as well as scrutinise how social science research could potentially disturb the 'naturalness' of online public interactions.

Although the use of publicly available data where the non-commercial copying and usage of data may be justifiable without seeking and gaining a valid consent (British Psychological Society, 2017; Seale et al., 2009); I decided, following recommendations

of the ethics committee of Lancaster University, to contact Doctor Sue Friedman, who is the executive director and founder of FORCE, and ask for her consent to utilise the data within FORCE message board for my research. Dr. Friedman is herself a carrier of a BRCA2 mutation. She was diagnosed with the genetic mutation at the age of thirty-three, about a year after being diagnosed with breast cancer. Five years after founding FORCE, Dr. Friedman left veterinary medicine practice in order to direct the organisation full-time. She is therefore very much invested in the cause, and the obtention of the consent required several email interactions and a discussion over skype (the FORCE headquarters are located in Tampa, Florida in the USA). Copies of documents utilised for gaining the informed consent are available in appendix C.

Furthermore, and considering the sensitivity of the research topic, the patient profiles are completely anonymised. I treat virtual usernames and pseudonyms with the same respect as for a person's real name, in order to prevent the risks related to the traceability of quotes online and their association with participants' virtual identity.

This research was approved by the Lancaster University Ethics committee prior to the start of the data collection formally, and followed Lancaster University's ethics guidelines thoroughly.

In the next section, I provide a reflective account of being male researcher writing about personal female experiences. I discuss male feminism and the controversies surrounding it.

5.6.6. Reflective account – on being and acting as a feminist male researcher:

Feminist researchers have been vocal about the importance of self-critical examinations of reflexivity. They particularly stressed the importance of reflexivity to understand how gender relations shape data collection (Kusow, 2003; McDowell, 1992; Takeda, 2012), as well as analysis (Galam, 2015; Pini, 2005). For feminist theorist, the experiences of oppression in society shape the interactions between researchers and research participants, and the power relations during the research

process from data collection, to interpretation and dissemination (Broom et al., 2009; Ward, 2016).

There have been divergent positions with regards to male researchers studying female subjects in the context of feminist research (Gardiner, 2002; Kimmel, 1998; Murphy, 2004; Stanovsky, 1997). Men being and acting as feminist constitutes a controversial question to say the least. This is partly because feminism has been concerned with the critique of masculinist forms of knowledge and the role of gender relations in constructing scientific objectivity (Haraway, 2006; McDowell, 1992). Some contend that feminism should remain and be preserved as the realm of women only. The argument here is that the focus should always be on what unites feminist research, which should be its central concern: women and the study of means of oppression through gender (Gilbert, 1994). Thus, feminist research should remain, within this view, “by, for, and about women” (Gluck and Patai, 1991, p.2). However, over the years, feminist scholarship saw an interest in studying adjacent topics such as the social construction of masculinity alongside femininity (McDowell, 1992), as well as raised some cautious calls for the participation of men in feminist movements and research (Pleasants, 2011). At the centre of these debates was the question of whether feminism is about the holding of feminist positions (in the sense of a set of beliefs and political positions with regards to the oppression of women in society), or women’s experiences (Heath, 1987; Hopkins, 1998).

Another important argument that disrupted the claims of feminist research as an exclusive domain for female researchers is the consideration of gender intersectionalities. While the French theorist, Julia Kristeva (1982) has drawn our attention to ‘women’ as a historical construct that gained a prominence as a category post-World War II; it is important to note as well the historical construction around other identity factors such as ‘race’, ‘class’, ‘sexuality’, and how these interrelate with gender to reinforce the experiences of oppression of women in society. By recognising the multiple dimensions of identity and means of oppression, feminist research has been able to stress the importance of intersectionality (Crenshaw, 1991). Thereby, giving more consideration to how gender interrelates with other identity determinants such as race, class, age, sexualities, (dis)abilities, and so on.

Hence, it has been argued that rather than constricting feminism as a women arena only, it should be viewed as "sites for a discourse that acknowledges the connection between feminist concerns and issues of race, class, and sexual orientation" (Breeze, 2007, p.60). An intersectional politics should be able to connect gender and other structural means of oppression such as race (and its connection to gene as described in chapter three), class, ethnicity, sexuality, nationality, and so on (Pleasants, 2011, Gurrieri et al, 2013; Maclaran et al.,2009). Thus, men could and should speak and act as feminists, and as an ally to women. As Hooks (1984, p.81) put it: "men have a tremendous contribution to make to feminist struggle in the area of exposing, confronting, opposing, and transforming the sexism of their male peers". Discarding men from the arena of feminism based on the dominance of male as gender, would be similar to discrediting white people in anti-racist solidarity due to them not being able to divest themselves of white supremacist thinking (Lemons, 1997). Through the consideration the intersectionality of the other core categories of political economy analysis with gender, we can get further depth of analysis and level of criticality.

For instance, in the present study, a similar argument could lead to thinking that a woman who is BRCA negative with a low risk of breast and ovarian cancers cannot account for experiences for BRCA positive women. This could have resulted in missing out on stellar analytical accounts of BRCA negative women that have advanced our understanding of the at-genetic risk identity for women. Science and technology provide new sources of power that we need to take into account in our analysis and political action (Latour, 1987). As Haraway (2006, pp.124-125) eloquently summarises this argument:

"I do not know of any other time in history when there was greater need for political unity to confront effectively the dominations of "race", "gender", "sexuality", and "class". I also do not know of any other time when the kind of unity we might help build could have been possible (...) White women, including socialist-feminists, discovered the non-innocence of the category "woman". That consciousness changes the geography of all previous categories; it denatures them as heat denatures a fragile protein. Cyborg

feminists have to argue that “we” do not want any more natural matrix of unity and that no construction is whole.”

One of the primary concerns for men doing feminist research has been the power relations during data collection. However, in my case the data collection was not affected by gender relations as I have collected my data online, and unobstructively (my intervention was limited to processes of selection and refinement of data, which was explained in detail in a previous section in this chapter). The only direct interaction that I had as a researcher was during the interactions with Doctor Sue Friedman, the executive director and founder of FORCE.

The main aspect where gender relations were at play was the data analysis, and reconstitution of narratives. These were private, intimate and very often painful accounts of women experiences. The narratives were the product of interactions of women within an online forum primarily. These stories were produced at a specific point in their lives, and provide a positioning of the narrative from a specific vantage point that has spatiotemporal as well as moral locations. Dealing with accounts of interactions of women sharing several commonalities (gender and genetic risk for HBOC) provided different ethical challenges rather than say myself (a cis-male researcher) probing in a research interview context to obtain rich stories. The challenge was more in relation to what-to-do with these accounts, rather than the power relations in obtaining them. Thus, I needed to pay a close attention to the content but also the context of creation of these narratives. As Faier (2009, p.82) put it, narratives are “part of the ongoing, dialogic, and constrained ways that people selectively make and remake the past as they craft lives and selves in the present”.

As Janet Finch (1984) argue, ethical considerations with regards to gender relations should not be reserved to data collection but also the analysis and overall usage of the research material. An aspect that cannot and should not be neglected is that the framing of these narratives in this thesis has been performed by my own critical interpretation of these stories. Thus, this framing was very much shaped by my own experiences, perspectives, biases, as well as my epistemological and ontological

commitments within this study. Nevertheless, I strived to locate these narratives in their social, cultural and historical contexts within my analysis. Positioning theory proved to be helpful with regards to these aspects, as it allowed me to approach women's narratives with a particular attention to the spatiotemporal as well moral locations of the various subject positions, and how these women were locating themselves as well as the other. It also provided me with the tools to connect these subject positions with the social, cultural and historical contexts.

Consequently, I found myself in a situation where I was constantly critically reflecting and engaging with my own biases, as I was doing the several rounds of analysis and connecting with the wider contexts. The narratives I analysed were critical in intertwining the personal and political. This was reflected in my movement from several rounds of thematic analysis (as explained in a previous section in this chapter) to an examination of how these narratives are connected to wider social, cultural and historical conditions of the construction of a biological and genetic citizenship. In line with my commitments to engage with the politics of performativity, my analysis sought to politicize these accounts and connect them to wider ideological and moral concerns.

In taking a more socio-historically and cultural contextual approach to the analysis of my narrative, I was able locate the women I studied within material and social practices. I am hoping that this will help better understand the tensions and conflicts in the construction of at-risk genetic subjectivities, as well as how prevention discourse, and their market solutions, lodge themselves as a constitutive part of these subjectivities rather than an outcome of analysis. In doing so, my analysis did not draw on (and hopefully did not reproduce) prejudicial representations of BRCA positive women.

In the next chapter, I focus on the cultural and historical contexts of breast and ovarian cancers, and their redefinition as genetic diseases. I present a historical overview of breast cancer in the media, before dissecting the public declaration of Angelina Jolie in *The New York Times* about undertaking a preventive double mastectomy following her diagnosis as a carrier of a faulty gene.

Chapter 6: HBOC, BRCA mutation, and the consumption of prevention

The previous chapter focused on the methodological commitments of this study. In it, I discussed the grounding of this thesis within a social constructionist approach, the details of the analytical framework that combines three key concepts from discursive psychology in order to connect the situated with the cultural and historical contexts, as well as the research methods for data collection, refinement and analysis.

This thesis explores market performativity in the context of an online forum concerned with genetic propensity for breast and ovarian cancers, and possible preventive actions that could be taken. In this chapter, I shall focus on the cultural and historical contexts of breast and ovarian cancers, and their redefinition as genetic diseases. This chapter is structured as follow: first, I explore the social construction of breast cancer, and the dominant themes surrounding the narrative of the disease. This leads me to focus on the survivorship discourse, particularly in relation to two strands: the mainstream breast cancer movement on the one hand, and feminist activism on the other hand. This raises questions with regards to the place and effects of the discourse of survivorship when reconfiguring breast and ovarian cancers through a genetic lens. I present a brief overview of breast cancer in the media, before focusing on the public declaration of Angelina Jolie in The New York Times about undertaking a preventive double mastectomy following her diagnosis as a carrier of a faulty gene. A thorough analysis and discussion are presented in the final sections of this chapter, with wider connections to the performativity of the at-genetic risk individual, and their practices within the market of prevention.

6.1. Social Construction of breast cancer:

As I have discussed in chapter three, the notion of control of degeneracy is central to genetics, whether it is expressed through the discourses of obligation and coercion of eugenics, or the discourse of individual choice of contemporary genetics. One of the main reasons I decided to choose cancer as a disease is the dominance of narratives of fear and control surrounding it. Cancer has frequently been described as “the most feared of modern diseases” (Clarke and Everest, 2006, p. 2591). In her seminal work ‘illness as metaphor’, Susan Sontag (1978) explores the punitive and prejudicial character of illness metaphors in modern medicine. Sontag focuses on cancer and tuberculosis, as they both constituted symbolic representations of fearful diseases of respectively the 20th and 19th centuries at the time the book was written (the book was written before the epidemic of AIDS). Writing this work while being treated for breast cancer herself, Sontag explores the blaming language within disease narratives, which frequently depicts the situation as a loss of personal control.

Indeed, cancer’s language is often characterised by metaphors of battle and movement. We talk about the *uncontrolled growth or proliferation of malignancy*, and the inability to control this growth without specific interventions (Lantz and Booth, 1998). Aspects such as the ‘staging’ of the disease, from prevention to early detection to stage I to IV, participate as well in the intensification of the individual experience of cancer, as they add to the theatricals of the movement of cancerous cells. On the other hand, the cancerous body becomes a *control freak*. As Fox (2002, pp. 357-358) describes: “the cancerous (cancering) body: The body subjects itself to censorship, to moralistic outrage. It appraises itself: ‘this part is good, it can remain; this part is bad, it must be excised or burnt or poisoned or overcome by positive mental effort’. The body is conservative, it is suspicious of novelty, of otherness: it is a control freak because the worst consequence is to lose control”. The body oscillates between loss of control and control frenzies. Drawing back on Austin’s perlocutionary effects from chapter two, the cancerous body as a ‘control freak’ is an effect of the iteration of the narrative of cancer as a loss of personal control. The need to organise and control something frightening and chaotic stems from its initial representation as such. The

processes through which these effects take place are eloquently described by Fox in the above quote.

Several scholars within sociology of health and illness have stressed the dominance of the medical framing of cancer, which exacerbates the discourse of fear within the disease narrative¹. A medical framing of cancer focuses on technomedical discourses as well as pharmaceuticals and surgery interventions (Clarke and Everest, 2006). This sets other framings to the background, such as the political framing which focuses for instance on the relationship between inequalities and the incidence of cancer, or environmental contaminants (Brown et al., 2001). Framing a disease in a specific way has important implications for determining the sites of responsibility and blame, as well as legitimising the appropriate tools of control.

Within the present study, I focus on a specific type of cancer, hereditary breast and ovarian cancer (HBOC), and a specific set of genes, the BRCA genes (BRCA1 and BRCA2). Without going into complex scientific details about these type of genes and cancers, inheriting a mutation in BRCA1 and BRCA2 is considered to be linked to an increased risk of female breast and ovarian cancer². They have also been associated with other types of cancer as summarised in table 1 below. The labelling of the gene is related to breast cancer only however, as BRCA is an acronym for BReast CAncer, and the genes are known as BReast CAncer 1 (BRCA1) and BReast CAncer 2 (BRCA2). This is what led the gene to be commonly known as the breast cancer gene, despite being associated with other types of cancer (I will get back to this focus on breast cancer at the end of this section). Breast cancer is overall a quite common disease

¹ Having said that, I am not intending to draw on the 'disease mongering' literature. This literature has been concerned with the corporate selling of sickness that both widens the scope of a disease and contributes to the growth of the market of technoscientific interventions, or what Moynihan et al. (2002, p. 886) label "corporate construction of disease". Despite some valuable inputs, the analytical use of this scholarship is quite limited. It suffers from symptoms similar to those of Critical Discourse Analysis (discussed in chapter four). The issues are primarily its pre-conceived normative judgement and critique, and a tendency to move too quickly to grandiose claims about the phenomena it examines.

² The direct causal mechanism between the BRCA mutations and the development of particular cancerous cells is yet to be elucidated. As elaborated by a report by the NHS (The Royal Marsden NHS Foundation Trust, 2016, p. 2): "we also do not yet understand why the *BRCA1* and *BRCA2* mutations primarily give a high risk of breast, ovarian and prostate cancers, rather than other types of cancer". Nevertheless, research has identified an increased frequency between those types of cancers and BRCA mutations as detailed in table 1.

unfortunately. It affects one in eight women at any given point during their lifetime, although occurring more frequently post menopause. The two gene-mutations account for about 20% of hereditary breast cancer, around 5 to 10% of all breast cancers, and approximately 15% of all ovarian cancers (Pal et al, 2005; National Cancer Institute, 2015); with a risk of occurrence at a younger age for mutations carriers.

Cancer Type	General Population Risk	Risk for Malignancy ¹	
		<i>BRCA1</i>	<i>BRCA2</i>
Breast	12%	46%-87%	38%-84%
Second primary breast	2% within 5 years	21.1% within 10 yrs 83% by age 70	10.8% within 10 yrs 62% by age 70
Ovarian	1%-2%	39%-63%	16.5%-27%
Male breast	0.1%	1.2%	Up to 8.9%
Prostate	6% through age 69	8.6% by age 65	15% by age 65 20% lifetime
Pancreatic	0.50%	1%-3%	2%-7%
Melanoma (cutaneous & ocular)	1.6%		Elevated Risk

1. [Ford et al \[1994\]](#), [Easton et al \[1995\]](#), [Ford et al \[1998\]](#), [Robson et al \[1998\]](#), [Breast Cancer Linkage Consortium \[1999\]](#), [Verhoog et al \[2000\]](#), [Satagopan et al \[2002\]](#), [Thompson & Easton \[2002\]](#), [Hearle et al \[2003\]](#), [Kirova et al \[2005\]](#), [Robson et al \[2005\]](#), [van Asperen et al \[2005\]](#), [Chen et al \[2006\]](#), [Risch et al \[2006\]](#), [Tai et al \[2007\]](#), [Graeser et al \[2009\]](#), [Evans et al \[2010\]](#), [van der Kolk et al \[2010\]](#), [Kote-Jarai et al \[2011\]](#), [Iqbal et al \[2012\]](#), [Leongamornlert et al \[2012\]](#), [Moran et al \[2012\]](#), [Mavaddat et al \[2013\]](#), [van den Broek et al \[2015\]](#)

Table 1: Risk of malignancy in individuals with a Germline BRCA1 or BRCA2-Pathogenic Variant

Source: Petrucelli et al. (2016)

In the rest of this chapter, I explore how the narratives surrounding BRCA genes and their mutations add an additional layer of configuration to female cancerous bodies³. The narrative will be centred mostly on breast cancer. The main reason is the cultural

³ I will not be addressing men’s breast cancer in this study. Male breast cancer represents less than 1% of breast cancer cases, and has a prevalence of 1 in 1000 men (compared to 1 in 8 for women). However, it is not the low prevalence that motivated my decision. For the sake of coherence of this thesis, I decided not to include the gendered aspect of the disease, as the complexity of the experiences of men with breast cancer would take this research in a different direction. There is also the context of Transgender people affected by breast cancer, which adds another layer of complexity to their experiences of HBOC in a hetero/cis-normative society. These different contexts of breast cancer could potentially be explored in a separate study with different research questions and a different theoretical framework.

dominance of breast cancer. Ehrenreich (2001, p.45) argues that breast cancer has become “the biggest disease on the cultural map, bigger than AIDS, cystic fibrosis, or spinal injury, bigger even than those more prolific killers of women – heart disease, lung cancer and stroke”. Breast cancer has a high visibility in the media (Clarke and Everest, 2006). It has become a highly political disease attracting a large amount of research funding leading some critics to call it “the pinnacle of charitable causes” (King, 2004, p.473), and enjoying the lion share of cancer community funding (Klawiter 2008), as well as the largest share of research funding from the biggest research organisations on cancer such as the US National Cancer Institute (King, 2006). Although in appearance benign (and even positive one could argue), this cultural hegemony has important implications for the construction of women’ bodies who at risk or diagnosed with breast cancer, as well as the framing of other non-mammary related cancers, such as ovarian cancer⁴.

The marketization of the breast cancer movement tremendously increased the profile of the disease (Bell, 2014). Above all, it is the survivorship discourse and the ‘pink ribbon’ as a symbol for survivors that attracted a variety of corporate sponsorship for breast cancer awareness campaigns, or what King (2006) has called ‘pink washing’. The ‘breast cancer survivor’ has become an iconic figure for hope, not only for people affected or at-risk of breast cancer, but also shaping a narrative of survivorship for cancer in general. As Moynihan (2002, p. 169) noted, “Breast cancer, with all its apparent connotations, has become the exemplar of all other cancer journeys and protocols”. The discourse of survivorship is highly dominant within cancer narratives, and the breast cancer movement (including the pink ribbon symbolism) has certainly been a driver for this dominance. Bell (2014) argues that we have been witnessing a ‘breast-cancerisation’ of cancer survivorship. In order to understand the historical and cultural context of HBOC and the BRCA gene, the rest of this chapter focuses more on breast cancer, rather than ovarian cancer, particularly with regards to the survivorship discourse. Survivorship has been a key narrative in constructing the identities of

⁴ This cannot be attributed to the prevalence of breast cancer. For instance, in 2009, there has been almost as much cases of men with a history of prostate cancer than women with a history of breast cancer (2,500,000 and 2,747,000 respectively), as reported by the Surveillance, Epidemiology and End Results (SEER). Similar tendencies have been registered in Canada during the same year (Bell, 2014).

women with cancer and shaping their relationship to their bodies, as well as the practices they undertake with regards to their condition. Unpacking the biopolitics of the breast cancer movement is therefore a key point to start with.

This is of most importance to the present study as the pre-ill narrative has a co-constitutive relationship with the survivors' one. Genetics shakes the definitions of diseases particularly in terms of understandings of causality as previously discussed in chapter three, shifting the focus from the ill to the pre-ill. With such a redefinition, there is a potential for tensions and loss of legitimacy, as the word 'survivors' bears the underlying assumption of facing a life-threatening situation. However, the discourse of survivorship is necessary for the breast cancer movement as it has been effective in mobilising actors within the network of breast cancer (research, funding bodies, regulatory bodies and so on). These aspects make the transition of the discourse from ill to pre-ill of primary importance, which is the focus of the remaining of this chapter.

The following sections explore the dominance of the survivorship discourse within breast cancer movement, as well as the tensions with other narratives, including the translation of the survivorship narrative from the ill to the pre-ill body.

6.2. The dominant discourse of survivorship:

As elaborated in the previous section, the discourse of survivorship is dominant within cancer narratives, and has been a driver for the breast cancer movement in the past few decades. Breast cancer has gone through various cultural reconfigurations since the 1970s, going from "a stigmatized disease and individual tragedy best dealt with privately and in isolation, to a neglected epidemic worthy of public debate and political organizing, to an enriching and affirming experience during which women with breast cancer are rarely 'patients' and mostly 'survivors.'" (King, 2004, p.475). Thus, 'survivor' and survivorship have penetrated ubiquitously breast cancer, cancer, and even popular discourses. Nevertheless, its developments, as well the meanings ascribed to it, are often left unquestioned, and the culture surrounding breast cancer

presumes that women affected by the disease should embrace the identity (or 'subject position' as discussed in the methodology chapter) made available for them. There has been historically two distinct approaches to breast cancer activism. On the one hand, there is the activism that focused essentially on fundraising. This strand has worked towards the destigmatisation of the disease, as well as the fundraising for research, screening and education. It contributed strongly into shaping the treatments, the screening methods, as well as the number of spaces for support available for patients. The mobilisation around the pink ribbon is a great example of such activism. However, this type of activism does not necessarily challenge the established approaches of its areas of action (research, screening and education), as has been pointed out by feminist critiques (Klawiter, 2000, 2008; King, 2004). On the other hand, feminist activism has been geared towards political action. The main purpose of these activists is destabilising the dominant methods of understanding and acting on breast cancer. Some of the major topics that it addresses are environmental contaminants as a cause for cancer, the blurring of the lines between prevention and early detection, as well as issues of access to the marginalised such as poor people, ethnic minorities, disabled, and LGBT women.

Another aspect where the two approaches held an antagonist point of view is the concept of survivorship. Proponents of the first movement view survivorship as a symbol of hope. This narrative of hope very much contrasts with the one of fear that dominates the breast cancer discourse. It also extends beyond the single individual/patient, onto the hope for a cure. The hope for a cure is the primary driver for research, and the necessity to generate funding in order to achieve this aim. Approaches to generate funding have been very diverse. These range from all the pink ribbon branded product (such as the Estée Lauder Breast Cancer Awareness' range in figure 24 below), the different fundraising races and marathons (such as the Susan G. Komen Foundation's *Race for the Cure*), or the MacMillan free kits for fundraising events (the latest one being the free Coffee Morning kit to host a get-together/fundraiser). The symbolism of the mainstream breast cancer activist movement through a vivid pink coloured ribbon is a surprising choice at first. Indeed, pink is a colour constructed in our contemporary culture as girly, pretty, and healthy, which makes it an odd choice

for a disease such as breast cancer that is characterised by a loss of womanhood (King, 2006). However, this colour works in perfect symbiosis with the overly optimistic and positive tone of the survivorship discourse. Another iconic example of this movement is the *Breast Cancer Research Stamp* that was unveiled by Hillary Clinton in 1998. The slogan of the stamp's campaign was *'Fund the Fight, Find a Cure'*. There are several interesting linguistic devices within this slogan. First of all, the fight is formulated as defined and the cure as unknown through the use of the determiners *'the'* and *'a'* respectively. Furthermore, the ordering of the sentence alludes to a causal mechanism between the acts of funding the *'fight'* and finding a cure; *finding a cure* is constructed as a direct consequence of *funding the fight*. It also constructs the act of *finding a cure* as a collective act. This specific formulation has a function of framing the *'right'* ways of fighting breast cancer as established and somewhat indisputable, and the cure as a subsequent collective effort that is contingent on the funding of the fight. Such practices construct survivorship and cure as individual acts of philanthropy performed within the arena of consumer culture (King, 2004).

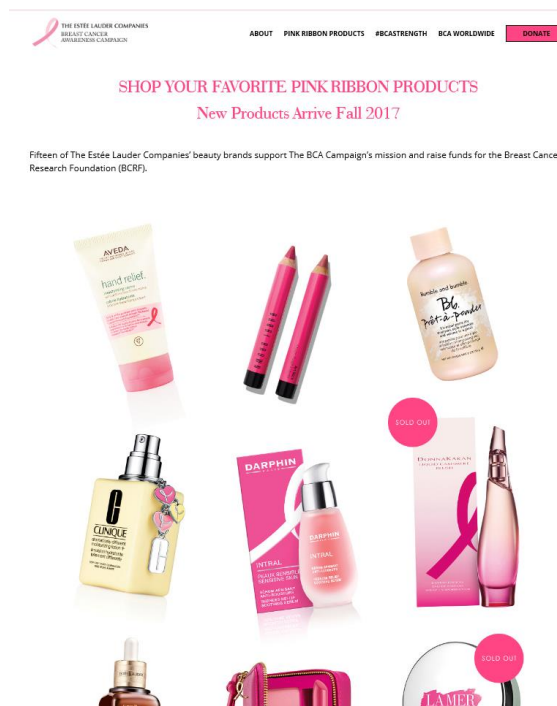


Figure 24: Estée Lauder Breast Cancer Awareness' range for fall 2017

Source: <http://www.bcacampaign.com/pink-ribbon-products/> [Accessed: 08/2017]

Feminist critiques have pointed out the profound political effects of the practices surrounding the survivorship movement, and suggest to view them as an exercise of fulfillment of obligations as part of the individual's *biological citizenship* (Rose, 1999a). The model figure of the biological citizen is framed as a compassionate consumer, but also a consumer of compassion, who is actively involved in philanthropic programs in an effort to strive to become the *ideal* biological citizen. Survivors are depicted as "courageous, self-responsible, high-order citizens" (king, 2004, p. 489). However, this biological citizen does not challenge established methods of organising against breast cancer. Their duties are delineated into securing funding, volunteering in events, and participating in clinical trials when applicable. Bell (2014, p. 62) view biological citizenship within the breast cancer movement as "the subsequent willingness of white, middle-class women with a history of breast cancer to participate in research as part of their perceived duties as 'good' biological citizens".

As observed by feminist and queer theory critics on the AIDS epidemic before, the usage of positive metaphors in disease narratives can have important political implications. First of all, and as King (2004) argues, an overly optimistic and hopeful configuration of breast cancer has an effect on diminishing the rage of activists particularly with regards to the activism against environmental contaminants, leaving a hereditary/individualist view dominating. Second, the narrative of survivors can alienate women who are going through the side effects of breast cancer treatments, a poor prognosis, or dying from breast cancer (Kaiser, 2008). As much as they can be inspiring and uplifting, success stories do not work for everybody, especially for people going through the disease. Their primary function is more geared towards the celebration of the advances and heroism of biomedical sciences, as well as the different actors involved in making the success story a reality. As Ehrenreich (2001, p.48) put it: "In the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the 'survivors' who merit constant honor and acclaim. They, after all, offer living proof that expensive and painful treatments may in some cases actually work". Finally, the survivorship discourse reconfigures activist's actions through a consumer culture lens. The plethora of pink ribbon branded products that are available, as well as the other examples discussed above,

are a great testament of such reconfiguration. Feminist activists have been vocal about their criticism of the marketisation of the breast cancer movement. For instance, the Breast Cancer Action (a key organisation of feminist cancer activism) launched in 2002 the *'Think Before You Pink'* campaign to expose corporations' *pink-washing* practices and encourage consumers to be critical and reflexive about their consumption of pink ribbon products, especially with regards to the actual amounts that go into the cause.

Parallel to the mainstream breast cancer movement, feminist cancer activism was committed to providing a space for the unheard voices. Taking inspiration from the LGBT movement around the AIDS, this movement has been challenging the upbeat discourse of survivorship. Indeed, the core principles of the model of AIDS activism was the organisation of the fighting against the demonization of people affected by AIDS, yet the movement was equally dismissive of the trivialisation of the condition through overly positive messages. Similarly, feminist cancer activism is critical of the normalisation of women bodies who are affected by breast cancer. Whilst the mainstream breast cancer movement promoted unscarred, heterofeminine albeit cancerised bodies, feminist activists championed making spaces available for the expression of "alternative images, alternative discourses, and alternative ways of embodying breast cancer" (Klawiter, 2008, p. 169). Indeed, survivorship stories put forward what Frank (1995) called a *'restitution narrative'*. Through technologies of the body such as breast reconstruction, prostheses, wigs and a careful choice of clothing, the transformation of breast cancer survivors' bodies, so they can mirror the image of healthy ones, is not only made possible but encouraged within the survivorship discourse. Feminist activism highlights how the dominant discourse of survivorship actually distorts the ugly realities of the experiences of women living with breast cancer. Instead of the 'normalised' body, the movement gave a space for the scarred, the one-breasted and un-breasted bodies, as well as other non-conformist and marginalised identities. Mostly, feminist breast cancer activism was committed to a culture of patient empowerment. Empowerment is understood, within this context, as giving a voice to expressions of sorrow, anger, grief and other unpleasant emotions to those who were alienated by the survivorship discourse, and strongly contributed

to environmental activism and alternative ways of cancer prevention. It “celebrated the ongoing struggles of women ‘living with cancer’” (Klawiter, 2008, p. 169), rather than the overly positive image of cancer survivors. The movement was also dedicated to mobilising support, care and compassion for women living with cancer, especially the marginalised such as disabled, LGBT, ethnic minorities, and poor women.

Within the current study, the disease is reconfigured through genetic knowledge as a genetic disease. As I am focusing on individuals’ at-genetic risk of breast cancer, I am moving the analytical focus in space and time: from the ill to the ‘pre-ill’ body. This leaves me with the following questions: what happens to the survivorship discourse during this movement? Are there any tensions between its narrative and the genetics’ one? And what are its effects (if any) on the pre-ill body? These are implications that I had to take into consideration when formulating my research questions (presented in the previous chapter) and building my theoretical framework. In the next section, I provide examples of narratives of breast cancer in the media, and start drawing the dominant themes particularly when moving to a redefinition of breast cancer as a genetic disease.

6.3. Breast cancer in the media:

The mass print media plays an important role in shaping cancer discourse about the nature of the disease, diagnosis, prevention, and treatment (Clarke and Everest, 2006). The framing of the disease participates in informing health policies as well as personal experiences of cancer.

King (2004) traces the evolution of breast cancer in media in the 1990s, from ‘*Anguished Politics*’ to ‘*[This] Year’s Hot Charity*’. In 1993, the breast cancer activist and artist Matuschka featured in the *New York Times Magazine*. The image was a self-portrait and clearly displayed a mastectomy scar in the original location of her right breast. The top right part of the dress was cut in such a way as to make a statement with this visual. The headline reads: ‘*You Can’t Look Away Anymore: The Anguished Politics of Breast Cancer*’ (Ferraro, 1993). The narrative of the article was very much influenced by feminist activism, addressing issues of prevention, public awareness, as

well as the linkages between environmental contaminants and disease incidence rate. Three years later, the tone changed completely. In 1996, breast cancer was proclaimed 'year's hot charity' in the *New York Times Magazine* (Belkin, 1996). The previous image of the scared body, that was described by some readers as 'shock therapy' (anonymous, 1993), left the space to a photograph of Linda Evangelista, fashion model on the way to becoming breast cancer activist at the time. The visual was a head and shoulders shot of Evangelista, coiffed with her iconic haircut at the time, and with her left arm across her chest, covering her breast in a much stylised fashion pose. The narrative of the article was centred on the willingness of corporations and politicians to support the cause, thanks to the work of activists and survivors on the cultural appeal of breast cancer, associating it much more with heteronormative conceptualisations of femininity. The two covers are displayed in figure 25.



Figure 25: Breast Cancer from politics to charity in the 1990s. On the right side, NYT' cover featuring Matuschka in 1993 (Copyright © New York Times Magazine). On the left side, Linda Evangelista' Billboard in 1996 featured in the NYT' story (Source: <http://www.ytime.com.ua/ru/22/148/7> [Accessed: 08/2017]).

The two headlines are manifestations (but also agents in shaping public understanding of the disease) of the two main strands of breast cancer activism. Did the reconfiguration of the disease through genetics discourse push to the side the environmental factor advocated in the 1993 headline? And what happened to the survivorship discourse, promoted in the 1996 story, on the way?

In the next section, I analyse the op-ed by the American actress, film director, screenwriter, and author Angelina Jolie, that was published in *The New York Times* on May 14th, 2013. In her piece entitled '*my medical choice*', Angelina Jolie revealed to the public her decision to undertake a double mastectomy following her diagnosis as a faulty gene carrier. In the previous chapter, I discussed the rationale for the choice of this particular piece (as well as the Angelina 'effect'). The analysis will hopefully help answer the questions above, as well as stimulate new questions for the analysis of FORCE forum interactions.

6.4. Analysis of '*my medical choice*':

I identified three main polarities within Angelina Jolie's letter: fear/hope, factuality/subjectivity, and control/anxiety. First, I explore the construction of these polarities. This include situations where one of the conceptual poles is privileged within the discourse. My focus is also on instances of production or re-arrangements within the discourse. Finally, I move the discussion onto the overall activist tone of the piece, and its wider effects. A copy of the letter, '*my medical choice*', is available in appendix A.

6.4.1. Fear/Hope:

Despite the apparent neutral tone of the piece's narrative, *fear* was a dominant discourse. Throughout the whole piece, Angelina Jolie seems to be legitimising the fears about the risk associated with carrying the faulty BRCA gene, developing breast cancer, dying and not being able to be there for her children. The piece starts with a

metaphor of battle, which is an extremely common metaphorical system within cancer narratives, '*MY MOTHER fought cancer for almost a decade and died at 56*' (capitalisation in original). Starting with a 'lost' battle already positions cancer as a strong 'enemy', and calls for an impeccable strategy to defeat it. The piece does not address cancer in general however; it is concerned, as the title explains, with Angelina Jolie's '*medical choice*' (she was not diagnosed with cancer). She further positions herself within the narrative through the use of '*I have always told them [her children] not to worry, but the truth is I carry a "faulty" gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer*'. The use of the discourse marker '*but*' is of particular interest here. It does not have a referential contrast function only, but performs as a rhetorical device to reassess Angelina Jolie's need to worry. It contrasts with her telling her children not to worry that she could have the same faith as their grandmother, and redirects the focus to her 'truth' of carrying a faulty gene. The function here is reassessing the need to worry, or the fears with regards to the risk of the occurrence of breast and/or ovarian cancer. The fact that carrying a 'faulty' gene, BRCA1, '*sharply increases her risk of developing breast cancer and ovarian cancer*' legitimises the fear, and paves the way for the rest of the story, narrating the actions taken against those fears. The sense of responsibility can also be clearly located within the formulation '*I carry*', which positions Angelina Jolie as having a sense of self with regards to the faulty parts within her body, and the need to act upon this deficiency. In contrast, she could have used, for instance, '*I have inherited*', which would have completely reconfigured the attribution of blame. It would have been located within the meaning of inheritance, therefore blaming bad luck or ancestors. The metaphor of carriage within genetics discourse will be dissected in chapter seven.

Another example of a manifestation of *fear* within the narrative was the use of the metaphorical formulation '*living under the shadow of cancer*' (emphasis added). This formulation emerged within the genetic conceptualisation of cancer, and creates a new sense of the experience of the at-genetic risk individual. It positions cancer as almost inevitable and omnipresent in the at-genetic-risk individual's life and thoughts. The formulation '*under his shadow*' is idiomatic, or as Derrida (Derrida and Moore, 1974) explains a dead metaphor through its '*usure*'. This idiomatic expression can

suggest a protection (or Divine Providence as suggests its original use in the *Book of Lamentations*), or a danger (through its movement within the healthcare discourse). Within the HBOC narrative, the new formulation '*under his shadow*' brings a reconfiguration of the disease implying a high causality of the disease by the faulty gene. As parker (1988, p. 187) puts it: "each act of interpretation requires the production and reproduction of the system of language and, crucially, the production of new metaphors which disrupt the system".

Instances of *hope* were also present; mainly when discussing the advances of biomedical sciences, whether it concerned preventive procedures as such double mastectomy or body enhancement through post-surgery breast reconstruction. For instance, when Angelina Jolie writes '*I feel empowered that I made a strong choice that in no way diminishes my femininity*', her utterance performs two functions primarily. First it links her feeling of empowerment to (1) the freedom of making a choice, and (2) the availability of strong options to choose from. It also connect the choice to a major construct that is associated with breast cancer treatment, which is the loss of womanhood through the removal of breasts. In line with the discourse of survivorship discussed in the previous section, her statement reinforces the view that breast cancer survivors' bodies can mirror heteronormative images of the healthy body through making the right choice. However, the utterance shifts the argument in time and space, from the ill to the pre-ill body.

6.4.2. Factuality/Subjectivity:

The letter oscillates between factual descriptions and other more subjective statements about Angelina Jolie experiences. Examples of factual descriptions within the letter include '*Breast cancer alone kills some 458,000 people each year, according to the World Health Organization, mainly in low- and middle-income countries*', or '*It has got to be a priority to ensure that more women can access gene testing and lifesaving preventive treatment, whatever their means and background, wherever they live*'. The use of evidence, whether of quantified nature or not, gives the utterances an appearance of straightforward descriptions of the 'world-as-it is' (Edwards and Potter, 1993). Examples of subjective statements include '*I do not feel less of a woman*', or '*I feel empowered that I made a strong choice that in no way*

diminishes my femininity'. The utterances refer to emotional states, and constructions of femininity and womanhood for post-mastectomy patients.

An interesting aspect in this case was the choice of pronouns and subjects within the construction of factual and subjective claims. While the first person was primarily used in subjective statements, factual claims were populated by the use of the third person. In the extracts above, for instance, the first person pronoun 'I' was used in subjective statements, and the neutral pronoun 'it' was used in factual claims. Another example for this transfer of subjectivity can be seen in Angelina Jolie's presentation of the quantification of her risk. She transitioned from *'the truth is I carry a "faulty" gene, BRCA1, which **sharply** increases my risk of developing breast cancer and ovarian cancer'* (emphasis added) to *'My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer'*. While the first utterance presents a non-numerical quantifier, *'sharply'*, that has the function of intensifying the narrative around her risk; the second utterance presents cold factual numerical quantifiers, 87 and 50 per cents. Alongside this movement of the formulation of the evaluation practices, there is also a transition from the use of 'I' when presenting a non-quantified intensification of the risk, to calling expert voices, *'my doctors'*, to present factual figures about the same object (her risk) being quantified. As I will discuss in depth in chapter seven, the neutral pronoun 'it' as well as the call to expert voices, constitute rhetorical devices used to conceal subjectivity and establish objectivity in speech; whereas the first person pronoun 'I' refers to a sense of responsibility of one's actions (Harré and Harris, 1993; Pennycook, 1994). In uttering *'I carry a faulty gene'*, *'I had an 87 percent risk of breast cancer...'*, or *'I feel empowered'*, Angelina Jolie is not signalling an actual self or ego, but referring to a moral location. Referring to a moral location means having a sense of one's own responsibility. She is therefore acknowledging (implicitly or explicitly) her rights and duties as a *'faulty gene carrier, an individual having 87 percent risk of breast cancer'*, or an *'empowered'* individual.

6.4.3. Control/Anxiety:

As discussed previously, both genetics and cancer discourses are strongly associated with narratives of control, loss of control, and anxiety. It is therefore not surprising

that the themes were prevalent within Angelina Jolie's letter. These were entangled with constructions of subjectivities, as well as references to moral responsibility. The first obvious example is the title of the piece itself, *'my medical choice'*, which signals an ownership of medical destiny; an aspect that has been a subject of praise in the media's response to the letter as discussed earlier. Other examples include *'once I knew that this was my reality, I decided to be proactive and to minimize the risk as much as I could'*, or *'I started with the breasts, as my risk of breast cancer is higher than my risk of ovarian cancer, and the surgery is more complex'*. The use of the first person pronoun *'I'* is again a signal of a sense of responsibility of self-governance with regards to different practices and decisions – from the proactivity to minimise one's risk to the ordering of the cutting of defectuous organs (breast then ovaries). The narrative of control could also be found in the career management in relation to BRCA identity in *'During that time I have been able to keep this private and to carry on with my work'*. For a female icon such as Angelina Jolie, who is very much known for her physical appeal, a double mastectomy could potentially be detrimental to her career. Indeed, the filming of the blockbuster *Maleficent* (released in 2014) started in June 2012, where Angelina starred in the leading role as Maleficent; whereas the procedure for her preventive surgery took place in February 2013. The control of the privacy of genetic data has been for a long time a controversial topic, as individuals can be subject to discrimination at work, access to insurance and so on; which legitimises the need to control the privacy of the genetic identity. Another instance of a control narrative is the utterance *'They (her children) can see my small scars and that's it. Everything else is **just** Mommy, the same as she always was'* (emphasis added). The case here is a control of *'identity'* and *'self'* through the control of body image by the means of reconstitutive surgery. The faulty genes and defective organs are constructed as *'other'* to the self. What remains of this *'other'* after the preventive surgery is the *'small scars'* only. The scars are the reminiscent of the defectuous organ; however, the subject position *'Mommy'* is stabilised through the qualification of these as *small*, therefore limiting the effects of the scars.

However, this sense of control is presented as contingent on the access to a *'blood test'*, as well as medical experts providing information, and performing the calculation

process. The remainder of Angelina Jolie's piece focuses on this notion of access and takes an activist tone, which is the focus of the rest of my analysis.

6.4.4. Discussion - Evidence-based activism:

*'Cancer is **still** a word that strikes fear into people's hearts, producing a deep sense of powerlessness'* (emphasis added). Angelina Jolie sets the tone for her activism for access to genetic screening through this utterance. Although there is no mention of genetic predisposition, BRCA or preventive measures, the utterance paves the way for a discussion around these issues. The use of *'still'* implies that cancer should not be striking fear into people's hearts anymore. The reason for this can be found when connecting the second part of the utterance to other claims in the letter. The effect stated for cancer still striking fear is the production of *a deep sense of powerlessness*. The opposite of the production of powerlessness is *empowerment*. Angelina Jolie mentions elsewhere *'I feel empowered that I made a strong choice that in no way diminishes my femininity'*. As I have discussed earlier, this utterance links her feeling of empowerment to the freedom of making a choice, and the availability of strong options to choose from. This constructs powerlessness in the other sentence as caused by either an absence of freedom of choice, or a restricted/unavailable access to 'strong' options to choose from. The options are delineated later on in the letter; in for instance *'but today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action'*. The use of the indefinite article *'a'* preceding *'blood test'*, to present genetic testing, has the function of trivialising the latter, implying that its access should not be problematic. Following that, she makes a causal connection between the performance of this blood test and taking action. The conjunction *'and'* has the function of ordering and sequencing her argument, but also making a causal mapping. Through this formulation, Angelina Jolie constructs the individual action plan against the still scary cancer, as dependent on the performance and access to genetic testing. After presenting access to genetic testing as the condition for action against cancer, she delineates the problem in utterances such as *'The cost of testing (...) remains an obstacle for many women'*, and *'it is my hope that they, too, will be able to get their gene tested, and that if they have a high risk they, too, will know that they have strong*

options'. The argument comes full circle when she presents the cost of testing as a barrier for the availability of 'strong' options for women who might be a high genetic risk of HBOC.

As Pomerantz (1978, p.119) argues, part of the business of blaming involves "treating an event, e.g. an 'unhappy incident', as a consequent event in a series. An antecedent action, one which is intendedly linked with the 'unhappy incident', is referenced. The actor of the antecedent action has the status of a candidate blamed party". The 'unhappy incident' becomes a product or a consequence of a restricted of access to genetic testing. The restrictions are attributed to the cost barrier. The empowerment of individuals is also framed within the access to genetic testing; thus, taking off the cost barrier should enable this form of empowerment.

Later on during the same year (2013), the US Supreme Court ruled on a case regarding patent protection on BRCA1 and BRCA2, and came to the decision that "A naturally occurring DNA segment is a product of nature and not patent eligible merely because it has been isolated" (Supreme Court of the United States, Syllabus, Association for Molecular Pathology et al., v. Myriad Genetics, inc., et al., p. 2). After several re-appeals, Myriad Genetics decided finally to end the patent dispute on the BRCA gene in 2015 (Pollack, 2015). This resulted in the possibility of cheaper testing options for the BRCA gene to be available to the public. Following that, some have argued that the Angelina Jolie letter had an effect in shaping the US Supreme Court' decision (Caldwell, 2013).

Rabeharisoa and colleagues (2014) used the term '*evidence-based activism*' to capture patients and activists' practices on knowledge mobilisation when addressing issues related to the governance of healthcare. Indeed, Angelina Jolie's deployment of facts and figures, as well as her call to notorious expert voices seems in line with such a concept. However, while Rabeharisoa, Moreira, and Akrich (2014, p. 123) argue that this form of activism "targets both epistemic and political issues", I argue that the present case of evidence-based activism targets politics issues of access only. On the other hand, it perpetuates the geneticism discourse, as I have demonstrated through this analysis, and presents it as an enabler for the empowerment of individuals labelled at-genetic risk.

6.5. Concluding thoughts:

Biomedical and public health discourses play a central role in delineating the meanings of being 'at-risk'. Categorising an individual as being at-genetic risk for breast and ovarian cancer places them in "a liminal category of wellness: neither actually ill (yet) nor fully well" (Lupton, 2012, p. 17). The reconfiguration of cancer as a genetic disease generates a sense that the apparently healthy body is actually concealing a malignancy, which has a high chance of growing at any given time. Subsequently, the individual experiences life *under the shadow* of cancer. While destabilising the control of the body by conceptualising a part of it as defectuous, genetics discourse fosters simultaneously a sense of control, by making additional options available to reduce uncertainty. Thus, genetic information is constructed as empowering individuals, through the catering of new choices for health risk management (Hallowell and Lawton, 2002). On the other hand, health risk management is an individual moral responsibility under neoliberalist governance. Failing to comply with the ethical practices to 'fix' the body and control the risk is, therefore, constructed as a moral negligence (Lupton, 1995; Peterson and Lupton, 1996; Beck-Gernsheim, 2000).

In line with a Butlerian performativity, I attend with the present research to the ideological problems associated with the epistemological category 'at-genetic risk'; particularly in relation to the moral responsibility of consuming preventive procedures. The next chapter will further address these concerns by exploring market performativity in the context of an online community, FORCE, that attends to individuals with a genetic propensity for HBOC.

Chapter 7: Analysis of FORCE interactions

The previous chapter focused on the cultural and historical contexts of breast and ovarian cancers, and their redefinition as genetic diseases. In it, I dissected the ideological underpinnings of the survivorship discourse, as well as presented an analysis of breast cancer in the media. An important part of my attention was directed towards the public declaration of Angelina Jolie in *The New York Times* about undertaking a preventive double mastectomy following her diagnosis as a carrier of a faulty gene. At the centre of the discussion was the empowerment through the availability of knowledges and choices for health risk management, as well as the individual moral responsibility to address these.

This chapter further addresses these aspects, and presents the analysis and findings from the biosocial community FORCE. All the extracts copied in this chapter from the message board are the property of FORCE. Copyright © FORCE-Facing Our Risk of Cancer Empowered, Inc., Tampa, Florida. All rights reserved.

Similarly to Pettinger's (2012) treatment of Punternet, FORCE can be considered as a market device (Callon and Muniesa, 2005) enrolling a multitude of actors to help qualifying the quantification of genetic risk, and evaluating the various procedures and market solutions to deal with this percentage of risk (or lack of quantification in some cases as we will see). There are strict guidelines with regards to the mentions of specific doctors' names. Thus, the qualification and quantification processes concern more the female bodies and the appropriate procedures, rather than specific healthcare practitioners and their services.

Through the provision of the 'pre-ill' subject position, genetics provides new definitions of 'health capital', and attributes responsibility to patients before the

beginning of the disease; with the 'the duty to get better' shifting to 'the duty to stay healthy' (Greco, 1993). Whereas, the value of 'getting better' and 'staying healthy' by 'not developing the disease' remain undisputed, the contradictions and messiness of valuations emerge from the process of evaluation of risk itself. This evaluation comes through its quantification (percentage, possibility to calculate, process to calculate and so on), nature (genetic related to BRCA, genetic 'unknown', family history, environmental, and so on), as well as the procedures to reduce it. Staying healthy becomes a sort of 'KPI' of biological citizen' ability to act responsibly, with the objective of maximisation of one's health and the minimisation of the risk of genetic illness.

FORCE operates as a device in both stabilising and destabilising the valuations of these preventive procedures in relation to individual female bodies. This is performed by constantly providing up-to-date research (that can reinforce or discredit the procedures) through their website and annual conference, connecting consumers with diverging opinions together as well as with experts, and also through involving the end users in the co-creation of knowledge through their enrolment in clinical trials.

FORCE forum is composed of interactions of women, performing a qualification of risky bodies as candidates to radical preventive procedures in order to reduce their risks and maximise the duration of the status 'healthy', as defined by biomedical discourses. It represents a space where rights, duties, and responsibilities are constantly evaluated and re-evaluated, and attributed to the carrier of the faulty gene.

This chapter is structured as follow. First, I summarise the four main narratives, which contain the extracts dissected in this chapter. Following that, the analysis is structured around groups of discursive devices and what they 'do'. First, I start with an analysis of quantification rhetoric which tackles both numerical and non-numerical forms of quantification. The second part is centred on pronouns and the function of indexication. Third, I focus on the business of blame attribution through the usage of

extreme case formulations. The fourth section scrutinises the use of passivisation and its functions with regards to agency and process. Fifth, I will move to metaphors and ideology, where I introduce Derrida's *usure*. The final part will explore the discourse of empowerment and its intimate relation with responsabilisation of individuals.

7.1. Stories from the Biosocial community FORCE:

In this section, I present four narratives from my dataset, each one summarising a specific thread. This is to portray the type of conversations between the different forum contributors, as well as introducing some of the recurrent participants mentioned in this chapter.

7.1.1. Narrative 1: 'Cancer or Post-surgery Menopause effects?'

Megan is 46 years old and she started having some abnormal bleeding recently. She is worried because she is having heavy periods even when on birth control while she was used to have no bleeding at all during the same circumstances. Ultrasound showed small fibroids as well. Her mother was diagnosed with stage 3 ovarian cancer at the age of 55 and died at the age of 62. Megan remembers the period between the diagnosis and her mother's death being a very rough seven year. The fact that she is getting closer to the age of diagnosis of her mother is frightening her even more. She also has a strong family history as well, as both her maternal grandmother, and maternal great-grandmother died of cancer. Before dying, her mom gave her the following advice, 'Have kids and then get a hysterectomy'. Her mother's death occurred prior to Megan getting married, and having children.

Megan made an appointment with an oncologist to discuss genetic testing and risk factors. He suggested total hysterectomy provided the sudden onset of bleeding/fibroids, as well as the strong family history. Her oncologist did not recommend genetic testing because *'he said it wasn't foolproof and might just muddy*

the waters'. Total hysterectomy and a dramatic risk reduction: what seemed like a good idea in the exam room, wasn't as good for Megan after consideration. She has small children, and this is inducing two major fears with regards to her at-risk situation: on the one hand, she is worried about getting ovarian cancer and dying young and leaving her children while they are still so little. On the other hand, she is terrified of the hysterectomy effect on her body, and subsequently her relationship with her kids. She keeps reading that the surgery-induced menopause will cause dramatic changes in her body and her sleeping patterns. What if the total hysterectomy ruins her life and she might not even have a real risk of getting ovarian cancer?! One of her children has autism, which increases her responsibilities even more. In a nutshell, she is equally scared of having cancer, and of turning *'into a mess'*, both psychologically (depression, insomnia, mood swings) and physically (weight gain, urinary incontinence, hot flashes, night sweats), as a result of post-surgery induced menopause.

The first reply she had on the forum was from Liz. Liz jumped straight on the genetic aspect of the question. She thinks that Megan's oncologist did her a disservice by not referring her to a geneticist especially that he moved to conclusions too quickly in arguing against having genetic testing. Liz believes that a discussion on genetic testing should be held with a geneticist only, and recommends to Megan to check additional information on FORCE, and provides her with a couple of educational links about genetic screening and information around genetics in general. Megan partially acknowledges Liz point *'It's true what they say--to a hammer everything looks like a nail. So a surgeon recommends surgery'*. However, she goes beyond Liz' point and attempts to make sense of her doctor position and rationalise his advice. Megan's mother genetic status is actually unknown. Provided she didn't have any sister or other female relative from her mum's side either, this would make the knowledge about genetic status of little relevance. Liz replies back with the same focus on genetics, *'but the field of genetics has as much new research (if not more) as other medical specialties'*; and while acknowledging the importance that Megan made about her mum's genetic status, further insists on the importance of testing.

Following that, Megan does not make any further reference to Liz' point, and starts her post with *'I'm curious about how others have felt physically after total hysterectomy'*. She then redirects the conversation to one of the main fears discussed in her initial thread, menopause. Megan appears to make a certain distinction between natural menopause and surgery-induced menopause. On a positive note, a friend of hers went recently through natural menopause, and describes it as the best thing that ever happened to her. There is also another thing that is scaring Megan, which is actually breast cancer. What if she goes through the total hysterectomy procedure to finally get another type of cancer - breast cancer? She will end up then with both menopause and cancer! Although two different oncologists have expressed to her how they find BRCA test useless, she is now considering seeking support and information from a genetic counsellor.

Angie, Laura and Tracey, all went through preventive hysterectomy and reassure Megan about the post-surgery menopause. Angie is BRCA2+ and her menopause kicked off on day 4 post-surgery, but she found it manageable, and feels now more at peace than ever. Laura is BRCA1+ and had a DaVinci full hysterectomy; to then go and ran a 5K marathon less than a month after. Laura had also a lot of hesitation during the decision process, but she prayed a lot and *'decided [my] sweet Savior would not reveal this truth (genetic status) to [me] for [me] to live in fear'*. She considers the knowledge of her status as a tool for her to take action and free herself from fear. Tracey is BRCA1+ as well, and has got both a DaVinci full hysterectomy and a prophylactic mastectomy. She has been taking oral hormone therapy since the surgery and hasn't had any menopause symptoms yet, which happened 8 months ago at the time of typing the message. Tracey highly recommends genetic counselling as well, as she considers that, in addition to helping her with her decision-making, counselling made the genetic information readily available for her children in the future.

Jumping on Megan's claim on how genetic testing could be of little relevance should the status of her mother be unknown, Georgina explains how she has inherited her bad genes through her father. Both Georgina and her sister got the BRCA mutation through their dad. Georgina already went through the hysterectomy and is now taking oestrogens and feels normal. She had some issues with taking the pill after the birth

of her daughter, but did not experience any side effects with the oestrogen patches. Quoting the 'Schoolhouse Rock', Maureen recommends genetic testing as well: *'Knowledge IS power!'* Maureen is planning to have a preventive hysterectomy later during the year as well, although she shares the same fears as Megan; end up being some "sweaty, angry, crazy person that my son doesn't want to be around". Maureen believes that any person deciding to undertake a preventive surgery is highly courageous.

Jennifer comes with a different story to the other contributors. Jennifer has a strong BRCA history in her family, and her mom died of ovarian cancer. However, she tested negative for any BRCA mutation, and consider it as a big relief. Jennifer does not want to go through hysterectomy as she doesn't think she will do well with menopause. Like the other girls, she strongly recommends genetic testing, as it can allow the opposite scenario "You may very well be surprised that you are NOT at risk!"

Directly replying to Jennifer post, Megan notices her claim on being BRCA negative. She explains to Jennifer how wrong her reasoning is, and links it to why her oncologist downplayed the importance of genetic testing in her case. With genetic testing, there is potentially a risk of a sense of false security. Also, menopause happens at some point or another regardless of the hysterectomy. After clarifying these aspects, Megan gives some update on her situation: She made a decision to proceed with the total hysterectomy, scheduled the surgery, arranged care for her children, to finally find out that the doctor was not available on that particular day. This gave her 'cold feet', and she decided to temporise the course of action of the preventive procedures. In the meantime, she got the results for genetic screening. Megan is BRCA1+, and the testing revealed an Ashkenazi Jewish heritage as well. Thus, her main dilemma currently is whether to undertake the surgery with the former surgeon, or another one with a better reputation, but located far away from her.

Although Megan did not mention again her fear regarding menopause again, Leah brings it back to the conversation with a pragmatic tone, 'here's my 2 cents... menopause SUCKS but you should still have the risk-reducing surgery'. In addition to that, Leah informs Megan that she should be able to take a hormone therapy in case she has preventive mastectomy as well (provided she does not have any prior medical

history of Breast Cancer). However, Megan has not considered mastectomy at all. She hasn't even thought about the specification of the hysterectomy (DaVinci), which made her question the standard recovery times. Jade answers Megan with a focus on breast cancer. Jade is BRCA 1+ and has been given a 85% chance of getting breast cancer in her lifetime, following her genetic screening. Her dad is the carrier of the faulty gene, and the first onset of breast cancer in her family was her older sister when she reached 42 years of age. She has had BSO recently and is taking a low dose estrogenic patch. She hasn't felt any side effect yet.

Megan is now considering more seriously discussing preventive mastectomy with her surgeon. She is less scared overall with the mastectomy in comparison with the hysterectomy, as her main fears are linked to the menopause effects on her body. One of her deepest fears is how it could affect her relationship with her children. She still find it strange to have a major surgery while she is not actually sick. Jade shares similar fears with Megan. However, she explains that the situation with her children actually empowers her to make a decision and move forward. *'I actually feel empowered by my kids. From my children's perspective, I know my kids would want me to do everything in my power to keep me on this Earth as long as possible'*.

After more debating around hormone therapy, Megan updates everyone with her final decision, which is to undertake prophylactic bilateral mastectomy (hereafter PBM), bilateral salpingo-oophorectomy (hereafter BSO), and hysterectomy. Her only concerns now are the timing between the different procedures.

7.1.2. Narrative 2: 'Negative for BRCA..... But still at high risk!'

Tiffany is 45 years and has a strong family history of breast cancer. Her mother has just been diagnosed this year with breast cancer at the age of 88. Tiffany has two sisters: one died of breast cancer, and the other one does not communicate with the rest of the family. She has very dense breasts, and is full of fibroid cysts in both breasts,

which she finds so uncomfortable just before her cycles. She had 3 breast biopsies all in the left breast and all have come back clear.

Tiffany has recently had the BRCA testing done, and the result is negative. Her breast surgeon however, claims that she has a 50% risk of developing breast cancer based on her family history and the denseness of her breasts. She is frustrated by the fact that she is unable to gather more information from her family, especially from the one surviving sister that does not communicate with the rest of the family. Tiffany wants insure gathering as much information for her daughters' family history as possible. She has 2 daughters, aged 21 and 23. Her husband had Hodgkin's Lymphoma at the age of 36, and also has a sister that developed breast cancer at 36 years old, and another who passed away recently due to pancreatic cancer. Tiffany is planning to have her husband tested for the BRAC gene as well, again for the sake of documenting thoroughly the family history for their daughters, so they can have the adequate genetic information to make informed decisions.

Tiffany finds her situation overall very frustrating. She had already decided to undertake a preventive surgery, should the genetic screening results have been positive. However, being negative for the BRCA gene mutation with a high risk due to family history and dense breasts *'still leaves you in the unknown'* as she describes. Although she is happy with being negative and having had her breast MRI with no identified tumours, she is debating as to whether she should continue to monitor her risk closely or proceed with the preventive surgery. She would ideally work on a healthy lifestyle and close monitoring, before proceeding with the surgery. However, the downside of this option is the risk of developing breast cancer during that *waiting* time. This is leaving her in a great confusion.

Roxy and Ivy were the first ones to reply to this thread, and both their situations were bearing similar traits to Tiffany's: They both tested negative for the BRCA gene mutation, despite having a strong family history of breast and/or ovarian cancer. Roxy is 55 years old, and has a family history of BRCA2, however her genetic screening results were negative. Roxy has been having frequent benign cysts in her breasts since the age of 30. Four years after her menopause, she was diagnosed with an early stage breast cancer. Although her doctor put forward the possibility to treat the tumour

with surgery followed by a course of radiation, she decided to go for a PBM. She is now *'living free of cancer and the FEAR of cancer, too'*. Ivy has a strong family history of both breast and ovarian cancers. Her mother tested negative for the BRCA gene mutation, and Ivy results were negative as well for *'any known mutation'*. Her genetic team believe that they both do have a genetic mutation, *'just not one that they know about yet'*. Ivy finds being BRCA negative with a strong family history very scary; *'as a negative BRCA I do sort of feel in no-mans land, but nothing can change the history of early deaths in my family'*. She believes that a negative test can actually give a false sense of security.

Tatiana and Katia also share the same profile, with a high-risk status but negative for BRCA mutation. However, Tatiana who is 30 years old has already scheduled her PBM; and Katia has already had a hysterectomy, but not a mastectomy, as her surgeon is a *'bit conservative'*. On the other hand, Ivy identifies now as *'uninformative'*, as she finds the label adequate for her situation as negative for any known mutation. This new label scares her. Although she feels that the right thing to do is having her ovaries and tubes removed provided her family history; the fact that she tested negative for BRCA is giving her *'cold feet'*. Ivy cannot make up her mind about her breast cancer risk.

Nina has a similar profile: BRCA negative with a strong family history. In an attempt to make sense of her status, Nina paraphrases what her group coordinator said at their local FORCE meeting *'The difference between 25% and 85% risk isn't the path we take, it's how much time we assume we have to move along that path'*. This quote directs the conversation in a discussion about risk counting. The conversation is led for a while by Ivy, Tatianna and Nina. Initially, Ivy does not understand what the quote really means; but Tatianna explains that quote means that the percentage of risk has no correlation with the time of the onset of cancer. Ivy finds it then very frustrating that she has never been given any percentage with regards to her risk of developing ovarian and breast cancers. This scares her even more. Tatianna, who has been through a similar situation, understand a *'high risk as a high'*, and this is what lead to undertake the hysterectomy. Ivy's family history is mainly filled with cases of ovarian cancer, with no breast cancer in her family that she is aware of. She is leaning towards undertaking the hysterectomy, but is still scared of the post-surgery effects especially

the menopause. Tatianna's post-surgery experience has been pretty good. Her family members were also very supportive. Tatianna's mother went through difficult times, especially with the effects of chemotherapy while battling cancer. Her family did not want to re-live those horrible moments, and therefore fully supported her with the preventive surgery. Shirley relates to Tatianna's experiences, especially with the story of her mother. Shirley's mother battled cancer as well, and suffered heavily from the effects of chemotherapy. Shirley and Tatianna find many similarities in their family history. They both have a strong family history from their mothers' side. Referring back to risk calculation processes, Ivy insists on the false security that being BRCA negative gives, *'Also we must not forget other genes - take the newly discover RAD15D gene, and there's TP53 and PTE'*; thus, leaving the calculation process largely based on the unknown.

After a long discussion on numbers and a negotiation to arrive to a consensus on a definition of high risk, Rebecca joins the conversation. Rebecca is 53 years old, and has recently got out of a long, dysfunctional marriage. She feels like she has just discovered her sexuality, including the enjoyment she experiences from having breasts. However, this complicates what would have been a logical decision: undertaking the PBM. She does not feel ready to give up what she has just rediscovered. Even with the reconstruction, there is no guarantee that everything goes smoothly and that she experiences authentic feelings again. Rebecca has been consulting a therapist, and the therapist says that she has made her decision months ago to go forward with the PBM with reconstruction; but she is still going through the education process before making her decision out loud. What she finds particularly scary and discouraging is the long process of getting her body back and the mental process that goes with it. She has however a strong family history, and this is even more frightening to her. *'At least now the choice is mine...empowered, right?'*, she adds. From a different perspective, undergoing a preventive surgery would give her time to choose her surgeon and plastic surgeon carefully, in contrast to a scenario where she would have to rush this decision following a sudden diagnosis of breast cancer. She can also start going through the grieving process of the loss of her newly

re-discovered sexuality. She recommends few readings to her fellow forum members, and concludes with *'information is power'*.

Tiffany, who initiated this thread, has not made any intervention since her initial post.

7.1.3. Narrative 3: 'I think I made my decision, but my dad does not understand...'

Victoria is 27 and she is BRCA1+. Victoria has decided to undertake PBM and reconstruction. Her mother is BRCA1+ as well; she had ovarian cancer and is currently in remission. Her mother had both PBM and reconstruction. Additional family history includes her mother's cousin passing away due to breast cancer at the age of 29.

Although Victoria has already made her decision to undertake the preventive surgery, she is encountering a major obstacle. Her dad does not support her decision. He thinks that she is making a radical decision, which has not been fully thought through. Her dad is a firm believer in a healthy lifestyle to prevent cancer. Victoria feels that she really needs his blessing to proceed, and feel handicapped by this situation; especially that she was hoping to have her surgery scheduled soon.

Morgan recommends Victoria to have her father Join the FORCE community as well to educate him. Morgan is 28, and is BRCA1+ as well. She has her mastectomy scheduled for this fall. Luckily for her, her family has been supportive throughout the process, but she had to educate them along the way. On the other hand, Dawn faced a situation that bears similarities to what Victoria is facing. Her father was indeed not understanding of her decision-making, and any attempt to make a conversation with him was a complete failure. She decided then to put her feelings into writing, and put it all in a letter expressing what she could not say out loud to him. The letter enclosed her screening results, with a clear mention about the evaluation of her high risk of developing breast cancer. The letter proved to be helpful in solving their disagreement. In addition to that, Dawn decided to go for breast reconstruction, which ultimately convinced her father, *'As soon as I told him I could get "new ones" he was relieved I think'*. She advises Victoria to put herself in her father's shoes, and

relate to what he's going through. She advises her to explain to him that she knows how hard it is for him as well to go through this situation, but that she does not want him to see her battle cancer. On a different note, Dawn agrees with Victoria's father, and believes as well in a healthy life style to prevent cancer, but *'the experts seem to think it is not worth the Gamble'*.

Having faced a similar situation as Victoria, Christine could never have her father understanding and/or accepting her decision to undertake the preventive surgery following her diagnosis with BRCA mutation. Her dad did not even agree with chemotherapy when she was diagnosed with breast cancer. In the end, she says she *'had to just let it go and focus on the parts of my relationship with my father that didn't involve my BRCA status or cancer'*. She encourages Victoria to share her feelings regarding the topic with the FORCE community.

Dawn jumps again on the conversation, discussing complication with her own situation this time. As Dawn is taking time to make a definite decision about the preventive surgery, her father is getting impatient after finally being convinced with the relevance of the preventive surgery. She explains how this is creating a gap between her and her family, friends and even her therapist. Dawn feels that she is letting everyone down. An aspect, that is further complicating her case, is that whenever she decides to make steps forward, it suddenly takes forever to get to things scheduled; which makes her second guess her decision, *'This is an emotional roller coaster I can not wait to get off of'*.

Victoria followed Morgan's advice, and Showed the FORCE website to her dad, as well as an informative article to read. She also wrote him an e-mail explaining her decision. The main obstacle that she is facing in order to convince her father is that he is more into eastern medicine. Victoria does not subscribe to that strand of medicine however, *'I would love it if a healthy lifestyle brought down my risk, unfortunately it does not'*. Victoria feels that only the girls on this website can actually understand her, as she keeps on receiving support from women on the forum. This time from Alicia, Erykah and Patricia; who all have different stories but bear some similarities to Victoria's case.

Alicia has been diagnosed with BRCA mutation, and fortunately had her family supporting her decision to undertake PBM. However, her best friend did not support her decision, which Alicia found hard to digest. Following that, she decided to take her best friend along to her appointment with the plastic surgeon. This proved to be very therapeutical, as her friend appeared to be much more understanding after that, and gave Alicia her blessing to go forward with the procedure. Alicia used the same strategy with her boyfriend with a similar success. She therefore recommends to Victoria to take her father along to her doctor's appointment and let him hear the statistics.

Another contributor supporting Victoria, Erykah is convinced that she is not making an uninformed/rushed decision based on the family history she provided. Erykah is going through quite an opposite situation with her family. Her mother had ovarian cancer at the age of 42. Following that, there has been several other episodes of ovarian cancer in her family. Since then, her family members have been *'on me like white on rice since I was in my late 20's to have the ooph/hysto'*. She eventually decided to get tested and was diagnosed BRCA1+. Ultimately, Erykah decided that she will have a hysterectomy, and is even considering having a PBM alongside.

Finally, Patricia is BRCA1+ positive and the family history revealed that she inherited the bad genes from her dad and grandad who tested positive as well. Even though, they were not supportive of her decision as they were *'male'*, she chose to undertake the preventive surgery without overthinking about how they feel, and whether they were accepting or not of her choices. She advises Victoria to be proactive and push her dad to think similarly.

Back to Dawn, who is still struggling with her decision making. Her hesitation is aggravating her relationships with family, and caregivers. Most notably, her indecisiveness is exasperating her father, who clearly articulates how he does not like way she is handling the situation. Even the nurses are getting frustrating. This has affected Dawn's mental health; therefore, she decides to get counselling. *'I guess I am just inconveniencing everyone one around me with my gene status. Shame on me!!'*. Christine (who is a forum moderator as well) proposes to have a private chat with her. Erykah relates to Dawn situation, and attempts to give her some moral support. She

explains how it took her about 5 years to make her final decision. Erykah describes how she went, similarly to Dawn, through difficult times with the medical staff. Nevertheless, they were cooperative and made some attitude adjustments after she explained her anxiety to them. What makes Erykah's situation even harder is that she has some family members in the medical field, with divergent opinions on how she should handle the situation.

Finally, Victoria updates everyone on her decision to proceed with the preventive surgery. She keeps updating everyone in the thread on her situation, throughout the months leading to her surgery, as well as after that. In her first post after the surgery, she describes difficulties sleeping and breathing but she is put on assisted breathing, which improves the situation. She explains to the girls, who are anxious about experiencing similar post-surgery symptoms, that the breathing difficulties are related to her asthma. Victoria keeps giving frequent updates everyone as soon as she started walking again, as well as when she regained the ability to eat. Erykah had also had her hysterectomy by that point, and the recovery is going well for her as well.

A couple of new girls joined the conversation later, explaining how they related to Victoria's story and her relationship with her father; and how this inspired them in their own decision making process.

7.1.4. Narrative 4: 'Just received my results... I am BRCA positive!'

Kim is 36 years, and had just received the information that she is BRCA1 positive. Her doctor recommends a combination of oophorectomy plus, either an increased surveillance by adding a yearly MRI to her mammography routine, or adding a prophylactic mastectomy. Kim's first inclination is to go for the oophorectomy plus mastectomy, but she is afraid she is rushing her decision. Kim has always had anxiety about breast cancer. Her mother is the only breast cancer survivor in their family. She was diagnosed with BC at the age of 49, and is 57 now and healthy. However, both her grandma and great grandma died of breast cancer. On her dad's side, his sister

had breast cancer in her early 30's and died at the age of 35. His aunt had breast cancer and died in her early 40's. Kim has 2 kids, who are 10 and 12 years old, and says that she is *'done with kids'*. While waiting for the results, it was obvious for her that a positive result would mean undertaking mastectomy. Now that Kim received the results, she is having doubts, and is asking for advice from her fellow forum contributors.

Tricia replies first to the threat. She has recently been diagnosed BRCA2 positive. Tricia is 30 years old and has 2 children as well – they are younger than Kim's children however, 4 and 1.5 old. Tricia was hesitating initially, but after an abnormal mammogram, a small tumour has been located. She is still awaiting for the results. Everything feels so new for Tricia as well, but she does not think that the decision to go through mastectomy is prematured as she says *'why wait? What's the point? If you know you want to do it, get it over with and stop living in fear'*. Kim relates To Tricia's story and feels like she is on the same mindset. Kim is trying to educate herself while waiting for her doctor appointment, and recommends two private Facebook groups as well - *'young previvors'* and *'BRCA sisterhood'*.

Having a similar profile to Kim, Michelle, who is BRCA1 positive, was having second thoughts about the PBM after receiving her genetic testing results. She has 2 children already, which makes her not consider removing the ovaries as not much of an issue. She did a surveillance mammography afterwards, and the results, alongside the MRI, indicated a benign area. Her surgeon decided to proceed with caution however, and performed a node biopsy that was negative. Albeit the result, this was the trigger to perform the PBM with expanders reconstruction. Post-surgery, it was found that Michelle had DCIS in her right breast (abnormal cells inside a milk duct in the breast), which is a sign of a very early form of cancer. This was at the same frightening, but also a relief for Michelle, as the surgery was performed just on time. Not relying solely on an increased surveillance proved to be the right decision, *'This again proves while ovarian cancer is much more difficult to detect, mammography and MRI imaging are not perfect'*. After further genetic testing, Michelle found out that she is of an Ashkenazi Jewish decent which explains her higher predisposition for breast cancer. Ultimately, Michelle advises Kim to go with her instincts.

The girls keep updating each other with their respective situations: Tricia received her biopsy results, and the tumour was benign, while Kim scheduled an appointment with her breast surgeon in 2 weeks.

A new contributor, Andrea who is 23 years old, joins the thread. Both she and her twin sister were recently tested for BRCA mutation: Her results came positive while her twin sister were negative. One of her main concerns is not being able to have children. Her doctor advised to have children early and then proceed with the preventive surgery. However, this constitutes a heavy decision for Andrea and her partner as they consider themselves still young and do not know whether they are ready yet to have children. Kim recommends to Andrea to educate herself through reading information on the FORCE website and other resources, while she is making her decision because she has the time factor in her favour, provided her young age. She advises also focusing on life style and diet alongside an increased surveillance. Kim explains how her overall life style changed since her diagnosis with the faulty gene, and how she started eating healthier, exercising and leading a healthier life style in general.

On a different note, Kim has made up her mind now, and is confident with her decision to undertake PBM. She is encountering some resistance from her sister however, who even though does not want to get tested, finds Kim's decision too drastic.

Kim demonstrates empathy towards Andrea's reluctance to undertake the preventive surgery, and explains how she faced deep hesitation as well upon reception of the genetic test results. Andrea is still frightened about how to face the delicate discussions with her partner and family. She confesses that she knew about the possibilities of BRCA gene since she was 16, and although she carried the fear of cancer all this time, she is happy she *'got tested though because although I feel out of control at times I have days I feel I have the knowledge to save my life'*. However, she cannot imagine herself living without children, so she is leaning towards an increased surveillance prior to having children and proceeding to the preventive surgery. Kim takes a moment to appreciate Andrea statement on knowledge *'we should all be thankful for this unfortunate mutation that we have because of that fact. We have the choice to reduce our risk drastically, a choice that most women don't have'*. Kim does

not think that carrying a genetic mutation should affect one's decision as to whether have children or not, and advice Andrea to take her decision regarding of her status as BRCA positive, as her children will already have some knowledge about their parents' genetic status.

Shannah relates to Andrea story, because she is facing a similar situation with her family, friends, and partner. Her decision making is affecting her relationship with her boyfriend. Most of the remainder of the thread is centred on Andrea, Kim and Shannah discussing their decision making process, and updating each other with the steps they undertook. One recurrent topic is the size of the breasts after reconstruction. Shannah is going few sizes smaller, which she looks at from the bright side as she will not have to *'wear 2 sports bra when I'm exercising'*. On the other hand, Andrea would ideally stay the same size after reconstruction. Kim, who is planning now to have all the surgeries at the same time, is going smaller as well – down from a size C to a B.

One of the new contributors, Alessia, is 18 years old only. Alessia's mother has been recently diagnosed with a stage 3 ovarian cancer, which is adding to her overall anxiety. She is confused with her BRCA status, particularly with some recommendations of not undertaking the genetic screening for BRCA mutation until the age of 25. She asks the other forum contributors about coping tips. Both Shannah and Kim agree that being 18 only gives her plenty of time to fully research the subject before making any decision, while ensuring that she is having a sufficient surveillance. Each of the girls has different coping mechanism, but quality time with the family and friends is the most recurrent theme.

Finally, Kim updates everyone on her surgery. The procedure went well and her husband and kids are taking good care of her. The recovery process is going smoothly.

Now that I summarised the main narratives, I present the analysis of the extracts from FORCE. The remainder of this chapter proceeds as follows. First, I start with an analysis of quantification rhetoric within the data, which tackles both numerical and non-numerical forms of quantification, and furthers to a discussion on the effects of the

quantification of the body on shaping the practices surrounding the consumption of prevention. The second section is centred on pronouns and the discursive production of selves, where the discussion will scrutinise the responsibility attached to subject positions. The third section takes the analysis to the business of blame attribution through the usage of extreme case formulations, where the strategies for presenting hesitation and doubt are connected to the different modes of accountability. The fourth section scrutinises the use of passivisation in everyday interaction, and its function of agency deletion in speech drawing the focus on processes, with the effect of reframing the attribution of responsibility and accountability. The fifth section focuses on metaphors within the BRCA gene discourse and takes a historical approach to scrutinise their role within the management of responsibility through their linkages with wider ideological systems. The final part will explore the discourse of empowerment and its intimate relation with responsabilisation of individuals. By taking a approach to analysing the discourse of empowerment and its effects in the context of HBOC, I explore the process through responsabilisation is not only facilitated, but also added a glossed and more appealing effect.

Each section ends with a brief conclusion, which summarises the findings of the section, as well as initiate a discussion that will build up into the next chapter.

7.2. Quantification rhetoric amongst lay people as a way to legitimise the course of action for a set of ethical practices:

In this section, I focus on quantification rhetoric. More specifically, I explore how the research subjects were deploying various numerical and non-numerical formulations to 'quantity', when constructing or undermining arguments. This section is organised as follow: the first part is dedicated to non-numerical quantifiers (such as *some*, *big*, *small*, and so on). The second part focuses on numerical formulations (such as percentages, ratios, absolute numbers, and so on). I explore how each of these formulations is deployed to obtain specific argumentative effects, and how this in turn

shapes the course of action of ethical practices within breast/ovarian cancer' pre-emption.

7.2.1. Non-numerical formulations:

The use of non-numerical quantifiers was frequent within the data. As the forum discussion was between lay people, it was often easier for the research subjects to include them within their account, rather than say having always to get some statistical data to present their narrative. However, considering non-numerical quantifiers as 'vague' alternatives only, would miss the chance of exploring the richness that they bring into the construction of arguments. As I demonstrate in the analysis of the following extracts, non-numerical quantifiers perform specific rhetoric functions, which would sometimes not have been possible with more 'precise' figures.

(1) *"I am 46 and last year started having some abnormal bleeding (heavy periods even when on birth control when I've always had no bleeding at all when on birth control). I had an ultrasound that showed small fibroids". Megan*

In extract (1), Megan expresses her worries about the recent bleeding she has been experiencing. Megan's family history of ovarian cancer increases her anxiety with regards to the bleeding. Within the formulation in this extract, Megan uses a non-numerical quantifier to describe her bleeding. She initially uses 'some' to describe the abnormal bleeding. Although it is a non-numerical quantifier, it is important not to see 'some' as a vague or imprecise estimation of the bleeding only. Within this context, 'some' functions as a device for both evaluation, contrast, and quantification of the abnormal bleeding. 'Some' bleeding is obviously different from 'no' or 'a lot of' bleeding, but also 'some' is illustrating the unknown within this context. The addition of the adjective 'abnormal' emphasizes the dimension of the unknown, and adds a layer of danger; therefore, potentially giving more legitimacy to any worries and subsequent actions to be undertaken. This construction of the argument leading to the decision on the set of ethical practices to follow starts with the description of the symptoms. A precise medical measure of a bleeding would not have had the same contrasting effect as the non-numerical quantifier within this context. Following that,

Megan attempts to explain what is abnormal about the bleeding. The unknown 'some' is replaced by 'heavy' to qualify periods on birth control. Megan adds a counter-argument to support her statement, the fact that she has 'always had no bleeding at all when on birth control'. 'No' as a quantifier represents nullity, the absence of something. The addition of 'at all' intensifies this quantification. The use of 'at all' is an example of what Pomerantz termed *Extreme Case Formulation*. In Pomerantz' work (1986) on extreme case formulations, she elaborated how particular formulations such as 'brand new', 'completely innocent', 'he didn't say a word', 'I really don't know', 'no time', 'forever', 'everyone' and so on can be deployed to warrant the rightness or wrongness of certain practices. For example, if a teenager says to his/her parents 'but everyone is going to that party', s/he is making a case that the activity of going to that party is acceptable or at least commonplace amongst other individuals that are their age. Pomerantz describes how extreme case formulations work in complaining, accusing, justifying, and defending, by using the extremes of available dimension for evaluations. In my analysis here, the addition of the extreme case formulation 'at all', suggests that bleeding on birth control, regardless of the amount, is most likely to be abnormal for Megan's body; therefore undermining any counter-argument that the bleeding could be normal and that she should not worry about it. It signals the unknown (some abnormal bleeding) also as a potential symptom of an underlying danger, therefore legitimizing further investigation and other ethical practices related to breast/ovarian cancer pre-emption.

A further explanation of the function of the non-numerical quantifiers used in this example can be found within dialectical syllogism. *No*, *all*, *some* are, in addition to *not all*, the four basic quantifier expressions that are the main object of study of syllogism of Aristotle's logic (Terrence, 2017; Londey and Johanson, 1984; Raphael, 1974). Two elements, 'some' and 'no', are of interest to further the analysis of the example above. First, I present the square of opposition that is used to identify four kinds of relationships between various pairs of categorical proposition in figure 26 below. Second, the development with plural quantification as informed by Boolos (1984) are of particularly relevant to the definition of the abnormal bleeding in the case above. Boolos argues that plural quantification can be inter-definable with second-order

quantification. He neatly connected it with the philosophy and the foundations of set theory.

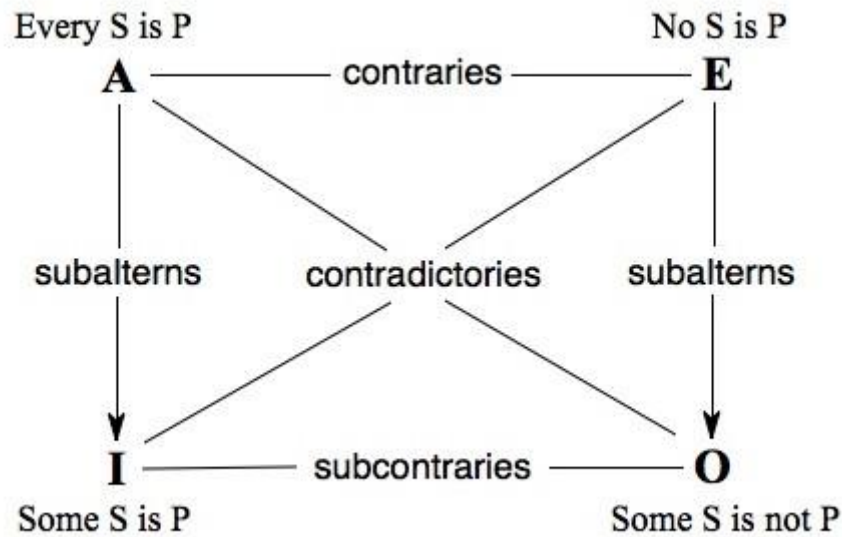


Figure 26: square of opposition
Source: Terence (Summer 2017 Edition)

The formulation 'Some abnormal bleeding', on its own, could have paved the way for speculation that this specific set of bleeding is abnormal, whereas there might have been a presence of another set that is normal. This set of bleeding (the abnormal one) represents actually a subset (of the total bleeding), as the total bleeding constitutes itself a set from the total body blood. So this could have left the argument that a specific subset at a specific time from the set of bleeding is abnormal. However, the other explanatory elements brought a different meaning to the equation. First of all, Megan added the birth control variable, which transforms the understanding of both the set and subset. The overall entity (human blood) is independent of this new variable; however the set 'bleeding' is dependent of it and this certainly brings another understanding to the subset – abnormal bleeding. Initially the birth control is just an add-on 'heavy periods even when on birth control': the new information here is that the periods are evaluated as 'heavy', which contrasts with their form during a

'normal period'. The addition of the focusing adverb 'even' transfers this evaluation to the specific context of being on birth control, ie. The heaviness of the periods persists through the added condition (being on birth control). This condition has an even more important function in the second part of the utterance, as it allows a contrasting effect that redefines the set and subset. In the second part, the condition of being on birth control is associated with the absence of bleeding through the use of 'no', and amplified by the use of the extreme case formulation 'at all'. If the 'normal' case is the complete absence of bleeding under birth control, then any bleeding under that condition is considered abnormal. This means that the subcontrary of 'some abnormal bleeding' (the subcontrary would have been 'some bleeding is normal'), that was left in the background at first, cannot exist anymore. Therefore, the utterance is conveying that no bleeding under birth control can be qualified normal in the case of Megan, or what could be termed as a universal negation for a specific case. Following that, Megan describes how she had her ultrasound and the diagnostic results. The sequencing of the utterance allows her to build a robust argument and therefore give more legitimacy to her anxiety and the reasoning behind following some specific ethical practices such as the ultrasound, bleeding monitoring, surgeon's visit, and so on.

(2) *"Im having the mastectomy with straight to implants early next year, for me hoefully it will be the shorter recovery and i really didnt like the thought of the other procedures, going a few sizes smaller than i am now too which will be strange, ive always been big breasted and going back to size i was in my late teens so will be a shock to the system, but on the brighter side i look forward to not having t wear 2 sports bras when im exercising lol"* Shannah (Emphasis added)

(3) *"I'm hoping to get all my surgeries done at one time. I'm planning on salpingo-oophorectomy & mastectomy with reconstruction. I'm hoping to go a little smaller, I'm a full C right now, would like to go down to a B maybe? I definitely don't want flaps, either. My preference is for silicone or saline implants, but I'm not sure which yet, as I haven't been to a PS yet."* Kim

Another example of non-numerical quantifiers that were fairly frequent is size evaluation quantifiers, such as *big* and *small*. When looking for instance at extracts (2) and (3), both '*big*' and '*small*' have a contrasting function, describing the trajectory from the current breast size to a reduced one. While Kim presents her breast size reduction as an individual choice, Shannah appears to struggle a little more with having smaller breasts. Shannah's use of '*Big breasted*' as such does not provide much information about how big her breasts actually are. Even though she is going just a few sizes smaller, it is the fact the state of being big breasted has a duration in time (as illustrated by the use of '*always*' in '*I have always been big breasted*') that adds to the intensity of her style of narration compared to Kim. Through this particular sequencing, Shannah highlights the difficulties she is going through in the process of complying with the prescribed ethical practices. While the presence of the faulty genes was responsible of the construction her new genetically at-risk identity, and the struggle with a faulty part within her body, located in her breasts; their absence through their removal has an effect in shaping a new body as well as a new 'identity' through breast reconstruction. Thus, Shannah already anticipates potential tensions in her future interactions with her post-surgery body. In the case of Kim, there is a transition from a non-numerical (a little smaller) to a quasi-numerical (as these sizes are themselves a translation from numerical interval measurements) quantifier. First, a '*little smaller*' is a smaller difference than just '*smaller*', therefore making a case for not questioning nor opening a debate about the size downgrade. Thus, placing the focus on the procedure and the material adopted rather than the actual downgrade; positioning the size as having mainly an indicative function. So within this formulation, Kim provides a quantification for her new breast through (*size B*), as well as the previous glossing that they are a '*little smaller*'. The contrast between the old and new breasts is highlighted by two different means: a numerical relationship (*full C to B*), and a non-numerical characterisation (*a little smaller*). This translation between the two formulations has a specific argumentative effect as it makes the speaker appear as having a sense of control of the situation and a well thought off decision process.

(4) “I have **small** children and am very worried about getting ovarian cancer and dying young” Megan (Emphasis added)

(5) “I will most definitely ask about the breast cancer risk. I have no problem having a mastectomy, to be honest, if that's what the doctor recommends. The hyster/ooph scares me due to the potential body changes, hormone problems, mood issues, etc., mainly because I have small children. If I didn't have kids to take care of, I wouldn't care about that so much either” Daphne

In the context of extracts (4) and (5), ‘small’ operates as a device for both evaluation and attribution of moral responsibility. By describing their children as ‘small’, Megan and Daphne not only provide an imprecise information about their age, but also make an inference about their vulnerable status provided they are only ‘small children’. The vulnerability of their children implies certain moral responsibilities that they have to fulfil as mothers. While both Megan and Daphne had a similar starting context (both associated strongly their decision making process, with regards to preventive surgery, with their responsibilities towards their small children), they came to different conclusions. Megan’s main fear is to die young and not be able to take care of her small children. She uses mainly the conjunction ‘and’ for ordering and sequencing her argument. This sequencing shows a causal mapping as well, in her line of thought. She is scared of a young death that could be caused by ovarian cancer, which will prevent her from taking care of her small children. Therefore, she is legitimising her worries about getting ovarian cancer. This paves the way for an argument to undertake a pre-emptive action to stop this from happening at the first place, and therefore legitimises associated ethical practices. On the other hand, Daphne expresses her fears with regards to the post-surgery menopause, and how it might prevent her from fulfilling her duties towards her children. The use of the script formulation ‘if plus modal verb’ associates the fear of the post-surgery menopause to the responsibilities of taking care of children. The use of double negation, in ‘If I **didn't** have kids to take care of, I **wouldn't** care about that so much either’ (emphasis added), in addition to the hypothetical nature of script formulation, makes Daphne less likely to have to legitimise her version of the story. The scenario of her children not existing is impossible; therefore, her position towards post-surgical menopause with regards to

her own comfort alone (in other terms, an isolation from the duty to care for others) is impossible to experience either. Through the causal links that she ascribes, she makes a robust case for not undertaking the pre-emptive surgery. She cannot be deemed irresponsible by her peers for not acting upon her risk, as the risk-reducing procedure would interfere with other responsibilities with a high moral rank. This sequencing acts as a shield protecting Daphne's accountability for her account. I discuss script formulations in further details in the next section. The two examples discussed here demonstrated how the non-numerical quantifier '*small*' in '*small children*' can be used with the same meaning, but serve two different rhetorical functions.

Whether it is elaborated or not, how small the children are, or how big or small the new breasts should be, it is important not to see '*small*', '*big*' or '*little*' as imprecise terms to describe the subject they intend to. Similarly to the example of '*some*' discussed earlier, these non-numerical quantifiers can, within a specific context, have an evaluative function, provide a quantitative contrast, or even ascribe a moral responsibility. Therefore, they can provide even more information than a specific abstract number. Non-numerical quantifiers have a mutually constitutive relationship with the objects they quantify. The meaning of '*some*' and '*no*' are constituted both by the quantifier themselves, the quantified object (abnormal bleeding), as well as the contextual relationship between both (Garfinkel, 1967). This meaning co-construction plays an important part in the incorporation of non-numerical quantifiers within the arguments, and its overall robustness.

7.2.2. Numerical formulations:

In this part, I delineate the practices through which numerical formulations are deployed to perform specific rhetorical functions such as making accounts more factual, managing interest, and contrasting.

(1) *"In fact, the most important determinant of survival for ovarian cancer is the stage of disease at diagnosis. For women diagnosed with early stage disease the five-year survival rate is more than 70%, but only a fifth of cases are diagnosed this early. For women diagnosed with cancer that has spread beyond the ovaries, the five-year survival rate is around 15%, and around a third of women are diagnosed with this stage of disease". Ivy*

(2) *"I feel that I have no choice but to have a my ovaries and tubes removed (I know I DO have a choice, but it doesn't feel like it), as the survival rate for ovca is so poor: In 2008, 6,537 women in the UK were diagnosed with ovarian cancer of which 4,373 women died from the disease - that is such a frightening statistic!" Ivy*

Ivy has tested negative the BRCA gene, despite having a strong family history for both breast and ovarian cancer. She describes her genetic screening results as negative for 'any known mutation'. This leaves her very scared about the course of action to follow, as she believes that a negative test can actually give a false sense of security. As it can be noted from the extracts above, Ivy uses various numerical quantifier and statistics. In extract (1), and before engaging in presenting statistics and data to illustrate her argument, Ivy starts by elaborating on a specific variable that she was about to describe in numbers. The variable is the stages of disease at diagnosis. Ivy makes a causal link between the stage of disease at diagnosis and the survival rate for ovarian cancer. She uses initially the adverb 'most important' to classify the stage of disease at diagnosis with regards to other determinants in relation to survival for ovarian cancer. In using maximum case to report the stage of disease at diagnosis, Ivy is asserting the dominance of early diagnosis as a determinant for survival rate. This formulation performs two rhetorical goals. First, it draws more focus on the statistics presented subsequently, by highlighting their 'extreme' importance. Second, it counters in advance any other arguments that are either in favour of other

determinants for survival rate, or that could undermine her argument using this particular determinant. The causal link made between the staging of the disease at diagnosis and the survival rate is of notable importance as well. Provided the dominance of the discourse of survivorship in cancer narratives, Ivy is giving additional credence to the notion of stages of disease at diagnosis.

Moving forward, Ivy provides the statistical relation between the two variables to present her case. Ivy uses the five-year survival rate as a definition for survival for ovarian cancer. She deploys two different forms of numerical quantifiers: percentages (70% and 15%) and ratios (fifth and third). Percentages were used for the five-year survival rate, while ratios were used to quantify the subset from the population diagnosed at a specific stage. The overall objective of Ivy, in this case, is contrasting two sets of women: those diagnosed with early stage disease, and those diagnosed with cancer that has spread beyond the ovaries. Although one could argue that ratios give a less precise quantification, they are performing another function here. More specifically, it is the movement from percentages to ratios that achieves the rhetorical goal: it makes the contrasting effect easier by providing a different form of quantification for each of the variables, therefore making the 'digestion' of the causal attribution easier and more straightforward for Ivy's audience. By combining these two different forms, she is able to get her point across more efficiently, which is contrasting the survival rate for the set of population diagnosed early versus those diagnosed at a 'late' stage. What Ivy is saying in other terms is that the survival rate is higher when ovarian cancer is diagnosed earlier, therefore it is better to make an early diagnosis. This constitutes another means to legitimise and reinforce the application of the ethical practices related to the diagnosis of ovarian cancer; particularly those blurring early detection and prevention (Fosket, 2010). However, by using statistical evidence, Ivy is constructing her claim as being more factual. The use of factual evidence in the way it is done here achieves two rhetorical goals: first, it contributes in constructing the 'out-therness' of the claim (Potter, 1996), making it appear more objective, unbiased, and therefore harder to argue with. Second, these factual descriptions portray Ivy's claims as neutral and not driven by any personal interest or hidden agenda, thereby increasing the sense of objectivity of her claim.

I discuss some additional observations here. First of all, a notable aspect is the lack of references in the factual evidence used. This was a general observation across all the data I have analysed in the forum. The figures presented, despite lacking sources and references, were left unquestioned, even when there were contrasting figures presented. Most importantly, they were used to construct robust arguments that were often used to nudge towards major decisions. Another observation is how particular scientific concepts were not only left unquestioned, but also had a constitutive relationship with lay people practices. For example, the five-year survival rate is not explained and is taken as an obvious definition of survival for ovarian cancer. A patient who survives five years from the date of first diagnosis of cancer is traditionally counted as 'cured'. This counting practice has several practical implications, such as providing a basis for comparative treatments in clinical randomised trials, as well providing glossed statistical figures that can be used in various types of media to communicate with lay population. However, Potter et al (1991) have argued otherwise and deconstructed this definition of the cured cancerous body. Their main argument is that this formulation constitutes an arbitrary choice of survival time. Indeed, it is a generalised/universal duration that constitute a relatively satisfactory period in term of length and precision, but that is not related to the evolution of individual bodies in the suspected course of cancer. They argue that cure and survivorship are constituted as countable through "a weave of social and calculation practices" (Potter et al., 1991, p. 348). Such constructions are reinforced by lay population' reproduction of the survivorship discourse in everyday speech, while at the same time shaping their decision making process. In this specific example, they are used to give credence to ethical practices such as early diagnosis.

In other cases, such as in extract (2), the numerical evidence provided is, although incomplete, taken unreflexively. There was no mention of the stage of diagnosis here. A similar inference to extract (1) is made however, that is that the survival rate is low. Whether the information is provided as a medium to highlight that the overall diagnosis is performed fairly late, or just naively quoted, is not really clear from this quote alone. The figures are presented in absolute numbers rather than percentages, which makes a direct evaluation harder to do. The choice of statistics of death rather

than survival is interesting as well, as the high number provides an additional dramatic magnitude. The intensity of the utterance is amplified by the sequencing of ideas and the qualification of the statistic as frightening. Although emanating from the same contributor to the forum (Ivy), extract (2) has a completely different tone to (1). While extract (1) formulation was a presentation of cold facts and figures, the style of extract (2) is more theatrical exposing the drama of choice making with regards to the risk reduction procedures. The factual evidence is selected and presented in a way to support the initial statement '*I feel that I have no choice but to have a my ovaries and tubes removed*'. The sequencing of the ideas places the blame of the unhappy incident on the poor rate of survival (the unhappy incident is the necessity to have the ovaries and tubes removed to 'fix' the risky body). The conjunction '*as*' is used for the sequencing of ideas. As a result of this sequencing, the unhappy incident is formulated as subsequent to the 'frightening' statistic. The attribution of blame to a statistic opens up a wide range of possibilities with regards to the potential actor/agents responsible for the unhappy accident. In this case, the responsible agent could be the poor diagnostic practices as the statistic, when combined with the earlier claim that early diagnostic equates a higher survival rate, which implies that a high number of cases were diagnosed at a later stage. Another possibility could be the treatment that is not effective enough, which leads to a high proportion of death amongst the diagnosed population. However, the tone of the sequencing leading to her decision making was very different from the rational and factual tone from extract (1). The causal link between the reported unhappy incident and the necessity to undertake the preventive surgery is not formulated directly. Ivy describes how she was left with no choice but to undertake the surgery, provided the frightening nature of the statistic. The causal link is made through emotion descriptions (and ascription of an emotion to a statistic). She formulates the decision to undertake the preventive surgery as not ideal (an *unhappy incident* in Pomerantz (1978) terms) but necessary (as subsequent of the blaming process). This process of attribution of blaming is another device to legitimise ethical practices to preserve the risky body.

There were however few other cases where forum participants were reflexively questioning the evidence at hand:

(3) *"I always think back to something my GC said at our local FORCE meeting (and I paraphrase):*

The difference between 25% and 85% risk isn't the path we take, it's how much time we assume we have to move along that path.

There's no guarantees at either end of the scale, you just have to educate yourself on your choices then make the decision that works best for you. Good luck! Xoxo" Nina

(4) *"Completely understand your thought process and I am in the 25% risk category. The only problem is in many of our cases, while we are BRCA negative, there is something going on...and yes we have two good copies of the genes that are tested, but not necessarily another gene that could be the culprit. In my case I was given a percentage completely based on family history with no other potential risks calculated into it." Katia*

Alongside the reflexive process, Nina (Extract 3) emphasises the notion of individual choice, with the use for example of '**educate yourself** or **make the decision that works best for you**' (emphasis added). She places the individual as the main actor to take responsibility of their 'faith'. Nina's account put the responsibility to seek information, educate oneself, process the information and make an 'informed' decision, at the level of the individual. The numerical quantifiers have a contrasting function, but in the contrary to the previous examples, they are engaged with reflexively as to how to utilise this numerical evidence and include it in the decision making process. The numerical evidence is again put under scrutiny in the other extract. Katia (Extract 4), who tested BRCA negative, has a strong family history. Katia's risk has been estimated as 25% chances of developing breast cancer in her lifetime. She is however questioning the process of quantification of her risk. A particularly interesting element is her use of '*our cases*' while referring to women who tested BRCA negative, but had a substantial family history. These were usually labelled '*uninformative*' in the forum. Beyond the grouping under a label of people sharing specific feature (BRCA negative, but with a substantial family history), Katia is constructing another subgroup: *the 25% category*. This categorisation implies a set of similar ethical practices prescribed to the

subscribers to it. It is not the category itself that is problematic for Katia, but the reasons she fell into this particular one, as she questions the accuracy of the calculation process. Katia feels that there were some discrepancies alongside the risk calculation process, due to her BRCA Status being negative. In *'There is something going on'*, she implies the presence of the unknown – an unknown that is very likely affecting her chances to develop the disease. While this formulation has initially set the possibility that it could be any factor, the following utterance delimits this to it being a genetic factor, albeit an undiscovered one. The discourse marker *'but'* is used as a rhetorical device to reinforce the legitimacy of further action. It contrasts with the good news of the presence of *'good copies'* of her BRCA genes within the body, and redirects the focus to the potential presence of unknown faulty genes. The delimitation of the unknown factor to it being a yet-to-be-discovered-faulty-gene is a clear depiction of genetic determinism at work. The engagement of lay individuals with this ideology results in them reducing the definition of particular health problems to causal inferences that are strictly dependent on the gene.

7.2.3. Concluding thoughts:

In this section, I tried to outline some of the rhetorical strategies through which numerical quantification accounts are formulated to take part in the construction of arguments, and how they contribute to their robustness by giving them a sense of *'out-there-ness'*. There were various ways to present the same figures (percentages, ratios and so on), and I tried to demonstrate how each of these (or the combination of different presentations) performs a rhetorical function that legitimise a particular course of action with regards to cancer pre-emption. Similar strategies were deployed in the Angelina Jolie letter analysed in the previous chapter, where factualisation was frequently associated with quantification. In that context, non-numerical quantifiers were associated with personal narratives of risk, whereas the numerical ones were often deployed in conjunction to experts' voices. Therefore, there are several rhetorical strategies involved in numerical formulations of risk amongst lay population. The notion of risk itself is strongly related to numerical quantification. A *'risk'* is something that can be calculated to be given a numerical value (in order to be

qualified afterwards as *high, medium, low*, and so on). The field of epidemiology plays an important role in providing the tools and formulas for risk calculation. However, while risk tends to have an encompassing effect in epidemiology, as this field deals with groups rather than individuals; the common discourse in the forum, however, was risk as individual ('my individual risk'): risk calculated partially on family history, but mostly on genetic information. This notion of risk being 'individual' when adding the genetic information variable has been heavily criticised within the sociology of health and illness scholarship. Sociology of genetics scholars have argued that, while the progress of genetics brings with it a redefinition of risk calculation, it constitutes just another stratification or what Tutton (2012, p. 1726) labelled "new categories of collective differences". The patient populations are "stratified according to their genotype for a particular disease" (Kennedy, 1997, p. 155). A body that is labelled as being 'at risk' implies the movement of the healthy body from the domain of the 'normal' and safe to a domain of danger. I have also demonstrated in the examples above that the 'nature' of risk as genetic, in the context of HBOC, makes it commonly understood as calculable: because it is genetic, it should therefore be calculable; and it is calculable because it is genetic. While the presence of the faulty BRCA genes made the process of calculation possible, therefore shaping individuals' subjectivities as well as legitimatising certain ethical practices; a negative screening result left room open for speculations about the unknown. Indeed, even when the risk was calculated alongside a negative screening result, there were speculations around the presence of yet-to-be-discovered genes, leading to discrediting the calculation process. The genetic discourse has become so pervasive, within the context of breast and ovarian cancers, that most ethical practices appeared to be revolving around faulty genes, whether they are present or absent, known or unknown. The course of action of ethical practices is centred on the belief system around the risky object, as well the various scenarios depicted around the consequences of the risk.

In the next section, I look at the role of pronouns in the production of subjectivities in everyday speech. I explore important function such as the sense of self and location of time, space and responsibility; the rhetorical expressions of social interaction,

inclusion/exclusion and authority/communality; the construction of the other; as well as the establishment of objectivity through concealing subjectivity. These have important implications with regards to the moral positioning of the at-genetic-risk individual, as well as the interplay between subject positions and the ethical practices to follow to ensure the preservation of the body.

7.3. Pronouns – and the discursive production of selves:

In this section, I focus on the function of pronouns in everyday speech. More specifically, I explore their role in the production of subjectivities within the genetic disease discourse, drawing primarily on positioning theory as informed by Davies and Harré (1990) (discussed in detail in chapter four). This section is organised as follows: The first part is dedicated to the pronoun ‘I’ and the indexicality of time and space on one hand, and the indexicality of responsibility on the other hand. The second part is dedicated to the pronoun ‘You’ and the linguistic expression of social interactions. The third part is dedicated to the pronouns ‘We/They’ and the rhetorical expressions of inclusion/exclusion and authority/communality on the one hand, as well as the construction of ‘the other’ on the other hand. The final part is dedicated to the pronoun ‘It’ and how objectivity can be established through concealing subjectivity.

7.3.1. ‘I’ – and the indexicality of time, space, and responsibility:

In this section, I analyse how the sense of self, and of personal identity is expressed through the use of the first person singular pronoun ‘I’. Whether the personal identity is constructed as being a BRCA positive, uninformative, woman, mother, girlfriend; the pronoun ‘I’ has a function that goes beyond an innocent referencing to a label. I shall demonstrate in this section how the pronoun ‘I’ has an indexical function for space, time, and responsibility, thus giving a sense of self (rather than referencing to a self, or ego). This development of a sense of self requires a certain emotional commitment to the category membership and the embodiment of a moral system organised around this membership. As I demonstrate in the analysis of the following

extracts, this construction shapes subsequently the course of action of ethical procedures.

(1) *"I find typing helps. i sort of doing my own little book of past and present type things combined with how i feel about things now and it is helping. I think its important for you to have time for yourself to think it through too, i have found going to the gym helps - i hadnt been for years until recently and am a heavier weight than id like to be so im finding combining that with zoning out for a bit helps. it isnt an easy path and you wont automatically wake up the next day knowing 100% what to do. But whatever you feel like on that day we are all here to help each other through it. Like i said if you want to chat, vent or have any questions my email is on last post"* Shannah

In extract (1), Shannah describes the various strategies she is deploying to deal with her BRCA status. Shannah is BRCA positive and, similarly to other women in the thread she is contributing to, is experiencing various challenges after her diagnosis as BRCA positive. Not only is she having difficulties making her decision with regards to the course of action of preventive procedures, but she is also experiencing some issues with regards to her relationship with her boyfriend. When looking closely at the way Shannah performs her descriptions, an aspect that stands out is the frequent use of first person formulations. Whether it is in *'I find typing helps'*, *'I sort of doing my own little book...'*, or *'I have found going to the gym...'*, the description of the various strategies involves the use of the pronoun *'I'*. From a traditional cognitive perspective, the multiple deployment of *'I'* could be seen at first as an innocent use, referencing to incontestable self-practices. The subject would appear to simply narrate routines, such as keeping a diary or going to the gym, that are helping her to cope with her recent diagnosis. The strategies that she is describing, range from diaries, to physical activities. Later in the conversation, she associates these to other strategies including diagnostic procedures, food supplement and prophylactic surgery. It is interesting how Shannah appears to split her strategies (perhaps unintentionally) into two categories: those that meant to be targeting at an emotional level (diary recording *'how she feels'*), and those targeting at a physical level (Gym *'correcting the body'*).

However, when moving beyond a logic of a unified and rational self as the side of thought and action, and considering the interconnectedness between discourse and subjectivity and the constant shaping and reframing of subjectivities; the first person pronoun 'I' becomes much more complex and problematic in its usage (Pennycook, 1994). For instance, when looking at 'I' in the formulation '*I find typing helps. i sort of doing my own little book of past and present type things combined with how i feel about things now and it is helping*'; Its use signals a reflexive self as Shannah describes her strategies to manage her feelings about the condition.

Harré and Harris (1993) suggests looking at 'I' as indexical, that is their grammar is rather similar to 'here' or 'now'. Seeing how problematic the definition of self can be (Further discussion in chapter four – Methodology), 'I' cannot be considered as referring to an 'actual' self or ego. The circumstances in which 'I' have been uttered become therefore necessary to make the sense of the statement complete. For instance, '*I find typing helps*' could have been formulated using the passive form '*typing helps*'. Whereas, the latter would have referred to a general consensus, the explicit use of the first person pronoun signals an indexicality of the statement ('*typing helps*') with the spatial location at which the act is performed ('*finding typing helps*'). The performance in this case is the act of 'finding'; which means the location is the embodied speaker (ie. Shannah). This positions Shannah's claim about the fact that '*typing helps*' not as a statement of something considered as a 'universal truth', but rather as something located within her experiences, and the findings derive from these. In addition to the spatial location, the tense of verb '*find*' in conjunction with the pronoun 'I' indexes the content with a temporal location, namely the moment of typing the statement and sending it in the forum. Both constitutes the spatio-temporal location indexed by the pronoun 'I'.

Besides the spatio-temporality, the use of the first person pronoun in the above extract is related to a further indexicality. The additional layer is located at a moral level. As Harré and Harris (1993) describe, this involves analysing the triadic relation between the speaker and the storyline to which the utterance in question contributes on the one hand, and its illocutionary force on the other hand. If Shannah is positioned as reliable by her fellow forum contributors, then the utterance '*I find typing helps*'

might be taken as a strategy that is worth following. In the case where she is not positioned as reliable, then it could just be taken as part of Shannah's game to either launch a trend for instance ('BRCA diaries'), or just draw attention to herself as an individual attempting 'everything' to prevent the occurrence of breast/ovarian cancer, and subsequently asking covertly for praise or validation of her category membership as a previvor. When looking at another example of the use of 'I' in in '*I sort of doing my own little book*', the moral indexicality could be Shannah presenting herself as taking ownership of her own responsibilities, and putting her personal strategies to fight against her condition into work, depending on how she is positioned by her fellow forum contributors.

Following that, Shannah discusses strategies related to the preservation of the body - '*I think its important for you to have time for yourself to think it through too, i have found going to the gym helps - i hadnt been for years until recently and am a heavier weight than id like to be so im finding combining that with zoning out for a bit helps*'. These consist on physical activities, and Shannah links these to her overall coping mechanisms with her BRCA diagnosis. In '*I hadnt been for years until recently and am a heavier weight than id like to be*', the indexicality of morality operates as a mean of 'pleading guilty' for Shannah. She makes a causal link between '*heavier weight*' and the lack of physical activity. This is performed by the combination of the use of the first person pronoun 'I' with the coordinating conjunction '*and*'. In this context, the coordinating conjunction '*and*' does not only have an ordering function, but also functions as a device to attribute causality. The combination of 'I' with the coordinating conjunction '*and*' functions as a device for attributing causality, as Shannah is attributing her '*heavier weight*' to the fact that she hadn't been to gym for years. She is acknowledging the importance of going to the gym, and by the same token attributing the blame for this weight gain to her own negligence; emphasising the acceptance of herself as a responsible agent for the outcome of this particular condition. Through this formulation, she is also presenting herself as 'awaken' and reflexive, as a consequence of her recent diagnosis.

Shannah is therefore presenting herself as having a sense of her responsibility to take her faith in charge, and follow a certain set of ethical practices through which she

takes control of her life and manage her somatic existence. Rose (2007) describes these practices as 'life strategies' put in place to forecast potential risks or variations in risk levels and anticipate the probable onset of a disease. The following extracts present different practices of indexicality.

(2) *"I have small children and am very worried about getting ovarian cancer and dying young. However, I'm also terrified of the hysterectomy. I keep reading that it will cause dramatic changes in my body, in my psychological state, in sleeping, etc. I'm afraid the hysterectomy (including ovaries) will ruin my life and I might not even have a real risk of getting the cancer. Will my quality of life be that bad after hysterectomy?" Megan*

(3) *"I'm curious about how others have felt physically after total hysterectomy. The oncologist pretty much said that I'm about to go through menopause anyway, so the hot flashes and other issues are going to happen sooner or later regardless. I have a friend who has gone through natural menopause and says it's the best thing that ever happened to her! But it seems like having the ovaries removed makes the whole thing harder, physically speaking (as far as after-effects)." Megan*

In the two extracts above, I first notice the use of different expressions of voices of knowledge in 'I keep reading that it will cause dramatic changes in my body, in my psychological state, in sleeping, etc,' and 'I have a friend who has gone through natural menopause and says it's the best thing that ever happened to her!'. Both expressions involve the use of the first person pronoun 'I' as a reference. Also, both voices share in common the fact that they emanate from lay voices. However, in the first case ('I keep reading') the source is a written text, although anonymous here, and the voice is an interpretation of this text; whereas in the second, the source is an experience of a friend, and the voice is a reporting of this narrative. There is, therefore, a multitude of voices of knowledge shaping the decision making process, as well as providing additional subject positions for Megan.

For the purpose of the analysis, I focus on 2 specific parts only within extract (2) and (3): '*I keep reading*' from extract (2), and '*I have a friend*' from extract (3). Both utterances share some similarities as to where the source of knowledge is located. In the first example, the spatial location of this knowledge is within Megan's reading; whereas the spatial location in the second example is within Megan's reporting of a friend's narrative. When looking more closely at '*I Keep reading*', the information is more specifically located within Megan's understanding and interpretation of those readings. The temporal location is unspecified and presented as recurrent, provided the verb tense used (present continuous) and the nature of the verb used ('**keep reading**' indicates recurrence). With regards to the moral location, it is dependent on whether Megan is positioned, by her fellow forum readers, as competent in her sense making of the information read. If Megan is positioned as competent, then the utterance might be taken as a warning against post-surgery menopause effects. On the other hand, if Megan is positioned as incompetent, then the utterance might be taken as part of her game of overdramatising her situation; or it could be her trying to give legitimacy as to why she is indecisive with regards to the preventive procedure, thereby sustaining her category membership as a previvor with the associated duties. She might also be positioned as being scared of the preventive surgery and merely making excuses as to why she doesn't want to proceed. In extract (3), Megan gives a contrasting information (it is important to note that this happened at a different time in the conversation after a couple of days of debating in the thread). The source of her information is different in this case as well. She is narrating her friend's experience with menopause. She specifies however that her friend went through '*natural*' menopause. Megan makes a distinction between natural and surgery-induced menopause as far as menopause effects are concerned. The spatial location is a slightly more complicated. It is located neither in Megan's nor her friend's experiences, but in Megan's reporting of her friend's narrative. These 2 examples show how complex subject locations can be. The more precise is the positioning, the more credible is the voice of knowledge.

Harré and Harris (1993, p. 113) state that “the sense of self, or personal identity; is a sense of location; not an awareness of an entity”. I have demonstrated, in this section, how the first person singular pronoun ‘I’ functions as a device for positioning. ‘I’ does not refer to an ‘actual’ self or ego, but function as a device for the indexicality to the existence of embodied and responsible speakers. It expresses a sense of self, rather than an actual self. A sense of self happens at two levels: (1) a sense of place and time, and (2) a sense of responsibility of one’s actions (Harré and Harris, 1993). The later signals a moral order that is of a particular importance to the present study.

7.3.2. ‘You’ – and the dialogic construction of the ‘other’:

In this section, I analyse how subjectivities are constructed in a dialogic way. More specifically, I focus on how the dichotomy ‘I/You’ shapes both sides of the conversation, as well as how the business of interest and responsibility are managed throughout the construction of these subjectivities.

- (1) *“Menopause SUCKS but you should still have the risk-reducing surgery.”
(Capitalisation in original) Leah*
- (2) *“It’s also a quality of life decision... if menopause is kicking your ass so badly then you might be willing to take the risk of higher chance of cancer in order to take hormones.” Joyce*

In extract (1) and (2), Leah and Joyce are giving some advice to Megan, who is struggling with her decision making process, especially with her fears towards the post-surgery menopause. Leah and Joyce hold two different positions, and articulate these in very different ways. The first important aspect is that the pronoun ‘you’ is followed by a modal verb in both extracts. However, the strength of the modal verb varies from extract (1) to extract (2). When recommending to undertake the preventive surgery, Leah uses the modal verb ‘*should*’. On the other hand, when considering the option of not undertaking it, Joyce uses the modal verb ‘*might*’ (in addition to ‘*be willing*’). ‘*Should*’ being a stronger modal verb than ‘*might*’, this already signals Joyce assuming less responsibility than Leah, with regards to Megan’s decision

making when it comes to 'risking' a higher chance of getting cancer by not undertaking the 'menopause-inducing' preventive surgery.

I now look closer at the combination of the use of the pronoun 'you' in conjunction with the formulations discourse maker/modal verb on one hand, and script formulation/modal verb on the other hand. In the first extract, Leah is advising for undertaking the preventive surgery. She starts by acknowledging the negative effects of menopause on the quality of life in '*menopause SUCKS*'. The use of capitalisation emphasises this act of acknowledgement. Provided the issue here is the post-surgery induced menopause, the statement '*menopause SUCKS*' is in favour of not undertaking the surgery. However, Leah follows it straight after by '*but you should still have the risk-reducing surgery*'. The discourse maker 'but' does not only have a referential contrast function here, but also functions as rhetorical device to reposition the preventive surgery as the 'right' decision. Despite the acknowledgement of the negative effects of menopause, the preventive surgery remains the action to follow within this particular formulation. The use of the discourse marker 'but' works as a device to increase the credibility of the argument, by signalling that both fears have been taken into consideration in the decision process making. The use of the modal verb 'should' adds a layer of moral indexicality to the argument. The use of 'should' in '*you should still have the risk-reducing surgery*' attributes the moral responsibility of undertaking the decision to Megan. In other words, the non-occurrence of the negative event (appearance of cancer) depends on the individual actor to make the informed choice to reduce the known risk (the genetic risk) by undertaking the preventive surgery. The use of 'still' is to acknowledge the negative effects of menopause, while stressing the responsibility of Megan in taking action in reducing her risk.

In extract (2), the modal verb is combined with the use of the if-then formulation. I will use script formulation to refer to conditional formulations, following the terminology within discursive psychology (Edwards, 1994). When looking closely at the claim '*if menopause is kicking your ass so badly then you might be willing to take the risk of higher chance of cancer in order to take hormones*', the first observation is that script formulation functions as a device here to shift the focus of the fear from

the risk of the occurrence of cancer to the risk of deterioration of the quality of life following the surgery-induced menopause. As Edwards elaborates, conditional formulations can be understood as general scripting devices that provide for inferences “in which temporal sequence, causality, and rational accountability are mutually implicative” (Edwards, 1997, p. 288). Since the formulation is hypothetical, Joyce is less likely to be asked to legitimise her version of the events, and taken as accountable for Megan’s decision (in case Megan follows the recommendation of not undertaking the preventive surgery). Also, the recommendation of not undertaking the surgery is linked to Megan’s own evaluation of the effect of menopause. This is emphasised by the use of the amplifier ‘so’ in *‘if menopause is kicking your ass so badly’*. The use of the amplifier ‘so’ here makes a case for potential serious effects of the menopause, that Megan would estimate not being able to handle. This formulation attributes even more responsibility to Megan, as it will be up to her to evaluate the effects of the menopause, and whether she would be able handle them or not; and subsequently decide whether they are serious enough to opt for taking chances for a higher risk by not undertaking the preventive surgery. A final stress (with regards to Megan’s responsibility) is achieved by the use of a weak modal verb *‘might’*. More specifically, it is the formulation *‘might be willing’* that functions a device to suggest that Megan has full responsibility to decide not to undertake the surgery, and should subsequently be willing to accept the trade-offs (higher chance of getting cancer). There is an expectation of rational obligation of the recipient (Megan) to decide what is more dangerous (ie. What fears to be acted upon?); which subsequently determines the course of action of ethical practices. This particular formulation allows also the process of attribution of responsibility to be performed in an indirect way. By presenting a factual relationship between quality of life and taking hormones, Joyce avoids presenting herself as anti-preventive surgery; therefore managing any potential stake or interest in presenting her particular position on the preventive procedure (Edwards and Potter, 1993).

Modal verbs refer to the moral responsibility of the actors to perform actions, as well as the speaker’s assessment of the probability of occurrence of future events. As Snejder and Molder (2005, p. 678) argue “the semantic properties of a number of

modals allow speakers to blur the epistemic and moral implications of their claims". This semantic ambiguity makes modals particularly interesting for performing attributions for responsibility and blame. The 'you' is therefore constructed in a dialogic manner. It is constituted within the 'I/you' dichotomy: The 'I' being the 'interest-free' advice giver, and the 'you' the advice receiver but also the agent responsible of making the informed decision.

7.3.3. 'We/They' – Collective subjectivities and the 'other':

In this section, I analyse how collective subjectivities are constructed in speech. I focus on the use of the first and third person plural pronouns. I demonstrate how the first person plural pronoun 'We' function simultaneously as a device for inclusion and exclusion. The 'other' is also shaped through the covert assumptions about shared communalities of the constructed of 'we'. I explore as well other ways of constructing the 'other' through the use of 'they' to call to an unspecified authority. The analysis focuses on the following extracts.

- (1) *"Completely understand your thought process and I am in the 25% risk category. The only problem is in many of our cases, while we are BRCA negative, there is something going on...and yes we have two good copies of the genes that are tested, but not necessarily another gene that could be the culprit. In my case I was given a percentage completely based on family history with no other potential risks calculated into it."* Katia
- (2) *"Did I make it sound like a competition?? Certainly not my intention, I merely wanted to point out that just because someone is BRCA negative doesn't mean they are home dry and low risk for cancer. We should be aware of other genetic mutations and of course symptoms, surveillance and family history."* Ivy
- (3) *"I agree with you about % risk. I just look at my family history and have to ask myself if I really want to take the risk? So they haven't found a mutation, and haven't given me a % risk to go on, but can I ignore history? I don't think so."*

Besides if my consultant is happy to perform the surgery then he thinks I'm at risk, as does my genetics team and my psychologist. It's hard though not to have something in black and white telling you, I guess that's why we go round in circles thinking about it!!" Ivy

In the extracts above, the different uses of 'we' and 'they' were certainly not unproblematic. When looking at extract (1), Katia is constructing a new collective identity through the use of 'we' and the possessive pronoun 'our'. Katia, who tested BRCA negative, has a strong family history. She is questioning the process of quantification of her risk; which has been estimated at of 25% chances of developing breast cancer in her lifetime. One of the strategies she uses, to undermine the arguments behind the calculation process, is the construction of a collective identity around that number, as well as other shared characteristics. This construction of the collective identity starts, therefore, with some shared features: a risk calculated at 25%, a BRCA negative status, and a strong family history. Katia starts this construction of the risk percentage as a category with the use of first person singular pronoun 'I' in '*I am in the 25% risk category*'; before moving to the use of first person plural pronoun 'We' and possessive pronoun 'Our' in '*The only problem is in many of **our** cases, while **we** are BRCA negative, there is something going on...*' (emphasis added). This ordering is not innocent. In the first instance, Katia positions herself within a particular collective: the 25% category. Following that, she adds the second shared communality of the collective which is the negative BRCA status. This second shared communality is positioned as highly problematic, as Katia describes how this diagnosis draws the attention away from potential unknown genetic mutations. This in turns is used to question the whole categorisation; and in so doing, legitimising the questioning of the quantification of the risk at 25%.

The use of 'we' and 'ours' in this extract implies as well some overt and other covert assumptions about shared communalities. When looking closely at the formulation '*The only problem is in many of our cases, while we are BRCA negative, there is something going on*', I first notice how some covert assumptions are made about individuals within the said category. Some of these covert assumptions include: an inclination of individuals within this category to rely on the negative BRCA status, and

the calculation that derives from it, in their decision process; as well as a tendency to consider themselves in the 'safe' category. In this extract as well, the movement from the use of the singular to plural, 'I' to 'we', within the speech emphasises the separation between the two statuses, as well as the sense of community. The responsibility to take action is individual, while the knowledge is collective (but specific to the uninformative community).

The use of 'We' also implies an "authority to speak for others" (Pennycook, 1994, p. 176). For instance in extract (2), when Ivy says '*We should be aware of other genetic mutations and of course symptoms, surveillance and family history*', she is not only giving some advice to her fellow 'uninformatives' (negative for BRCA gene, but carrying potential unknown mutations), but also claiming a right to speak and recommend a course of action for a larger group. As Pennycook (1994) describes, the pronoun 'We' has both an inclusion and exclusion function, and works simultaneously as a pronoun of solidarity and of rejection. The act of delineating the communalities of a 'We', defines a 'you' or a 'they'. By defining themselves as part of the group of 'uninformatives', both Katia and Ivy make covert assumptions about the 'other'. For instance in the case of Ivy, prior to making her claim '*We should be aware of other genetic mutations and of course symptoms, surveillance and family history*'; she states the following '*I merely wanted to point out that just because someone is BRCA negative doesn't mean they are home dry and low risk for cancer*'. Therefore, Ivy covertly positions the 'other' as perceiving the BRCA negatives as being 'home dry', or low risk for cancer. This 'other' includes, but is not limited to, BRCA positives. In the same vein, Katia's claim '*and yes we have two good copies of the genes that are tested, but not necessarily another gene that could be the culprit*' makes a covert assumption that 'they' (those that are excluded from the uninformative group through the use of 'we') need some education about the uninformative status, and the current limitations of the field of genetics. The 'we' versus 'they' can "produce different antonymic contrasts" (Wales, 1996, p. 61) that participate to the construction of those collective identities.

The construction of the 'other' can have different functions as well. For instance, when looking closely to extract (3) Ivy's use of 'they', in '*So they haven't found a mutation,*

and haven't given me a % risk to go on, but can I ignore history?', is performing a specific function. The pronoun '*They*' operates here as device to call to an unspecified authority (Pennycook, 1994). Ivy is therefore positioning the authority, responsible for performing the risk calculation, in a vague fashion; almost as a way of hiding the locus of authority. It is worth mentioning that the views of this authority contradict hers. Further in the elaboration of her claim, Ivy refers to specified authorities that she interprets as agreeing that she is at risk: '*if my consultant is happy to perform the surgery then he thinks I'm at risk, as does my genetics team and my psychologist*'. Through the use of a script formulation, Ivy suggests that in the event of impossibility of quantification of risk, the consultant's evaluation of the situation becomes a reliable assessment. However, the evaluation performed by the consultant is presented through his suggestion of a course of action (performing the surgery); and not by a direct elaboration of his assessment of the risk. Ivy makes an inference that these specified authorities believe that she is at risk, based on the course of action they advised, and portray this as an obvious conclusion through the use of script formulation. Then, she reinforces this inference by referring to the supporting advice from her genetics team and psychologist, making it even harder to argue with, as she is bringing several 'expert' voices to the fore to back up the act of qualification of her risk. Although she is only making an inference about the risk evaluation by her consultant, genetics team and psychologist, based on the agreement of the consultant to perform the surgeon; the reference to specified authorities is used here as a rhetorical strategy to undermine the evaluation performed by the unspecified authority responsible for the former calculation process. The specification of authorities is therefore not merely informative or descriptive, in this context, but rhetorical, as it counters various otherwise plausible recommendations of not undertaking the preventive surgery.

The '*other*' can therefore be constructed in different manners. It can be constructed within the '*We/They*' dichotomy. As I demonstrated earlier, the covert assumptions about shared communalities with the constructed of '*we*', construct the '*other*'. The pronoun '*They*' functions in this case as the signifier of an assumed other. It can also be constructed through other uses of '*they*'. In the example of extract (3), the use of

'they' operated as a device to question the process of calculation and undermine the conclusions subsequent to that process. In other cases, the call of an unspecified authority was deployed to formulate the statements as given, common knowledge, which increases their credibility and makes their truth harder to question.

7.3.4. 'It' – Establishing objectivity by concealing subjectivity:

In this section, I analyse how the 'neutral' pronoun 'it' functions as a device for concealing subjectivity and establishing objectivity, and subsequently increases the credibility of the claims, and legitimises choices.

- (1) *"I feel that I have no choice but to have a my ovaries and tubes removed (I know I DO have a choice, but it doesn't feel like it), as the survival rate for ovca is so poor: In 2008, 6,537 women in the UK were diagnosed with ovarian cancer of which 4,373 women died from the disease - that is such a frightening statistic!" Ivy*

An important element of the narrative in the extract above is the notion of choice. As Davies and Harré (1990) argue, the possibility of choice is tightly linked to the concept of agency. When an individual is faced with contradictory requirements in a particular situation, the possibility of choice provides them with the possibility of acting agentically. When facing contradictory demands, the choice making is entangled with (1) a complex weaving of the positions/locations that are within the various discourses, and (2) the moral structure that establish the legitimacy of those choices. The choice making is entangled as well with the different cultural, social and political meanings that are attached to those positions. For example in extract (1), the emotional meanings attached to having the ovaries and tubes removed shape Ivy's choice making especially after reading the forum stories of other women who went through the same procedure. Also, the ovaries being a strong symbol of femininity (within a heteronormative framing) and what it means to be a woman in a post-modern world, this shapes the emotional meanings of the procedure, and thereby the choice making. The political meanings attached to the numbers and statistics in the

political healthcare context shapes Ivy's sense making of the statistics, as well as the emotional meaning attached to the statistic (for instance when she describes the statistic as frightening), and subsequently the act of making a choice.

However, when it came to legitimizing her choice (of leaning towards undertaking the preventive surgery), Ivy opted for presenting herself as having *no choice* – almost presenting herself as having no agency, while acting agentically. One of the rhetorical devices she deployed to achieve this, is the movement from the pronoun 'I' to 'it' in '*I know I DO have a choice, but it doesn't feel like it*'. Another formulation of this utterance could have been '*I know I DO have a choice, but I do not feel like I have one*' (which would have been similar to her formulation at the start of the extract '*I feel that I have no choice*'). After stating her argument with her feelings of having no choice, Ivy acknowledges the availability of choice to her in '*I know I DO have a choice*' (capitalisation in original), but then negates its existence by '*it doesn't feel like it*'. Besides its stylistic nature, the movement from 'I' to 'it', functions as device to establish objectivity, since 'it' is a 'neutral' third person pronoun. The pronoun 'it' is deployed to conceal the existence of a specifically located subject within the statement (Pennycook, 1994). By concealing her subjectivity within her claim through the use of the pronoun 'it', Ivy achieves establishing more objectivity, and therefore giving more credibility to her decision making and 'choice'.

7.3.5. Concluding thoughts:

In this section, I tried to outline some of the rhetorical functions of pronouns and how they are deployed in everyday speech to construct subjectivities. The use of pronouns in everyday speech is certainly not unproblematic. As Pennycook puts it, the use of pronouns "opens up a whole series of questions about language, power, and representation" (Pennycook, 1994, p. 178).

Especially when located within HBOC narratives, the discourse of survival (and pre-emption in the case of communities revolving around the BRCA gene) is a dominant one, as previously highlighted when exploring HBOC in the media in the previous chapter. Beck-Gernsheim (2000, p. 125) contends that health has overall gained an

increasing value, and become a “magic word for gaining agreement. Health, or, more precisely, the promise of health, opens doors, elbows aside resistance, and brings Public support and money”. This has practical implications for the way we research, talk, and act upon health. As Pender (2012, p. 334) argues: “this change means that health now comes before and often displaces other values, paving the way for new medical technologies and procedures that can appear unconventional or extreme”. This process is iterative, as the said new medical technologies and procedures shape our definition of health by allowing for higher standards of prevention, diagnosis and treatment. When the access to these new standards is made available (both in terms of legal terms, geography, and cost), most individuals end in a situation where they have ‘no’ choice but to adhere to the newly established higher standards, and they are deemed responsible to do so. Settling for lower standards does not imply legal penalties, but it is (especially in the case of the sociocultural environment of cancer) perceived as weakness, as not fighting enough for survival (or previval). ‘Previvors’ are expected to present a sense of responsibility towards the preservation of their bodies, and the extracts above portray various levels of this moral accountability. The preservation of the body is defined in this context, as being achieved through making informed choices and following of a set of ethical practices. The ‘ultimate’ task of a subjectivity centred on preservation is therefore never fulfilled until the risk is judged completely ‘eliminated’. This brings legitimacy to practices such as the preventive mastectomy or oophorectomy, which could have been otherwise considered as radical, in order to achieve the preservation of the body.

In the next section, I look in more depth at the function of extreme case formulations in the management of blame and accountability in everyday speech. I explore important functions of extreme case formulations such as the justification of hesitation and doubt, as well as the maximisation and trivialisation of specific aspects of the narratives. These usages have important implications in the negotiation of accountability.

7.4. Extreme Case Formulations and Blame Attribution:

In this section, I focus on the use of *Extreme Case Formulations* in everyday speech. I explore their functions in the management of blame and accountability in BRCA discourse. More specifically, I focus on their usage in the justification of hesitation and doubt as a means for sharing accountability; as well as their function as a device for comparison when a speaker needs to trivialise one of the variables as a means to redirect the attribution of blame and responsibility.

The two extracts below take us back to menopause versus surgery effects narrative, where Megan presents her anxiety about the post-surgery induced menopause. I focus in this section on the use of extreme case formulation and blame attribution as informed by Pomerantz (1986, 1978).

(1) *“I’m curious about how others have felt physically after total hysterectomy. The oncologist pretty much said that I’m about to go through menopause anyway, so the hot flashes and other issues are going to happen sooner or later regardless. I have a friend who has gone through natural menopause and says it’s the best thing that ever happened to her! But it seems like having the ovaries removed makes the whole thing harder, physically speaking (as far as after-effects).” Megan*

(2) *“However, I believe whatever lasting issues there are after my BSO is nothing compared to having to deal with ovarian cancer.” – Jade*

In extract (1), Megan put initially a case in favour of the undertaking the preventive surgery. She presents a menopause as a natural phenomenon occurring within women bodies. The use of the adverb *regardless*, in *‘the hot flashes and other issues are going to happen sooner or later **regardless**’* (emphasis added), formulates the occurrence of menopause as an inevitable truth with which we all agree, and any arguing otherwise would be considered absolutely pointless (Schiffrin, 1982). In supporting her argument in favour for not worrying about the post-surgery effects, Megan reports her friend’s experience with natural menopause. Megan reports that natural menopause was the best thing that ever happened to her friend. The natural menopause is qualitatively evaluated as *‘the best thing that ever happened’* to

Megan's friend. The Maximum Case evaluation measure, *'best thing ever'*, is a device that proposes that the menopause not only can be positive, but could also be positioned at the higher end of enjoyment of the biological transformation a woman can experience in her lifetime.

This statement strongly contrasts prior evaluations in the conversation and 'common' knowledge about menopause. By reporting its effects as *'the best thing ever'*, Megan suggests that an extremely positive change can be attributable to menopause. It presents a direct causal mechanism between the menopause and the experience of her friend post menopause, attributing the beneficial effects to menopause. By describing the effect as *'best thing ever'*, it also positions menopause as having a major power over the quality of life overall. However, by presenting the case as an isolated one (as opposed to a recurrent one) happening to a single friend, it also leaves the field open for assumptions about the negative effects (which could be equally maximal).

Megan therefore builds a case for the bodily and psychologically changes that she describes to be attributed directly to menopause rather than the personalities or characteristics of the people experiencing it. Megan is therefore representing women bodies as dependent on unpredictable effects of menopause. This rhetorical strategy places both the act of dealing with menopause, and making an informed decision while taking into account the potential post-surgery menopause effects, outside her scope of abilities; thus, minimising her accountability. Through this formulation, Megan is giving legitimacy to her hesitation and doubts as to whether undertake the preventive surgery.

In extract (2), Jade is giving an advice to Megan, who is debating as to whether she should undertake the preventive surgery. Her main fear being the post-surgery induced menopause. Jade's argument is in favour of undertaking the surgery. Jade is BRCA 1 positive and has been given an 85% chance of developing breast cancer in her lifetime, following her genetic screening. Her dad is the carrier of the faulty gene, and the first onset of breast cancer in her family was her older sister when she reached

forty two years of age. She has had a BSO (Bilateral Salpingo-oophorectomy) recently and is taking a low dose estrogenic patch. She hasn't felt any side effect yet.

Jade describes her decision to undertake the preventive surgery in such a way as to place it as an obvious choice. In doing so, she is positioning her actions as *'rightdoings'* (Pomerantz, 1978), and based on an objective and well thought process. For instance, when uttering *'I believe whatever lasting issues there are'*, Jade provides for a comprehensive evaluation based on a long-term monitoring of the post-surgery effects. The adjective *'lasting'* points out towards a long-term monitoring of these effects, although it being merely based on assumptions made by Jade. On the other hand, the adjective *'whatever'* positions the post-surgery induced menopause as one amongst many other potentials effects of the preventive surgery. It functions as a device to minimise its importance as a side effect, as it also provides room for assumptions that there might be other more severe side effects.

Jade has experienced the post-surgery effects beforehand (as she went through the preventive surgery), but not experienced ovarian cancer. In her formulation *'having to deal with ovarian cancer'*, she therefore positions the experience of ovarian cancer as common knowledge. This positioning allows Jade to perform her comparison between the experiences of dealing with ovarian cancer, and the post-surgery effects (including post-surgery induced menopause). *'Nothing compared'* is a device to compare both experiences. It provides for an evaluation of the experiences of post-surgery effects when compared to those of ovarian cancer. It specifies the evaluation of the experiences of post-surgery effects as *'nothing'*: the low maximum possible. In the literal sense, the post-surgery effects are not null; but their description as the low maximum (using *'nothing'*) functions as a device to giving sense for what those effects are for the matter in question. The formulation *'whatever lasting issues there are after my BSO is nothing compared to having to deal with ovarian cancer'* is what Pomerantz (1986) labels as a maximum or extreme case formulation. The sense provided by this formulation is that the post-surgery effects are trivial, particularly when the threat of ovarian cancer is *'real'*. It provides for considering the decision to take the risk of developing ovarian cancer, just because of the fear of the post-surgery menopause, as irrational or unreasonable. This formulation also provides for the recognition of

Jade's *'rightdoing'* by undertaking the preventive surgery, and the legitimacy of the advice she provides to Megan. In specifying *'nothing'* as the evaluation of the post-surgery effects, she provides also a case for an audience who would potentially consider her decision as 'extreme'; an audience who might consider the post-surgery effects as too radical for an individual who is healthy (but with a 'strong' genetic predisposition to developing the illness). Potter et al (1991) call this type of glossing a 'preformulation'. As they put, a preformulation works as follow: "(That is), in the course of formulating an argument at the same time it formulates an expected counter-argument" (Potter et al., 1991, p. 339). The rhetorical goal that the preformulation achieves, in Jade's case, is the construction of the counter-argument (claiming that post-surgery effects as too radical, especially if considered for an individual who is 'healthy') as weak. Jade is therefore providing a case for an audience who could undermine the legitimacy of her advice.

7.4.1. Concluding thoughts:

Part of the business of asking for advice within this biosocial community is presenting the hesitations and doubts as legitimate. This constituted an important rhetorical strategy when the majority within the community were advocating following a specific set of ethical practices once an individual is diagnosed as a carrier of a BRCA mutation. Therefore, in order to present a situation as worthy of hesitation, individuals were portraying their fears with *Extreme Case formulations*. Part of this process is an invitation for sharing the accountability for the decision making, which was subsequently managed by the other forum contributors through the use of other strategies such as script formulations and modality, as I have discussed earlier. Extreme case formulations are also deployed by advice givers to strengthen their claims, and frequently associated with preformulations to anticipate counter-arguments.

In the next section, I look at the use of passivisation and their ideological function in the management of agency in everyday speech. I explore important functions of passivisation such as agency deletion and the reification of processes, as well as

formulations that are common within infectious diseases and how they translate in the context of the pre-ill body. These functions have important implications in reframing the attribution of responsibility and accountability.

7.5. Passivisation and the deletion of agency:

In this section, I focus on the use of passivisation in everyday speech. I explore their ideological functions of passivisation such as the management of agency in BRCA discourse. More specifically, I focus on their usage for agency deletion in speech, and how this contributes into reframing the attribution of responsibility and accountability. Through the analysis of the extracts below, I look as well at common passive formulations that stress the responsibility of the individual, particularly those within infectious diseases, and contrast them with the present case.

- (1) *“Unfortunately I haven't been given a % risk, it has never been mentioned, but based on the early death of my mother (52), my Grandmother (41), her sister (late 30's), and their Aunt (50), they think I'm high risk even though my mothers test was negative for "any known mutation". I have decided my risk is big enough to worry and I am (fairly sure) I am going to tell my Consultant I want an ooph at my next appointment...eeek!” Ivy*
- (2) *“Hi! I also have a strong family history of breast cancer (my mother, maternal aunts (two), maternal grandmother, and maternal great-aunt). My mother and I have tested negative for BRCA mutation. We likely have another unidentified mutation. I understand how hard it can be to decide where to go from here.” Tatianna*

Ivy is BRCA negative, but has a strong family history as she described in extract (1). Ivy's risk could not be quantified in percentage. To narrate the latter, she uses the formulation *‘Unfortunately I haven't been given a % risk, it has never been mentioned’*. An important aspect of this formulation is the use of the passive form, with the agent responsible for the absence of information, being deleted from the utterance.

Passivisation performs important ideological functions. As it can be seen from the extract above, Ivy's use of passive forms in '*Haven't been given and has never been mentioned*' functions as a device to turn a process into an entity; as the transfer of information (or the absence of in this case) is portrayed as a key factor for her to make an 'informed' decision. The passivisation functions as well as a device to delete the agent responsible for this absence of knowledge (quantification of risk), and to shift the focus on the absence of knowledge affecting the choice making (process) rather than a specific agent to be blamed. As described by Fowler et al (1979), some of the important ideological functions of passivisation are deleting agency and reifying processes (Fowler, 1991, Fowler et al. 1979).

The representation of the passivated subject has also important ideological functions as described by Theo Van Leeuwen. He (2008) delineates two different positions for the passivated social action: Subjection or beneficialisation. Subjected social actors are treated as objects within the business of representation. On the other hand, beneficialised social actors are represented as a third party that, positively or negatively, benefits from the activity. Through the formulation '*Unfortunately I haven't been given a % risk, it has never been mentioned*', Ivy represents herself as a negatively beneficialised social actor. She acquired this status as a result of a 'bad' knowledge transaction. The absence of quantification of risk is translated into something affecting her decision making process negatively.

This information about the absence of risk evaluation is then contrasted with the subject's family history. The discourse marker '*but*' does not only have a referential contrast function here, but also functions as a rhetorical device to reassess this absence of knowledge and the possibility of evaluating Ivy's risk, even though the risk couldn't be quantified. After presenting some family history, the agent, that was initially deleted in the passivisation process, reappears in the extract in '*but based on (...), they think I'm high risk even though my mothers test was negative for 'any known mutation*'. The information presented in this utterance contrasts to the one initially portraying an absence of knowledge about Ivy's risk in two different ways. First, the agent is designated by a pronoun in the latter statement, 'they' - albeit being a pronoun designating the unspecified. As I have previously discussed, the pronoun '*they*' operates as a device to call to an unspecified authority (Pennycook, 1994). Second,

the risk evaluation is represented qualitatively. Interestingly, its absence called to a quantification, specifying the absence of calculation of a percentage. Ivy uses the adjective *'high'* to refer to the qualification performed by the unspecified authority. The resurface of the agent, and the call to an unspecified authority through the use of *'They'* functions therefore as a device for hiding this locus of authority who supports Ivy's own view, but also mainly giving legitimacy to the qualitative evaluation of her risk as *'high'*. This operates therefore as a device hiding Ivy's subjective opinion or evaluation of her situation; thus, helping make the objectivity of her claim difficult to question.

Another interesting aspect here is that throughout the process from risk assessment (both attempts to quantify and qualify) to the making of an informed decision, there has been a shift in the attribution of responsibility and accountability. Whereas the responsibility of assessing the risk was attributed to *'they'* (an unspecified authority), the one about the decision making process was attributed to the first person through the use of *'I'*. The shift, from the unspecified authority to the first person singular pronoun, performs specific rhetorical functions. As I have demonstrated in a previous section, the pronoun *'I'* refers to having a sense of responsibility (in addition to the sense of time and place). Ivy expresses, therefore, her sense of responsibility regarding her own risk, while the assessment was based on an objective source (the unspecified authority). By using of the specifier *'enough'*, in *'I have decided my risk is big enough to worry'*, Ivy attempts to demonstrate that there has been a throughout assessment and reflection from her part and therefore giving more legitimacy to the following action; which is to discuss with the consultant about her decision to undertake the oophorectomy.

In extract (2), Tatianna presents a profile that is fairly similar to Ivy's. Tatianna has a strong family history of breast cancer. However, both she and her mother's test results were negative for the BRCA gene mutation. There is also, in this extract, the use of passivisation in *'have tested negative'*. The use of the passive form *'Have tested'* is a quite pervasive formulation within the current lay population healthcare speech. Neither Tatianna, nor her mother have performed the genetic test themselves. They went through a process of testing and getting results by agents that are deleted within the formulation *'I have tested negative'*. Even in the case of self-testing, the agency is

still dispersed: located within the interaction the testing device, the instructions leaflet, the patient's education process, and so on; but that would be a completely different case and analysis. This specific formulation (*'have been tested'*) makes it more likely to locate the blame fully within the *'tested'* subject, rather than attributing part of the blame to the agent performing the test. The location of blame is more obvious in the case of HIV/AIDS or sexually transmitted infections (STIs), where the tested subject is often established responsible for contracting, carrying and transmitting the virus/infection. In their study of the news media coverage of a doctor-patient HIV/AIDS contamination tracing investigation, Brown et al. (1996) describe how the Australian news media were casting *'villains'* and *'victims'*, amongst the population infected. A key aspect to this narrative is that the *'patient zero'* was a hospital obstetrician who happened to identify as homosexual. Brown et al. (1996) explain how asserting the doctor's sexuality, in the media coverage, was integral to establishing his *'guilt'* and allowing *'innocent'* affected women, who required the services of an obstetrician, to be exposed to the *'guilty'* perpetrator of the disease. Besides reframing HIV/AIDS as a disease of *the deviant other*, this discourse of moral outrage attributed the blame to the vehicle of the infection (ie. The homosexual obstetrician), and the authorities that allowed him to practice while carrying the disease. The formulation *'disease-carrying homosexuals'* was frequently deployed in Brown et al (1996) dataset.

There are some similarities and differences between the HIV/AIDS example, and the present case. Within the BRCA gene discourse, individuals need to be *'tested'* when suspected to be a potential *'carrier'* of a genetic mutation. The metaphor of carriage implies that the individual is considered as a vehicle for an anomaly. Identifying an individual as a *'vehicle'* has the implication that one of the ways to stop the transmission of the anomaly is to identify and prevent the means of the transmission of the anomaly through the carrier. Whereas in the HIV/AIDS discourse, the most common transmission in lay speech is sexual encounters and drugs intake (emphasising the deviant nature of the transmission); the BRCA gene mutation is inherited. The hereditary nature of the transmission of the BRCA gene mutation means that the transmission is performed through procreation. Instead of being

located in an interactive practice (human to human in sexual encounters, or human to object to human in drugs injections), the mode transmission is located within the body. In other terms, the risk is replicating in this case within the body, moving in time and space from a generation to another, rather than moving from a body to another in interaction. When moving from a body to another in interaction, the risk is considered as external to the recipient body; therefore, locating therefore the blame within the original host. However, when transmitted hereditarily, the risk is mostly internal (except if we consider the moral question of whether individuals carrying genetic mutations should procreate, which echoes to the eugenics discourse). I explore the linguistic functions of the metaphor of carriage in further detail in the metaphors section.

Procreation being considered traditionally as a 'natural' rather than a deviant activity, the notion of moral 'outrage' cannot apply similarly. Although the individuals within the forum were often debating about the appropriateness of having children, the most recurrent discourse was the necessity to transmit the information to their offspring, once they are 'ready'. The morality is located with the responsibility to transmit of information, reinforcing the discourse of '*knowledge is power*' that was dominant in the forum (I get back to this notion of knowledge as power in depth in the next chapter). The individual is therefore deemed, once the information is received and evaluated, to be responsible of the preservation of their bodies, as well as the communication of the information to the individuals they potentially transmitted the mutation to.

Similarly to Ivy, Tatianna translates her negative results for the BRCA mutation into the likelihood of presence of other genetic mutations that haven't been identified yet. Tatianna makes an implicit causal link between her strong family history of breast cancer, and the ('likely') presence of an unidentified mutation. Both Ivy and Tatianna make sense of their at-risk bodies as *genetically* at-risk bodies.

7.5.1. Concluding thoughts:

In this section, I tried to demonstrate the functions of passivisation in deleting agency and reifying processes. The agent was deleted or reintroduced within a certain authority, when the 'scientific' aspect of the evaluation of risk was questioned. The risky body was preferably understood in genetic terms, before deciding the course of action of ethical practices.

This 'geneticisation' (Lippmann, 1991; term explored previously in chapter three) of the bodies determined the course of action of the ethical practices. In both contexts, the negative results were made sense of as a limitation of the field. As previously discussed in the case of the Angelina Jolie letter, the lack of knowledge or access to knowledge is associated with a loss of control as the calculation of risk cannot be performed. The lack of knowledge was described as paralysing their decision making; a description that reinforces its polar opposite that is '*knowledge is power*', which was a dominant discourse in the forum. This conceptualisation of knowledge as empowering is similar to Rose's views of gene as an opportunity rather than a determinant only (2007). It is however entangled to a strong degree of genetic determinism. I explore this aspect of knowledge as 'empowering' in more detail in the final section of this chapter. What is of interest here, is that the agent responsible for the testing was frequently deleted in speech through passivisation; leaving the responsibility of what-to-do-with-the-available-information to the subject. This process of responsabilisation was left unquestioned, as the subject is medically labelled as the '*carrier*' (or not) of the BRCA mutation.

In the next section, I look at the role of metaphors in the management of responsibility and accountability in everyday speech. I explore important aspects such as metaphors of battle and journey, as well as the metaphors of body-as-container and body-as-bomb, and how they frame the body and the experience of the pre-ill body. This framing has important ideological functions in the process of responsabilisation of the at-genetic-risk subject.

7.6. Metaphors and the management of responsibility:

In this section, I focus on the function of metaphors in everyday speech. More specifically, I explore their role in the management of responsibility and accountability in BRCA discourse. This section is organised as follows: The first part is dedicated to metaphors of battle and journey, and how they travel from cancerous to pre-cancerous bodies through the geneticisation discourse; as well as the effects of this movement in translating the severity of practices (how radical they can be considered) between the ill and pre-ill bodies. The second part is dedicated to metaphors of control, with a particular focus on the metaphor of 'carriage' and how it frames the BRCA subject as a *container*, and the implications of this framing on the subsequent ethical practices to preserve the body. The final part is dedicated to the metaphors within the realm of mystical, and the tensions between the 'rational' and the 'mystical' formulations as well as the potential subsequent confusions. These tensions will be contrasted with the control narrative within the prevention discourse.

7.6.1. Cancer as a battle vs. Cancer as a journey:

- (1) *"I definitely think that you should get the genetic counseling and test as soon as possible. It will give you a lot of peace of mind and knowledge. I don't mean to quote from "Schoolhouse Rock," but "Knowledge IS power!" However, I do believe you are taking the right steps anyway--ovarian cancer is nothing to mess around with and it sounds like it's just rampant in your family. I am BRCA1 positive and was diagnosed with breast cancer in April. I will be getting a preventative hysterectomy later this year as well and I have the same fears as you do--that I'll end up being some sweaty, angry, crazy person that my son doesn't want to be around. But from what I've read, while there is an adjustment period, it does get better and they may be able to put you on some low-dose hormone therapy for a little while if necessary to get you over the worst of it. I think it will all be okay."*
Maureen

In extract (1), Maureen intervenes after Megan's claim on how genetic testing could be of little relevance provided the status of her mother is unknown. Maureen strongly recommends genetic testing; presenting it as an instrument of knowledge and reinforcing her recommendation by the statement "Knowledge IS power!". Maureen is planning to have a preventive hysterectomy later during the year, despite the fact that she shares the same fears as Megan - ending up being some '*sweaty, angry, crazy person that my son doesn't want to be around*'.

One of the rhetoric devices, Maureen uses to recommend the genetic testing to Megan, is the metaphor of 'rampage' in '*Ovarian cancer is nothing to mess around with and it sounds like it's just **rampant** in your family*' (emphasis added). Cancer's spread is frequently talked about, in expert and lay speech, in terms of movement. Cancer cells are said to be '*invasive*'; they '*colonise*' the body from the original tumour to far sites. In Semino et al (2004) study about cancer metaphors, oncologists were using combinations of literal references with metaphorical formulations to describe cancer '*entering*' the bloodstream. Examples of those references include describing parts of the body as '*sites*' or '*areas*'; or cancer getting '*dotted around*' in the skeleton, and '*lodging itself*' in the patient's bones.

The literature on metaphors and cancer delineated two distinct dominant sources that shape cancer metaphors: domains of fighting, war and battlefield (e.g. Sontag, 1978), and the domains of journey and travel (e.g Semino et al. 2004). The domain of battle ranges from labelling the affected individual as a survivor, to the language surrounding cancer treatment; where the language of the diagnosis is often fatalistic, which in turn shape the language of treatment that is centred on fighting against a deadly, insidious enemy (Sontag, 1978). This fight is ought to be won by any means possible provided the high value placed on health (Beck-Gernsheim, 2000; discussed earlier in the section on pronouns). Examples of the metaphorical formulations that are pervasive in cancer treatment are: '*bombarding*' areas of body with radiation, or treatment aiming at '*killing*' cancer cells. Bearing again similarities to linguistic formulations in HIV/AIDS discourse, metaphors in Breast cancer possess an overtly politicised character. The metaphors of war are not purely linguistic embellishments; they actually shape practices. As Annas (1995, p. 68) states: "military thinking

concentrates on the physical, sees control as central, and encourages the expenditure of massive resources to achieve dominance". Control, which is one of the key drivers behind a politics of prevention, constitutes a central feature as well, within metaphors of war. On the other hand, through the usage of metaphors of *'journey'*, cancer is mapped as a moving entity, travelling the body from a location to another before spreading to the whole body; it also maps other temporal aspects of movement such as speed of growth/movement or remission, as well 'pauses' in the journey, and so on.

The metaphor of cancer as *'rampant'* conceptualises it within both domains: war and journey. A potential final outcome of rampage is the sudden appearance or onset. For the purpose of the analysis, I consider an alternative literal polar opposite of rampant as *'sudden appearance'* or *'onset'*. Cancer is therefore conceptualised in this example as a rampant animal. The word *rampant* originates from the old French *'ramper'*, which means *'to crawl'*, and describes an insidious movement. Its use is common within the animal and vegetal realm to describe a crawling insidious movement. Rampant metaphors are common in the French military discourse as well, where it describes an insidious movement of the body to surprise the enemy. Whereas in the French language, the word *'rampant'* has a quite neutral prosody; its use in the English language has more of a negative prosody to describe a movement that is unrestrained or violent. Its usage also means in certain instances *'growing without check'*. The idea is therefore still an insidious movement, but with a menacing dimension drawing on both domains of war and movement. Those domains (Battle and journey) are not as distinct as it is in the case of Semino et al. (2004) findings.

The *'rampage'* of cancer, in the case of a pre-cancerous body, is performed through the transmission of the faulty genes. While the journey or travel metaphor of cancer is traditionally occurring within the body, spreading from an organ to another; the genetic narrative shifts this transfer in space to a movement that is performed from a body to another within the family. The rampage is performed through the movement of the 'bad' copies of the gene from a body to another through heredity. The genetics narrative also shifts this movement in time, as it is occurring in the movement of the genes from a generation to another; while the traditional journey metaphor follows a

narrative that is temporally located within the body lifetime, from the date of onset of the disease. Another difference as well is that the movement, within the genetic narrative, is located within healthy bodies; while it is, within the traditional cancer narrative, located within bodies affected with the disease. The genetic discourse performs therefore a spatiotemporal shift of these metaphorical formulations as well as the practices entangled with these. The spatial movement is from the affected/ill to the healthy/pre-ill body. The temporal movement is from the diagnosis of the body as cancerous to the diagnosis of the body as *carrier* of the 'cancer-gene'.

7.6.2. Body as a container for a ticking time bomb:

(2) *"I agree with you & Jessie, it's hard to relate to our families & friends sometimes. I have pretty good days, then I have days when the "tear attacks" come out of nowhere & I can't stop crying. I think that's just from holding it in for too long, trying to keep myself together. People think it shouldn't be that upsetting to know **you're a carrier**, but I feel like **a ticking time bomb**. My fear is not if I'll get BC, it's **when** I'll get it, it's always been my biggest fear. I realized not long ago that I'm the same age my aunt was when she died & my kids are the same age as my cousins were then & that really shook me up. I just take it one day at a time & I'm so grateful for this group! Feel free to email me at XXXXXXXXX@gmail.com" Kim (emphasis added)*

In extract (2), Kim describes how being BRCA positive affects her relationship with her relatives, and her fears about being sometimes misunderstood. She is thirty six years old and has recently received her screening results stating that she is BRCA1 positive. Kim has a strong family history as well, but is still hesitant as to whether she should undertake the preventive surgery.

There are several interesting metaphorical formulations in this extract. The first formulation is a pervasive one within healthcare discourse: the metaphor of carriage. The carriage of faulty genes is a common formulation within genetics discourse. It is however a metaphor that carries a strong ideological meaning. The BRCA positive

individual as a *'carrier'* is part of the metaphorical system, *disease as a possession*. Disease as a possession is one of the most common metaphor in infectious diseases (particularly within HIV/AIDS discourse) in both expert and lay speeches. Within this metaphorical system, people *catch, pick up, get, have, bring, acquire* or *contract* illnesses (Wallis and Nerlich, 2005). It is not only a metaphor of passive action as a receiver of a contaminant or mutation. People can also *carry, give* or *pass on* to others. They morph from being a recipient to a container to a transmitter of the agent causing the disease. *Disease as a possession* emphasises individual responsibility, as the affected person becomes an active agent in their own illness. An agent that can be accountable for contracting the infectious agent, for hosting it, and finally for transmitting it to a *'victim'* that becomes subsequently another host within the narrative. When a *'victim'* becomes a *'carrier'*, they are considered more as a danger or threat, rather than an object of compassion (Wallis and Nerlich, 2005).

The metaphor of carriage is considered an ordinary and indistinct part of the biomedical discourse. But what is its specific rhetorical function if it is so indistinct from the literal discourse? In his essay *'White mythology'*, Derrida (Derrida and Moore, 1974) coins the term *'usure'* to describe the death of a living metaphor. This death is metaphorical itself, and describes how the sharp and novel metaphor becomes ordinary and indistinct through constant usage (Billig and MacMillan, 2005). However, no matter how ordinary and indistinct they become, metaphorical systems still carry ideological meaning and perform specific rhetorical functions. For example, Gergen (1994) describes how metaphors of the mind as machine, within the field of psychology, saw researchers treating the mind literally as a machine within their projects. Similarly, the metaphor of carriage has become an ordinary and indistinct part of the medical lexicon. Nevertheless, it still conveys a strong ideological meaning and performs an important rhetorical function. Historically, the metaphor of carriage has been associated with infectious diseases and infected bodies. The carrier catches the infection from another infected body and becomes a host themselves. By *'becoming'* a host, the affected body is attributed agency. The body shifts from a passive entity, victim of the infectious agent, to an active agent that is accountable for the survival and movement of the infectious agent by carrying it. Specific care can be

prescribed (depending on the nature of infection) with regards to interactions with a carrier. The carrier has also the responsibility to limit his interactions with healthy subjects to avoid transmitting and spreading the infectious agent. The carrier is responsible and accountable for containing the infectious agent away from the healthy subjects. The way an infectious agent travel from a body to another bears some moral implications as well. The modes of transmission are traditionally classified as follow: contact, droplet and airborne (Siegel et al., 2007). The causal mechanism can be attributed to dirt, prolonged contact, sexual intercourse and so on. The example of HIV/AIDS is again a powerful one in this case, as the metaphors around HIV/AIDS are quite pervasive. The nature of the mode of transmission has reinforced the metaphor of HIV/AIDS as 'sin'. Wallis and Nerlich (2005) describe how AIDS as 'sin' was deployed to attribute causality (divine judgment), moral construction of the affected body (sinner), as well as prescriptive practices (such as repentance, abstinence, and moral education).

The framing of responsibility bears some similarities between infectious diseases and genetic predispositions to breast and ovarian cancer. Metaphors in genetics are powerfully pervasive devices as well. They have evolved greatly across time. For instance, the eugenics movement was characterised by heavily deterministic metaphors. Metaphorical formulations were reflection of how genetics were understood as determining personality and character traits, and therefore as a source of social and moral order (Nelkin, 2001). These included metaphors of the gene as the '*very soul*' of the individual, or formulations such as '*the blood will tell*'. Another dominant imagery of that era was the animal breeding metaphor with formulations such '*cross-breeding*' and the '*pollution of the gene pool*', and so on. Following the eugenic-inspired policies of the Nazis and the decline of eugenics, a cultural shift from genetic determinism (fostered by scholarly and public critics), shaped the metaphorical formulations and discourse surrounding genetics (for a full overview, please refer back to the literature review section on Eugenics, chapter three). From the essence of personal identity ('*master code*'), to a sacred entity ('*book of life*'), to a predictor of future fate ('*medical crystal ball*'), to a commodity ('*gene banks*' as '*national resources*') (Nelkin, 2001); metaphorical formulations surrounding genes

morphed historically shaped by scientific discourses, as well as discourses of literally and public policy critics, lay population and so on.

The growth of metaphors such as '*biological holocaust*' in popular media, shaped practices surrounding genetics as well. It made it less morally acceptable to prescribe individuals, with 'faulty genes', not to procreate. But while some metaphors, from the eugenics era, were deemed morally unacceptable; other formulations survived and thrived across the history of genetic discourses. For instance, metaphors such as '*master molecule*' were deployed by Francis Crick and James Watson when discovering the double helical structure of DNA. They described it as well as the '*code*' that '*carries*' the genetic information (Nelkin, 2001). This metaphorical formulation of a container that carries information further evolved to describe individuals inheriting genetic mutation – They are labelled as '*carriers*'. The moral dimension surrounding the carriage of faulty gene differs from the one surrounding the carriage of an infection in terms of accountability, with regards to the mode of transmission but does not differ from the responsibility of the carriage at individual level. With respects to the mode of transmission, as discussed earlier, it is not considered morally acceptable to prescribe individuals with 'faulty genes' not to procreate, even with the intention to reduce the transmission and spread of a genetic mutation⁵. The inheritance of a faulty gene is considered as an unfortunate event, rather than say a result of a sinful action as portrayed in HIV/AIDS narratives. On the other hand, the individual is still responsible for following a set of ethical practices for the preservation and survival of the body carrying the mutation, as well as transmitting the necessary information for their offspring so they can make informed decisions subsequently. The discourses of survivorship and previvorship puts an additional layer of pressure on individuals to follow certain ethical practices. As discussed previously in chapter five, the movement of destigmatisation of breast cancer has seen a discursive shaping from breast cancer as an individual tragedy, to breast cancer as an activist cause mobilising and organising public and political debate, to breast cancer as an inspirational journey (King, 2004).

⁵ However, there are currently heated ethical debates with regards to recent work-in-progress techniques of control such as embryos-gene-editing, allowing the correction of pathogenic gene mutations in vitro.

The discourse of survivorship and the movement from ‘patient’ to ‘survivor’ and ‘carrier’ to ‘previvor’ bears particular moral implications as well. As I have demonstrated previously in the section on pronouns and the construction of subjectivities, the celebration of the preservation of the body, entails additional moral expectations from previvors to follow certain ethical practices and make ‘informed’ decisions. The ‘carrier’, being the container of this mutation, is the main responsible agent for the preservation of the body. This metaphorical formulation works alongside the other devices I explored, to reinforce this subject positioning with the spatio-temporal as well as moral indexations associated.

The second noteworthy metaphorical formulation from extract (2) is the *gene-as-bomb* metaphor in ‘*People think it shouldn't be that upsetting to know **you're a carrier, but I feel like a ticking time bomb***’ (emphasis added). Alongside the pervasive *gene-as-disease* metaphor, another deterministic metaphorical formulation was fairly common in my dataset, which is the *gene-as-bomb*. These formulations assumed a strong causal link between gene and disease. Such formulations suggest that once a genetic mutation has been triggered, the result is inevitable. The formulation of *gene-as-bomb* is quite vivid and accentuates the destructive nature of the result – the result being the occurrence of cancer. The visual (metaphorical) representation of cancer as the result of a bomb explosion emphasises the intense nature of cancer narratives. The representation of the BRCA genes as a ticking-time bomb signals an inevitable explosion releasing the ‘deadly’ cancer. Kim stressed this aspect in ‘*My fear is not if I'll get BC, it's when I'll get it, it's always been my biggest fear*’. The use of ‘when’ for the script formulation suggests the quasi-certain occurrence of the condition, and therefore a different approach to the course of action of ethical practices. As the outcome (occurrence of cancer) is depicted as inevitable, preventives practices are assimilated at the same level of urgency as the curative ones, and the at-genetic risk body is formulated as quasi-ill, or ill in its own way. Another notable aspect is the use of the modal verb ‘will’. In the previous extracts involving script formulations and advice giving, the modal verbs used had a tendency to be of a weaker nature (section on pronouns in this chapter). Modals such as ‘should’ and ‘might’ were used in the instances where the speaker was involved in shaping the decision making process,

while still attributing the responsibility of the final decision to the carrier. In contrast, Kim uses a stronger modal verb 'will', which in conjunction with 'when', signals the quasi-certainty of the occurrence of the negative event; therefore presenting the urgency of the subsequent ethical practices as rational and unquestionable. The scripting device 'when' functions therefore as a device to legitimise certain ethical practices, and emphasise the responsibility of the individual to follow these practices in order to fulfil the task of the preservation and survival of the body.

7.6.3. Faulty gene as a 'curse':

(3) *"I'm so glad it helped and wasn't taken negatively. There were 4 girls in Mom's family too, and one son. The oldest daughter died of leukemia.*

*A somewhat interesting side note: The girls passed in 80', 85', and 90'. Then Granddaddy had a major heart attack in 95', thank God he survived. My poor Grandma was scared as h*ll when 2000 came around. She thought everything was going to be okay, but two weeks before the end of the year she was in a terrible car accident with a tractor-trailor. The doctors didn't expect her to survive the night, but she told family there was NO WAY she was going to pass in 2000, she insisted she needed to live until the new year to break "the family curse". She passed in Jan 2001 without ever having left the hospital. My Grandma was a strong woman, a teacher, sweet southern lady, active member of the Baptist Church, and no nonsense kind of person. It surprised me to hear her speak of a "family curse" but I can't say I blame her for thinking that way. Can't help but wonder if she was on to something. NOTHING happened in 2005" Shirley*

In extract (3), Shirley narrates her family history. She is BRCA negative but has a strong family history. From her narrative, there appears to be a pattern within her family history, with deaths happening at a specific time interval since 1980. Both Shirley's mother and her mother's twin sister died of Breast cancer at the age of thirty six and thirty one respectively. Shirley describes her mother's overall negative attitude towards chemotherapy after her diagnosis, as well as her own feelings of anger towards her mother for 'not trying harder'. The way Shirley refers to the course of

action she would follow is shaped by those previous experiences and stories, particularly the one with regards to the relationship with her mother.

One notable device in Shirley's speech is the use of the metaphorical formulation '*family curse*'. The formulation '*family curse*' was used by Shirley's grandmother to narrate and make sense of the death pattern within their family history. The possibility of occurrence of the negative event is causally attributed to some supernatural powers. The BRCA negative status was translated by Shirley's grandmother into the formulation '*family curse*'. The term '*curse*' is used at a figurative and metaphorical meaning (rather than a magical word or spell that has been uttered by an agent to actually bring bad luck to a family and their descendants). The negative BRCA results are not necessarily understood, in this example, in terms of an absence of faulty genes (as the absence of the known can imply a presence of the unknown-yet to be discovered; cf. section on quantification rhetoric), but of a presence of 'supernatural' forces that are the causes of the family history of breast cancer related deaths. In contrast with a genetic deterministic discourse that calls to a fairly organised set of ethical practices, the formulation '*family curse*' call to disorder and chaos. As a supernatural phenomenon, a curse can be broken only by another supernatural phenomenon. Although the meaning here is not literal but metaphorical, it signals that the course of action of ethical practices cannot follow a 'logical' path – the phenomenon cannot be controlled by a human rationale. The tensions between the '*rational*' and '*mystical*' formulations, shapes in turn the practices creating subsequently tensions between the set of practices to follow.

7.6.4. Concluding Thoughts:

In this section, I tried to outline some of the rhetorical functions of metaphors; and how their use in everyday speech goes beyond the expression of opinion in an efficient or embellished way. A historical approach proved to be helpful in understanding the ideological effects of metaphors, and how these can establish themselves as ordinary and indistinct linguistic formulations through frequent usage. This process of '*usure*' (Derrida and Moore, 1974) renders the ideological functions even harder to uncover.

Responsibility is attributed through the use of these indistinct metaphorical formulations in everyday interaction, without the speakers necessarily alluding to it in an explicit manner. Indeed, when using specific metaphorical formulations such as the metaphor of carriage for instance, individuals were reproducing specific ideologies.

Control, military, and journey metaphors function as rhetorical devices that frame subjectivities in a specific way, and thus shape the ethical practices to not only prevent but also contain diseases. Through metaphorical formulations, the BRCA gene is even given a quasi-divine power as it constructs BRCA positive women as '*living under the shadow of cancer*' as analysed in the Angelina Jolie letter in the previous chapter. Metaphors do not operate in isolation obviously, but in interactions with other rhetorical and moral systems. Within the genetic and breast cancer domain, the moral dimension associated with the genetic discourse has a delineating function on the control discourse. Nevertheless, those metaphorical systems play a major role in reinforcing the accountability and responsibility of the '*carrier*' of BRCA genes.

The following and final part focuses on knowledge, empowerment and power. In it, I explore the discourse of empowerment and its intimate relation with the responsabilisation of individuals. Moreover, I scrutinise how the discourse of empowerment participates in the performativity of the market actors and practices; consumers and consumption of preventive solutions.

7.7. The 'logic' of empowerment – The responsabilised subject as a market actor:

Knowledge as power, and the feeling of being empowered by knowledge and choice were recurrent themes in my dataset. But what does it actually mean to be 'empowered by knowledge and choice'? And most importantly what does it do? This is one of the central themes of this discussion chapter. First, I present one final extract to better contextualise the subject position 'empowered individual' in connection to some of the elements discussed throughout this chapter. Moving forward, I discuss

the informed/expert patient discourse within health narratives and its positioning as empowering consumers of healthcare services. This will lead me to scrutinise what 'empowerment' as a discourse actually *does*, starting from a brief history of the term, to its domestication within neoliberal ideology, and finally connecting empowerment with power through a Foucauldian lens.

I discuss in this section one final extract within my dataset, copied below. This long extract features several of the devices and the themes discussed throughout this chapter, with several interesting moments on knowledge, power, and empowerment.

(1) *"At fifty and three years out of a long, dysfunctional marriage, I feel like I've just discovered my sexuality and the positive aspects of having breasts. Better late than never, but it complicates an otherwise logical decision to undergo PBM because **I'm not ready to give up what I've just rediscovered**. Even with reconstruction, and as the posts on this site show, there's no guarantee that everything will go smoothly, that I'll feel like myself, or that no other health issues will emerge. Would that we could get assurances that would make this process more black and white. Thankfully, I have a therapist worth her weight in gold, and even though she says I made my decision months ago to have PBM with reconstruction, I'm still going through the education process before making that decision out loud. The thought of a long **process of getting my body back and the mental baggage that goes with that** is discouraging. But the thought of going through what my mother and so many others went through and are going through is downright frightening, and repeated biopsies and lumpectomies have the same outcome, just by a thousand cuts. **At least now the choice is mine...empowered, right?** By choosing PBM before a possible diagnosis of active bc, I can take my time, chose my surgeon and plastic surgeon carefully, and **start going through the grieving process** before trying to navigate it while recovering physically as well. If you've had all of the screening and haven't talked with a surgeon/plastic surgeon, I recommend it to you; where you live can really affect the options available to you. I'd also recommend a lot of reading, including the Breast Reconstruction Guidebook,*

*which is realistic and digestible. **Information is power** and together with the experiences on this site, I hope it helps manage my expectations and those of people close to me.” Rebecca (Emphasis added)*

After recently getting out of a long, dysfunctional marriage, Rebecca feels like she is discovering her sexuality at the age of fifty. Realising now the sexual enjoyment that she can get from having breasts, makes what she describes as *‘otherwise logical decision to undergo PBM’* complicated for her. The *‘choice’* of undertaking the preventive surgery is positioned as a rational one for Rebecca, provided her strong family history for breast and/or ovarian cancer. Her location within the subject position *‘high risk for HBOC subject’* bears the moral duty to preserve the body. This responsibility is an effect of the *‘knowledge’* of the evaluation of her risk being made available to her, and her location within a subject position associated with this knowledge. Through the contrasting of her case with her mother and *‘so many other’*, she constructs the possibility of undertaking the preventive action as a rational choice. Rebecca emphasises the aspect of it being a **free** choice, made available through knowledge, and connect it to a feeling of empowerment in the utterance *‘at least now the choice is mine.... Empowered, right?’*. However, this association between empowerment and choice is hesitant within the formulation, through the use of the informal exclamation *‘right?’*. The informal exclamation redirects her positioning as *‘empowered’* to a larger consensus; although, this inference is performed hesitantly through the use of extension points *‘...’*. Thus, Rebecca reflexively positions this association as part of a wider, dominant discourse (or lived ideology) that she might not necessarily understand or subscribe to rhetorically, but feels the moral obligation to subscribe to the practices attached to it, provided its location within the realm of *‘rational/logic’* behaviours.

The primary tensions with the choice making are located between the undertaking of the preventive surgery in order to reduce the high risk for HBOC, and the enjoyment of the newly rediscovered body and sexuality. The two choices are antagonist as the preventive surgery involves a removal of organs that are positioned as the new primary sites of female sexual pleasure for Rebecca. She also factors in her decision

making the potential risks associated with breast reconstruction as well as the length of the process for *'getting [her] body back'*. However, the positioning of undertaking the preventive surgery as the rational and logical choice to undertake, is performed at several moments in the extract. For instance, through the utterance *'but it complicates an otherwise logical decision to undergo PBM'*, Rebecca positions the prior statement of joy of rediscovering her sexuality as an obstacle to the doing of the rational choice. The business of contrasting, in this case, is constituted between the positive and negative outcomes of this new discovery, and is performed by the discourse marker *'but'*. As I have discussed previously in this chapter, the discourse marker *'but'* does not perform a referential contrast function only. In this case, it functions as a device for contrasting the moral duality associated with the discovery of Rebecca's sexuality, but also functions as a rhetorical device to present its later moral outcome as having serious implications for the survival of the body. Rebecca further explains her hesitation in *'because I'm not ready to give up what I've just rediscovered'*; therefore positioning her dilemma of choice between the realms of the rational and the emotional as legitimate. However, she later utters *'Thankfully, I have a therapist worth her weight in gold'* to introduce her decision to go with the 'rational' choice of undertaking the preventive surgery. The call onto the expert support' narrative, 'therapist', to present the decision making has several functions here. First, it positions the decision to go with the rational option as saving her from the dangers associated with an emotional, irrational choice through the use of the adverb *'thankfully'*. Second, it legitimises the struggle and difficulty of the decision making process, as it required the called an expert support within the field of 'mind' (psychology). Therefore, the tensions are located between the rational and emotional, the mind and the body, with two main subject positions at the front of the stage; the 'high-risk for HBOC subject' and 'the 50 year old woman who has newly rediscovered her body and her sexuality'. The two subject positions hold conflicting moral locations, which create tensions within the decision making; constantly reassessing the 'right' choice and relegitimising the hesitations through various rhetorical strategies.

A third and final main subject position within the extract, 'empowered subject', reconfigured the decision making process of Rebecca. Following the introduction of

the position 'empowered', the focus of the narrative shifts onto the availability of options and the choosing from these options, while emphasising the freedom of choice - '*at least the choice is mine*' (emphasis added). The empowerment, or the creation of the subject position 'empowered', is intertwined with the freedom of choice. Its framing, within the extract, positions it as a result of information gathering, where the information emanates from (1) biomedical knowledge such as genetic screening and medical surgery (preventive and aesthetic/reconstructive), and (2) self-education through self-help tools (such as the Breast Reconstruction Guidebook). This knowledge/information is considered the source of power ('*information is power*' in this extract), and the empowerment is a result of the transfer of this power to the subject through the gathering of information, in order to make a 'free/informed' choice.

Albeit hesitant in the enunciation of her location within the subject position empowered, Rebecca follows up with some realisations that she causally attributes to this position and the freedom of choice associated. This choice is constructed as allowing more *time* to perform subsequent important choices, such as (1) the selection of the surgeon and plastic surgeon, enabling to increase the chances of success not only of the preventive act, but also the artificial reconstruction of the object of sexual pleasure, as well as (2) the grieving of the naturally-existing object of sexual pleasure, as they are about to get cut from the body. Thus, the construction of the subject position, 'empowered', allows a reconciliation of the tensions between the rational and emotional registers. However, it is only able to perform this reconciliation through compromising on the emotional register, and achieves this through the provision of 'choice' as ultimately free, autonomous, and based on empowering information.

The subject positions 'informed' and 'empowered' are therefore key to the shaping of the practices of at-genetic risk individuals. They constitute pervasive subject positions that are made available for the BRCA subject as it can be seen throughout the dataset, whether it was in FORCE or HBOC in the media. Furthermore, they appear to be intimately connected. The following section will scrutinise the subject position,

‘informed/expert patient’, within healthcare discourse, with a particular focus on its connections to the notion of empowerment.

7.7.1. The ‘informed’ patient:

The linkages between knowledge, power and empowerment are pervasive in both lay and expert speeches. This gave rise to new subject positions being made available for consumers of health services such as ‘informed patient’ and ‘expert patient’. For instance, the notion of ‘expert patient’ emerged as a central topic in the UK health policy in the past two decades (Department of Health, 2001, 2015). In the meantime, the discourse of empowerment has been gaining more and more credence within healthcare over the years, with the adjective ‘*empowered*’ slowly replacing ‘*expert*’ to qualify the ‘ideal’ patient. The latest ‘NHS Five Year Forward View’, published in October 2015, and which sets out the NHS vision for health and social care models in the UK, put to the fore the centrality of the notion of empowerment to its health and social care policy. The title itself sets the tone clearly on this direction with ‘*New Care Models: empowering patients and communities*’. Patients’ empowerment is intimately linked to the education and support they receive to become autonomous; “Provider approaches will have to evolve towards making the empowerment, education and support of patients to self-manage their care a high and ongoing priority” (Department of Health, 2015, p.11).

Within this view, the empowerment of the consumers of healthcare services is possible through their transition from the status of ‘patient’ to ‘informed patient’; where the newly acquired knowledge and expertise enables autonomy in taking care of one’s life and making ‘informed’ choices. The internet has been a driver for the shaping of the ‘informed/expert’ patient. The plethora of web-based health related information is said to enable the education of patients, while the online forums provide spaces for support, information and stories sharing⁶.

⁶ Another actor participating in this process is the relative freedom of the pharmaceutical industry from the medical profession through market mechanisms, which allows online direct-to-consumer

The concept of informed/expert patient has been scrutinised within the sociology of health and illness, with several critics assimilating it to an extension of the Foucauldian medical 'gaze' (Wilson, 2001, Fox et al., 2005a). Requiring both the compliance to experts' prescriptions and an ownership of the control of one's health management, the paradoxical expert patient culture is said to reinforce a biomedical model of disease, through the iteration of normative ideas about health and illness within lay discourse and practice, rather than actually empowering the patient/consumer with a new model of healthcare. From a Foucauldian perspective, the expert/informed patient becomes a reflexive project of self-governance, reproducing the tensions between the disciplining of the body through medical models of thought and the aspiration to autonomy and self-care through the discourse of responsabilisation. The construction of biomedical science- literate patient/consumer is essential for enacting this form of governance, turning patients into responsabilised biological citizens. Within this frame, responsibility is intertwined with biological rationality; thus, shaping individuals' moral accountability for the preservation of their bodies.

The main line of argument is that the promise of autonomy of the empowerment discourse is restricted, in this case, to the self-management of healthcare; while still being tied to the dominant biomedical model. This led the critics such as Fox and colleagues (2005a) to question whether those patients are actually empowered through the subject positions informed/expert patient. However, what does it

advertising and online access to drugs, therefore transforming the interaction between patients and chemical interventions and enabling more autonomy to the patient-consumer (Fox et al, 2006, 2005b). Purchasing prescription drugs online (sometimes without requiring showing an evidence of prescription) is a growing phenomenon in the USA, especially provided the huge price discrepancy between the USA and Canada, leading more and more US citizens to acquire their drugs from Canadian online pharmacies (Mangan, 2014); despite the current US regulation restricting the import drug for personal use to approved drugs only, and with a maximum of three months' supply (FDA, 2017). However, this phenomenon is not exclusively American. In 2009, a survey commissioned by Pfizer, the MHRA (Medicines and Healthcare products Regulatory Agency, which is an executive agency of the Department of Health in the UK), The Patients Association, HEART UK, and the RPSGB (Royal Pharmaceutical Society of Great Britain) exposed that 15% of the British adults surveyed admitted purchasing prescription-only pharmaceuticals online without a prescription, therefore bypassing the UK healthcare system (Nuffield Council on Bioethics, 2010) (this survey was part of the '*Get Real, Get A Prescription*' campaign in 2009, which was supported by the aforementioned organisations). In addition to that, a study by the Nuffield Council on Bioethics revealed that around 62% of prescription pharmaceuticals purchased online were either non-conforming to GMP (good manufacturing practices), unapproved, or even fake (Nuffield Council on Bioethics, 2010); which adds to the alarming nature of the phenomenon.

essentially mean to be an empowered consumer/patient? The feminist literature and activist movement on breast cancer (such as Klawiter, 2000, 2008; King, 2004, 2006; Dubriwny, 2013, which have been discussed in depth in chapter five) has often presented the concept of empowerment, uncritically, through a positive light. Nevertheless, the notion of empowerment is much more complex than its apparent innocence might display at first. The next section provides a brief historical overview of the notion of empowerment, and connect it to its usages within the present case.

7.7.2. Empowerment history:

In the English language, empowerment is a word with a positive prosody. It is a term that has gained a wide momentum in Anglo-Saxon speaking countries and worldwide within the past couple of decades. However, it is difficult to trace the origins of the word. The term is used sometimes in its English form, untranslated, when used in other language, as it is difficult to find its direct translation to other languages.

For instance, there is no direct equivalent to '*empowerment*' within the French language. The most agreed upon translation is '*autonomisation*', which is the process through which an entity gains the autonomy to act. The term '*capacitation*', which has been borrowed in market studies, is also sometimes considered a close enough translation as well. Market studies' reference to capacitation draws primarily on Gilles Deleuze' seminal work '*Expressionism in Philosophy*', where he engaged with Spinoza's philosophy (Deleuze, 1992). Within this perspective, the mechanism of the body's capacitation represents "the specific means by which bodies acquire new capacities or powers in certain contexts and encounters, just as capacities are lost in other contexts" (Duff, 2010, p.628). Examples of market studies literature that explored capacitation at work include Duff's study (2014) on health and healthcare assemblages, Onyas and Ryan (2015) paper on market innovation tracing the transformation of a mainstream market into a new 'sustainable' one. Studies have focused either on technology (Hornborg, 2001, 2006), or regulations (Maesschalck, 2008; Loute, 2013) as enablers of capacitation.

What is notable is that both French terms, *'autonomisation'* and *'capacitation'*, have a much more neutral prosody than *'empowerment'*. Recently, the term *'empouvoirement'* has been coined by Benoît Thieulin, president of the National Digital Committee (Conseil National du Numérique), during a conference on public innovation and digital revolution in November 2014. The term, which is a breakdown literal translation of the English version (em-pouvoir-ment), was judged necessary in order to capture the meaning of empowerment that was lacking in the French language. Although French linguists appear to be sceptical towards the term (provided there is no equivalent for the verb 'empower' in French), 'empouvoirement' popularity has been slowly growing, particularly within the mainstream French feminist press. The Arabic language does not have a direct equivalent to empowerment either, and is pretty close to the French language in this case. The closest equivalent is التمكن which means endowing with the capacity to act ('capacitation'); with again a neutral prosody. In contrast, the Spanish Language has a direct translation which is *'empoderamiento'*. The etymology of *'empowerment'* is the verb *'to empower'*, which itself has a root in the noun *'power'*. The verb *'empower'* has a direct translation in Spanish, *'empoderar'*. This explains the possibility of existence of a direct translation in Spanish. However, the root of the verb *'empoderar'*, which is *'poder'*, can mean *'power'* as a noun, but also *'can'* or *'be able to'* as a verb. The latter shifts the meaning to a version that is closer, in terms of neutrality of the prosody, to the French or Arabic ones. Nevertheless, the Spanish *'empoderamiento'* has a very similar use to *'empowerment'* overall. For a full discussion on the etymology of empowerment, please refer to Lincoln et al (2002).

The etymology of *'empowerment'* already highlights some complexities of the term, especially considering its pervasive usage worldwide in the past two decades or so. The difference in prosody (whether positive or neutral) amongst languages shapes the effects of empowerment in use (similar to the case of the metaphor *'rampage and insidious movement'* discussed in the metaphors section of this chapter). It is interesting to see the term widely used in its English form in different other languages such as French and German. Thus, it is necessary at this stage to grasp the broader historical context and movements of ideologies in the construction of

‘empowerment’, in order to better understand its functions and performativity at work in everyday speech.

The term ‘empowerment’ can be traced to the 1976 publication of *Black Empowerment: Social Work in Oppressed Communities* by Barbara Solomon, where the term started to be formally used in research and social services (Calvès, 2009). Its early usages signalled a commitment to giving a voice to the oppressed, enabling them to fight against the dominating voices to which they were subjected. The empowerment was said to be realised through a movement from a *‘dominated consciousness’* to a *‘critical consciousness’* (Freire, 1974). The primary tools described in these early versions were education, particularly with relations to issues of domination, through the deconstruction of dominant constructs such as race and gender. The influences were very diverse, and included Freudian psychology, feminism, the Black Power Movement, and Gandhism (Sharma, 2008). It is in the mid-1980s that the term empowerment started to gain an increasing popularity, promoted by the feminist movement. The field of international development, influenced by the feminist movement, was also a platform for the term to infiltrate pervasively policy and program documents (Calvès, 2009). Despite the diverse influences, the focus of empowerment at the time was still addressing issues of inequalities and domination.

Whilst some feminist authors were protective of the term from its development with mainstream discourse, as empowerment became associated with an individualising notion of power promoting autonomy (which resonates with one of the French translations of the term), individual choice, access, and the maximisation of individual interests; they were equally dismissive of Foucault’s power/knowledge when articulating their arguments around feminist empowerment, as Foucault’s model of power was not deemed fit for elaborating a strategy of empowerment per se (Deveaux, 1994). I will get back to the Foucauldian understanding of empowerment later in this chapter. For now, I focus on the former concern of feminist scholars – the mainstream appropriations of the concept of empowerment. They lamented that the concept became utilised at the service of status quo; as a means for increasing efficiency and productivity at the service of a capitalist economic system. This was particularly the case in the sectors of healthcare and international development.

Within a neoliberal frame, being empowered is synonymous with choosing from a set of ethical practices that are pre-established by dominant regimes (although this choice is proclaimed as being 'free', which I will discuss in depth in the next section).

Within the case under study, 'empowerment' has followed a similar trajectory. As I have discussed in chapter six, and drawing particularly on the work of Klawiter (2000, 2008) and King (2004, 2006), empowerment was the primary strategy for the feminist cancer activism. They challenged the mainstream breast cancer movement through a commitment to providing a space for the unheard voices. 'Empowerment', within the feminist activist movement, advocated the expression of alternative images, discourses, and ways of embodying breast cancer. However, as I have demonstrated across the previous chapters, whether it was the case of the Angelina Jolie's letter, or FORCE website and forum discussions; empowerment is deployed, within HBOC and BRCA narratives, to express the freedom of making an informed choice, and the access to strong preventive options to choose from. Yet, these options are pre-configured by dominant biomedical regimes. Failure to comply with these practices was ascribed to individuals' irresponsibility, irrationality, ignorance, or simply 'giving up'. Within this particular framing, empowerment becomes at the service of the contemporary genetics' individual choice discourse, as well as the processes of responsabilisation as depicted by Foucault (2004), Garland (1996) and Shamir (2008) (discussed previously in chapter four). Figures 27 below highlights few examples from websites, which display, explicitly or implicitly, a similar usage of 'empowerment'.

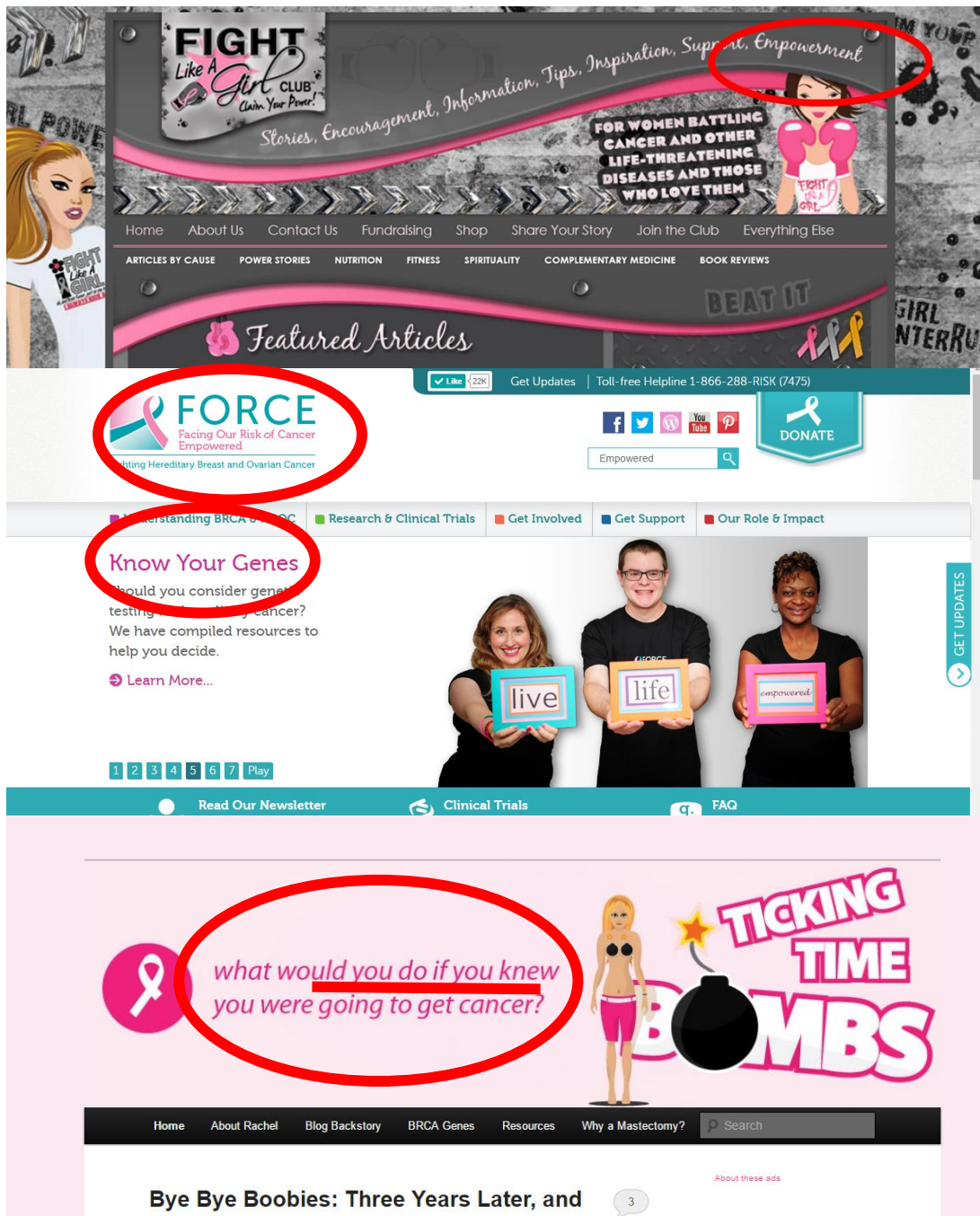


Figure 27: Three examples of biosocial communities, which highlight, explicitly or implicitly, empowerment as an effect of the application of biomedical rationalities. Websites from top to bottom: Fight like a girl' club, FORCE, and Ticking time bombs (emphasis added). Screenshots taken in 06/2016.

Is this transformation in use a reflection of the movement of the term from the critical spheres and its appropriation by mainstream discourses? Or is it shaped by the transformations in healthcare, particularly with the field of new genetics that strongly emphasises individual choice to distance itself from eugenics (as discussed in chapter three)? In order to answer these questions, I start with a discussion on neoliberal empowerment in the following section.

7.7.3. Neoliberal empowerment:

One of the cornerstones of neoliberal empowerment is the notion of freedom; which represents in this case the freedom from the dominant doctrines past its inception, but also the freedom to take action (Shankar et al., 2006). Being empowered is understood, within this ideological domain, as gaining the power to exercise choice. On the other hand, neoclassical economics emphasises the central role of markets in organising and structuring the use of resources. The individual can, therefore, aspire to the freedom of choice through market mechanisms; more specifically through the practice of consumption. This makes the subject position '*consumer*' key to the point I am making here. Indeed, the argument comes in full circle when considering some of the developments within mainstream marketing theory. An abundant literature proliferated in the past two decades or so on the shift of power from producers to consumers (Samli, 2001; Shipman, 2001; Murphy, 2000; Rezabakhsh et al., 2006); Including the growing literature on the so-called '*prosumer*', a neologism that signals the intertwining of processes of production and consumption (Ritzer et al. 2012; Chunyan et al., 2008; Toffler, 1980) (for a detailed critique of the concept of '*prosumer*' within marketing literature, please refer to Cova and Cova (2012)). Within this literature, this shift is commonly considered as *empowering* consumers, through the newly acquired power to choose, control and shape what they consume; and by the same token, prescribing producers to adopt a consumer-centric approach to provide them what they want, with developments such as 'customer relationship management'. Thus, the key for individuals to acquire this power is to adopt (consciously or unconsciously) the subject position of '*consumer*'. The function of

marketing becomes the empowerment of individuals by ensuring the freedom of consumption through choice.

However, if we consider marketing discourse and practice as a set of devices performing markets (Cochoy, 1998), then the subject position 'consumer' becomes a condition for felicity, as informed by Austin (1962). Whereas choice is put forward as empowering consumer; choice, within marketing ideology, is itself constituted through the bringing into being of markets, consumers and consumption (Dholakia and Dholakia, 1985). The beneficialised of choice (Van Leeuwen, 1996), that is consumers, are themselves a pre-condition to its existence; which undermines the argument of freedom, as advanced by neoliberal empowerment. This view also participates in exacerbating inequalities, as 'freedom' is conceptualised as contingent on participating in the market economy through the exercise of consuming and buying stuff. This exercise can only be made possible to individuals through selling labour power, renting capital, or utilising stored capital (Bourdieu, 1984). Disabled and poor people are therefore either partially excluded from this process, or deemed as carrying undesirable traits (Hache, 2007). This is where the connections between empowerment and responsabilisation process start to become clear.

Exercising the freedom to choose becomes synonymous with individuals' independence, within this perspective. This independence is also a requirement for individuals, as they have to take responsibility in the choices they make; therefore transferring responsibility from the state to individuals, or what I described in earlier chapters as the responsabilisation of individuals. The promotion of values of freedom and the desire of autonomy facilitates the process of responsabilisation.

Thus, responsabilisation is central to neoliberal governance, and "entails a host of policies that figure and produce citizens as individual entrepreneurs and consumers whose moral autonomy is measured by their capacity for "self-care"-their ability to provide for their own needs and service their own ambitions, whether as welfare recipients, medical patients, consumers of pharmaceuticals, university students, or workers in ephemeral occupations" (Brown, 2006, p. 694). However, the transfer of responsibilities from the state to individuals, or responsabilisation, comes in an embellished package with a notion carrying a positive prosody, which is

empowerment. Sharma (2008) argues that the elevation of 'empowerment' as a keyword in contemporary neoliberal discourse, is very much in line with the commitments to efficiency and effectiveness to replace the term '*welfare*'. The former U.S. president Bill Clinton clearly depicted this movement in an op-ed published in the *New York Times* (Aug 22nd, 2006) entitled '*How We Ended Welfare, Together*'. He positions the necessity to leave the state-dependency welfare systems, as beneficial to the majority and "exactly the change most welfare recipients wanted it to be". The welfare state system needed reform, according to Clinton, and this reform focuses on the dependency of individuals on the state. As he put it "most Democrats and Republicans wanted to pass welfare legislation shifting the emphasis from dependence to empowerment". Bill Clinton portrays empowerment as a key driver for the departure from the welfare state system; even more so than the economic growth; "of course the booming economy helped, but the empowerment policies made a big difference". Through the provision of 'independent', 'liberated' and 'informed' as subject positions for individuals, empowerment becomes a central governmental technology within the neoliberalist ideology (Cruikshank, 1999; Hindess, 2004; Sharma, 2008).

Instead of treating *empowerment* as ontologically given, I emphasise here its performativity, the politics of its performativity, and its co-construction as a cultural product of historical and political processes. Whereas responsabilisation has been advocated as enabling the empowerment of individual by its proponents; I argue that the discourse of empowerment actually enables responsabilisation processes through the provision of the subject position '*empowered*'.

In order to better understand the embodying of the subject position 'empowered' and its effects, I need to make a quick detour to a discussion on power. Both mainstream and critical developments of empowerment assume a movement of power, although a clear theorising of power is often missing from discussions on empowerment (Hardy and O'Sullivan, 1998). Recent mainstream developments of empowerment bear the underlying assumption that power is a resource that can be mobilised through choice making, with the liberation of individuals resulting from the availability and access to options and the freedom to choose from these options. Nevertheless, conceptualising

freedom as contingent on gaining more neo-liberal pastoral power (through the engagement in consumption practices), undermines the argument of 'absolute' independence granted for individuals (Hache, 2007). On the other hand, the early developments of empowerment, particularly within feminist theory and the black activist movements, drew on conceptualisations of power within critical theory, where power is understood as ideological, economic and structural. Whereas such a view can help explain power in terms of absence of resistance, and help achieve the empowerment of individuals and communities through a movement from a '*dominated consciousness*' to a '*critical consciousness*' (Freire, 1974 discussed in the previous section), it also bears similarities with the common issues encountered with Critical Discourse Analysis approaches, where ideological systems have a discursive effects 'in' mind (Korobov, 2001; Bamberg, 1997 - discussed in detail in chapter four); thus, conceptualising the liberation of individuals as possible through critical awareness. However, even with a commitment to giving a space to the unheard voices and equality, the critical approach does not clearly conceptualise how the equal sharing of power is possible through empowerment. Such an aspiration entails the assumption that there is a known amount of power that is available to be shared; and for an amount to be known and shared, it has to be finite. The main discrepancy in this case resides in understanding power as finite, with therefore the need to quantify it in order to fully manipulate it, and share it equally.

Both approaches, therefore, assume that there is an autonomous subject waiting to be liberated through either critical awareness or independence from the state. These assumptions entail that emancipation can be achieved through either the knowledge resulting from critical reflection (Hardy and O'Sullivan, 1998), or the engagement in consumption practices. The primary takeaway here is that both the meaning in use and the performative effects of the notion of empowerment are contingent on a prior conceptualisation of power within its usage. Both constructions of empowerment that I have discussed here refer to power as a "convenient, manipulable, deterministic resource under the control of autonomous, sovereign actors" (Hardy and O'Sullivan, 1998, p.459). Instead, in order to discuss what 'empowerment' actually does and its

effects as an ideological resource, I turn to Foucault's model of power to provide some concluding remarks in the following section.

7.7.4. Concluding thoughts:

As discussed in depth in chapter four, Foucauldian power manifests itself beyond the obvious threats and constraints, and operates within discourses and language structures. Various forms of power are embodied within knowledge systems. Within this perspective, power is best understood in relational terms. Thus, the discussion of the shift of power from producers to consumers discussed in the previous section becomes obsolete, as power cannot be contained in dualism. Power cannot be owned or lost, acquired or given away by producers or consumers; it delineates discourses of knowledge that constitute the subject positions 'producer', 'consumer'. These subject positions are very much shaped by neoliberalist ideologies, including the discursive practices of marketing.

Within the framing of empowerment of consumer through the availability, access and freedom of choice; the subject position 'empowered consumer' is brought into being. Thus, markets and consumption become key socializations agents shaping the meanings (including the rights and duties) associated with the subject positions 'empowered' and 'consumer'. In order to connect this to the present case, I am going to refer back to Derrida's iteration (chapter 2). As both labels represent stabilised roles through processes of iteration, there are certain expectations within a collective, who claim to be empowered by genetic knowledge and derived biotechnological interventions, from its members. Part of these expectations is the making of a 'rational' choice, where rational is pre-delineated within one of the main sources of empowerment: knowledge. Within Foucault's governmentality, choice becomes therefore a form of disciplinary power (Shankar et al., 2006).

Foucault's discussion on governmentality and technologies of self, helps connecting power, in relational terms, with neoliberal empowerment, in order to better understand the performative effects of the latter. Indeed, empowerment is translated into a 'liberating responsabilisation' (responsabilisation libératrice) through a

Foucauldian lens (Hache, 2007). The freedom is never absolute in this sense (and nor is power), but is instead a liberation “from previous cultural circuits” (Shankar et al., 2006, p. 1019). Within this perspective, empowerment can take place within the ‘logic’ of the market, liberating individuals from their dependence to the welfare state, but conditioning this freedom to adapting to the frame of ‘homo economicus’. Thus, the neoliberal assumption of a separation between politics and economy becomes obsolete (Lemke, 2010).

Individuals are, therefore, subjected to disciplining and liberating technologies simultaneously. The discourse of empowerment of individuals is said to enable at-genetic risk subjects to be liberated from the medical gaze by their freedom to make informed choices, and also the capacity (through education) to read and make sense of genetic information to take control of the body and risks. However, this discourse has also an effect of disciplining at-genetic risk subjects in terms of their relationship with their bodies and the defectuous organs; through the delineation of available ethical practices to preserve their bodies, and the knowledge systems surrounding these, as well as the framing of what constitutes a rational behaviour. What is happening here is a fetishisation of freedom and control, performed by the shaping of at-genetic risk subjects into consumers of prevention. As Rose (1999b, p. 262) put it, the at-genetic risk subject becomes “attached to the project of freedom”; and accomplishes this project through strategies of control.

I argue that the interactions between the discourses of genetics, cancer survivorship, and neoliberal governance, bring into being an entity that is necessary to the sustention of the market of preventive solutions for HBOC; and which I call here the ***consumer-entrepreneur of self-preservation and survival***.

The next chapter connects the elements explored in the analytical chapters, with a discussion organised around the entrepreneurial self, category membership, responsabilisation, clashes of modes of responsibility, and process.

Chapter 8: Discussion

In this chapter, I connect the elements explored in the previous analysis chapters, and organise their discussion around the entrepreneurial self, category membership, responsabilisation, clashes of modes of responsibility, and process. This chapter is structured as follow. First, I start the discussion where I left in the previous chapter, with the consumer-entrepreneur of self-preservation and survival. I reconnect with Foucault's discussion of the individual as entrepreneur of himself, and the debate on human capital. Second, I move to the other important part of the framework of this thesis with a focus on process. Linking again with Derrida's iterability and usure, I highlight how the iterable model of the discourse of 'empowerment' and the subject position 'empowered' participate in the process of the bringing into being of the self-entrepreneur. Thus, I move beyond the study of subjectification in markets to discuss the tensions and conflict in making sense of, belonging to, and sustaining a category membership. Tension and conflict alongside category membership are at the centre of the following sections, where I start by discussing the possibility of risk calculation as well as the credibility of the calculation models at the core of the category previvors. In order to sustain the category membership, women need to fulfil the duties of a good genetic citizen through the consumption of preventive solutions. Thus, self-care becomes a responsibility, and an enterprise embedded within biomedical rationalities and neoliberal targets for maximisation of health capital and cost efficiency. But what happens when self-care clashes with other modes of responsibility? The penultimate section of this chapter refocuses the discussion on the co-constitutive relationship between empowerment, responsabilisation and self-care, and how this relationship shape market actors and consumption practices, taking into account the misfires of this performativity. Finally, and drawing on Jacques Derrida's

undecidability, I discuss the performative effects of tensions and conflict as not only a risk but also a chance to destabilise.

8.1. The consumer-entrepreneur of self-preservation and survival:

I start this discussion where I left it in the last chapter, with the entrepreneur of himself; who blurs the line between consumption and production, as he is his own producer of survival (and satisfaction?) through the consumption of preventive solutions. I argue that the interactions between the discourses of genetics, cancer survivorship, and neoliberal governance, bring into being an entity that is necessary for the sustention of the market of preventive solutions for HBOC; and which I call here the *consumer-entrepreneur of self-preservation and survival*.

Foucault initiated this notion of individual as entrepreneur of himself under neoliberalism. For Foucault, homo oeconomicus is not a partner of exchange but an entrepreneur – an entrepreneur of himself. As Foucault (2008, p. 226) put it: “homo oeconomicus as entrepreneur of himself, being for himself his own capital, being for himself his own producer, being for himself the source of his earnings”. In a sense, this entrepreneurial self is the embodiment of human capital. I will get back to the notion of human capital later, as it is key to contrasting the present case to Foucault’s analysis. For now, I focus on this entrepreneurial self as his own producer. But ‘what does he produce?’ Foucault asks. As he argues, it is the production of oneself satisfaction that is at stake. And how is the production of one’s satisfaction performed? Through consumption practices as he argues. Rather than thinking of consumption as process of exchange and reducing it to a buying behaviour, Foucault talks about the man of consumption, who becomes a producer through consuming. Thus, consumption, under neoliberalism, becomes an enterprise activity, by which the individual produces his own satisfaction. This activity is dependent on the capital that he has at his disposal.

In the present case, the aim of the enterprise is the reduction of the risk of the occurrence of HBOC and the preservation of the heteronormative female body. Prevention becomes constitutive of the at-genetic risk subject as part of their

entrepreneurial activity. The practices of sustaining the category membership, previvor, are very much dependent on the adherence to this entrepreneurial self. The discourse of genetic and the geneticization of illness plays an important role here. It allows a strong sense of objectivity to the enterprise activity, and gives it more credence and legitimacy. Moreover, geneticism provides foundations for calculation models that allow a risk-management approach to tackle illness, and thus constitutes a project that is in line with mainstream health economics models such as '*health as commodity*' and '*health as investment*' (Grossman, 1972; Cropper, 1997). Within these models, health is best understood as health capital, which can be increased through investment in health. Here, good health is synonymous with a higher utility for market and non-market activities, and can be maximised through curative and preventive care services. Geneticism allows the construction of more precise and credible models for risk calculation, thereby legitimising the investment in preventive care services, whichever form they take, to minimise risks. Thus, I argue that geneticism is inscribed in the heterodox assemblages of discourses and market devices that shape the market for preventive solutions and products. It contributes to a performative discourse of the consumer-entrepreneur of self-preservation and survival, who is geared towards the maximisation of *future* health and the preservation of the heteronormative body.

I get back now to the discussion on human capital, and what the present study tells us about this aspect. Foucault (2008) describes it as a unique form of capital. Indeed, the capital (which is traditionally conceptualised as what makes a future income possible) is in this case inseparable or constitutive of the individual who owns it. Foucault distinguishes two types of elements that constitute the human capital: innate and acquired elements. By innate elements, he refers to hereditary factors and genetic makeup, whilst the acquired elements are associated with the formation of human capital throughout a lifetime. Foucault stresses acquired elements as being at the core of neoliberal analysis. He positions educational investments at the centre of neoliberal strategies for the formation of abilities-machine or human capital. These educational investments include education, healthcare, professional training, etc. but

also the time invested by parents to raise a child, as well as other forms of disciplining and capacitating. Through these educational investments, there is a process of disciplining of the self-entrepreneur. This performed entity constitutes “a kind of machination, a hybrid of flesh, artefact, knowledge, passion and technique” (Rose, 1996, p.153).

However, Foucault did not view the genetic-make-up-as-human-capital as a major political issue at the time. It is important to stress that the lectures on biopolitics date from the late 1970s, and much has been done in the field of genomics since. The Human Genome Project (discussed in chapter 3) did not start until over than years after these lectures. Foucault discussed the question of the improvement of genetic human capital, and the potential issues associated with what he calls ‘the racist effects of genetics’. However, these innate elements are taking today a more and more important part in the construction of the human capital.

The case discussed in this thesis outlines concerns that are similar to what Foucault discusses in terms of control of the genetic risk that may negatively impact the human capital. However, these are not performed in an outward racist way of selection of coupling and discriminatory ways of reproducing, but through control of the at-risk body, as well as the education of the progeniture on the risks associated with inheriting a faulty gene. This is not to say that his fears of the ‘racist effects of genetics’ were unfounded, far from that. However, they have (1) taken different forms, and (2) are still in the process of materialisation through novel technologies, while confronting ethical and regulatory barriers. First, the control is performed through a spatial delineation of the areas of danger to the human capital within the body, and the deletion of this danger. This is coupled to a focus on the aesthetic re-creation of the heteronormative body. This way the human capital has less risks of deterioration in the future, and still resembles aesthetically the heteronormative one. Therefore, women bodies constitute sites of control, where geneticism pushes the neoliberal body project under the banner of individual choice. Moreover, these practices are intimately associated with the responsibility to educate any offspring who may carry the same risk to the human capital. Thus, there a combination of an improvement of innate elements, and acquired elements for future generations based on the same

risk assessment. Second, the materialisation of outward racist genetics is still a possibility in the future – but not through a selection of partner for procreation necessarily. Scientific techniques such as *in vitro fertilisation*, which allows the identification of faulty genes prior to the implantation of the embryos, or *gene-editing embryos tools* (such as CRISPR gene editing) that enables the correction of pathogenic gene mutation at the level of embryos, could well completely transform the place of innate elements as part of the study of human capital.

While this study focused on the first alternative forms of improvement of innate elements of human capital, future studies could explore how the second forms could metamorphose innate elements of human capital in the future, as well as the ethical and regulatory obstacles for their marketisation.

In the next section, I move to the **process** of the bringing into being of the consumer-entrepreneur of self-preservation and survival. By reconnecting with Derrida's iterability and usure, I discuss the iterable model of the discourse of 'empowerment' and the subject position 'empowered', and the role in the process of the bringing into being of the self-entrepreneur.

8.2. The process of enacting the consumer-entrepreneur of self-preservation and survival:

For this ontological entity to exist (consumer-entrepreneur of self-preservation and survival), there is a prior requirement of the mainstreaming to the pre-ill of biomedical rationalities, as well as neoliberal ideologies of responsabilisation and self-care (Beckmann, 2013). This is facilitated by the provision of the subject position, 'empowered', with all the set of rights and duties attached to its moral location. Within the framing of the empowerment of consumers through the availability, access and freedom of choice, the subject position 'empowered consumer' is put centre stage; and with it comes the sets of rights and duties attached to its moral location. Thus, markets and consumption become key socializations agents shaping the

meanings (including the rights and duties) associated with the subject positions 'empowered' and 'consumer'. Through the iterable models of these subject positions, the access to genetic knowledge becomes synonymous with certain expectations as part of the category membership. Part of these expectations is the making of a 'rational' choice, where rationality is pre-delineated within one of the main 'sources' of empowerment: knowledge. Thus, choice becomes a form of disciplinary power, and the discourse of empowerment acts as a glossed form of responsabilisation. This form of responsabilisation, or liberating responsabilisation (*responsabilisation libératrice*, Hache, 2007), is stripped from aspects of guilt that can be attached to responsibility, and promoting self-realisation, self-reliance and self-care. Empowerment has a co-constitutive relationship with responsabilisation, as it constructs responsibility not only as an ability that can and should be acquired, but also as the ultimate way for emancipation. In this case, not doing anything to prevent HBOC occurrence is not an option. Through this socio-cultural and historical analysis of 'empowerment' and 'empowered' in the context of HBOC, I hope I demonstrated the process through which responsabilisation is not only facilitated, but also gains some appeal through the discourse of empowerment in biomedical and popular discourses.

A historical approach proved to be helpful in understanding the ideological effects of discourses such as 'empowerment' or metaphors such as 'carriage', and how these can establish themselves as ordinary and indistinct linguistic formulations through frequent usage. The processes of '*iterability*' (Derrida, 1972) and '*usure*' (Derrida and Moore, 1974) renders the ideological functions of discourses and other devices even harder to uncover. Responsibility is attributed through the use of these indistinct formulations (that can be literal or metaphorical as part of a specific discourse) in everyday interaction, without the speakers necessarily alluding to it in an explicit manner. Indeed, when using specific formulations, such as the metaphor of carriage within biomedical discourses for instance, individuals were reproducing specific ideologies. In this case, the formulations still carry ideological meanings and perform specific rhetorical functions, no matter how ordinary and indistinct they become. These 'worn-out' metaphors acquire a more 'universalised' status, while still carrying traces of lost meanings that perform specific functions.

Through the reproduction of these ideologies, these women were indexing particular commonsensical notions which in turn shape the locations of their subject position. Ideologies (lived and intellectual) strongly shape the moral locations that the individual inhabits. The subject position has a moral location, where a set of rights and duties are ascribed. The consumption of prevention constitutes both a right and a duty within the consumer-entrepreneur of self-preservation and survival, as it represents an essential requirement in order to fulfil the responsibility to preserve the body. Therefore, the act of consumption results from the temporary stabilisation of subject positions; as they make a set of rights and duties, rationalities and practices available for individuals. These subject positions are both ephemeral and exclusionist, as each location entails the exclusion of the 'other'. In addition, the individual carries traces of the dislocations from previously inhabited moral locations. The remnants of the previous locations still continue to exist, and can sometimes clash with the new moral location. This process of displacement and replacement is not unique to subject positions but also to meanings, as they feed into each other through indexing. The displacement of meaning from its previous locations allows the prevalence of a new idealised and universalised form of meaning. However, the traces of the previous locations are never completely erased, and invoke a multivocal meaning. In a sense, the new meaning dominates by virtue of the presence of the other, and not its erasure. The remnants and traces of the lost meaning resurfaces to disrupt meaning and being, and therefore take part of the performativity of new ontological structures, as well as the fragilization of existing ones. These locations, dislocations, and relocations can result in tensions, when the various ethical domains conflict, as well as when the singular character of the practice clashes with the universal character of the moral order.

The Derridean concepts, *iterability* and *usure*, proved to be helpful in understanding the ideological effects of these devices, and how they can establish themselves as ordinary and indistinct linguistic formulations through frequent usage. This is particularly relevant when these formulations become considered an ordinary and indistinct part of a specific discourse, and in so doing, shaping identities and practices. The notions of iterability and usure are intimately connected as the process of

displacement of meaning to a universalised form comes through the process of *iterability*, to result in the *usure* of a metaphor. These concepts (or in Derrida's (1974) terms *quasi-transcendental logics*) form as an ensemble the terrain of the undecidables (Laclau, 1996); which are essential to the existence of the political and the ethical.

The various discursive devices and iterable models I explored in the previous chapters hold important functions in constituting identities, and thereby practices, rights and duties that sustain the category membership of previvors. By considering practices as co-constitutive of subjectivities, I have engaged with the multiplicities of scenarios of tension, conflict and disruption, and highlighted the instability inherent to the entrepreneurial self. By doing so, I move beyond the study of subjectification in markets to discuss the tensions and conflict in making sense of, belonging to, and sustaining a category membership. The next section focuses on category membership.

8.3. The legitimisation and maintenance of the category membership:

What being a previvor 'means', and what being a previvor 'implies doing' were core themes across the dataset. Most importantly it is the category membership that had an important role in shaping the practices of BRCA positive women. The previvor category is the ephemeral stabilised result of interaction of various discourses and materialities, such as biomedical construction of genetic knowledge and genetic diseases, as well as the practices of prevention that are constitutive of this category.

Biomedical knowledges shape the relationship of individuals with their bodies. As such, genetics, risk and cancer transform the body into a highly quantifiable and segmented one. The intertwinement of these discourses constructs prevention as an extension of survival; thereby positioning the practices of risk reduction and preservation of the body as central to the category membership of survivor/previvor. The possibility of calculation and the credibility of the calculation model allows the objectification of the risk, as well as the category previvor itself. The objectification of the process of risk estimation enables the rationalisation of choice making process,

which is made from a set of ethical procedures geared towards the preservation of the body. In addition, the survivorship discourse is inscribed within the previvor category; thus, attributing a set of rights and duties that are traditionally associated with the 'ill' category. The spatio-temporal shift performed by the various devices (metaphors, pronoun systems, etc.) I explored in the previous chapters allows the movement of this set of rights and duties, and positions it as part of the category membership of previvors. Sustaining the category membership requires subscribing to this set of rights and duties, and the need to legitimise any doubts or hesitation.

On the other hand, the cases of non-quantifiable evaluations of risk lead to tensions and confusion within the decision-making process. It also leads to the attribution of responsibility back at the state and science; often blaming the limitation of science, lack of research funding, or incompetence of the medical staff. In this case, it is the geneticisation of HBOC that frames the individualisation of the body and its care as a matter of identification of shared biomarkers of illness and the calculation of risk associated to this illness. This is performed through devices such disease redefinition, credible calculation models, but also other 'hidden' devices such as metaphors of the body as a container of mutations, or the metaphors of movement and war which redefine the biological enemy as within, and the necessity to fight as part of the category membership. These devices are embedded within heterogenous agencements, and shape not only the set of ethical practices to preserve the body, but also the attribution work of accountability and responsibility. Thus, the responsibility is negotiated at various levels (1) ideologically, ranging from biomedical rationalities to neoliberal self-governance to commonsensicalities; and (2) in interaction, through the legitimisation of category membership, hesitations and doubts, as well as advice giving through the use of modality and script formulations.

Self-care is realised through the scrupulous following of a set of ethical practices and the consumption of preventive solution; thereby allowing to fulfil the duties of a good biological citizen, and the sustaining of the category membership. As discussed earlier, the practices of sustaining the category membership, previvor, are very much dependent on the adherence to the entrepreneurial self. Thus, self-care, in this

context, is an enterprise embedded within biomedical rationalities and neoliberal targets for maximisation of health capital and cost efficiency. Tension and misfires occur when moral locations conflict between different subject positions associated with 'opposing' modes of responsibility. This is particularly the case when 'self-care' clashes at the same time and space with 'care for the other'. This in turn disrupts the category membership. I explore these tensions in depth in the next section, where I address neoliberal empowerment in connection to responsabilisation in the context of the consumption of self-preservation and survival. This leads to scrutinise the tensions between responsabilisation and other competing moral responsibilities.

8.4. Responsibilisation and the logic of self-care:

Responsibilisation is a key element within neoliberal governance and ideology, shaping market actors as well as their practices and interactions (Rose, 2007; Shamir, 2008). While proponents of this form of governance advocate responsabilisation as enabling individuals' 'independence' and 'empowerment'; I argued previously that empowerment discourse actually enables responsabilisation by facilitating individuals' subscription to its ideology. Indeed, the logic of empowerment, through patient education and rational choice, serves a channel for "mainstreaming biomedical rationalities and neoliberal notions of responsabilisation and self-care" (Beckmann, 2013, p. 171); thereby, facilitating the bringing into being of the consumer-entrepreneur of self-preservation and survival.

Neoliberalism conceptualises responsibility as enacted through the logics of personal choice and autonomy, which in this case are reinforced by the rhetoric of genetic determinism of disease causality; therefore emphasising individual accountability. As Merry (2009, p.403) put it: "a responsabilised society does not see individuals as socially situated but as autonomous actors making choices that determines their lives". However, this responsibility is portrayed differently from a culpabilising form of responsibility, and rather positively as a liberating responsibility (responsabilisation libératrice) (Hache, 2007). Empowerment represents, therefore, this glossed form of responsabilisation, stripped from apparent aspects of guilt, and promoting self-

realisation and self-reliance (Cruikshank, 1993). Thus, responsibility is constructed as an ability that can and should be acquired, and made appealing through the promise of emancipation and empowerment advocated by its proponents. This responsibility translates, in theory, into individuals making the right choices by themselves, and maximising health capital through the means of preventive interventions. However, this conceptualisation constructs, by the same token, self-control as a prerequisite for health. Moral responsibility becomes intertwined with prevention, reconfiguring the rights and duties of patients. Through the provision of the 'pre-ill' subject position, genetics attributes responsibility to patients before the beginning of the disease; with the 'the duty to get better' shifting to 'the duty to stay healthy' (Greco, 1993). Staying healthy becomes a sort of 'KPI' of biological citizen' ability to act responsibly, with the objective of maximisation of one's health.

In a society where responsibility is transferred from the state to individuals, self-surveillance and self-assessment techniques constitute important audit and accountability practices through which the individual is governed (Shore and Wright, 2011). These self-surveillance and self-assessment techniques follow a set of ethical practices that are pre-defined by knowledge systems such as biomedicine. Mol (2008) suggests viewing the translation of medical knowledge into health information and course of action as a *technology of compliance*, rather than a source of empowerment. By clustering populations into biosocial communities centred on disease-causing-genes, genetics participates in the construction of collectives, which partake in the auditing process of their peers, who share similar biomarkers. Throughout my dataset, individuals were constantly calling onto the diverse strategies of self-surveillance and self-assessment they were undertaking such as keeping a diary or focusing on oneself through exercise, in order to tick the boxes from the auditing checklist before moving onto asking for advice and help from the other members of the collective. Within this perspective, responsibility becomes "a form of reflexive prudence, and individuals and collectives must increasingly conduct moral evaluations of their actions in relation to their potential effects, calculating and designing their life course in ways that attempt to mitigate harm and risk, and maximise benefit to themselves and others" (Trnka and Trundle, 2014, p. 139). This layering of accountability is better understood through

Dilley's 'modes of accountability' (1992) discussed in chapter two; where the 'at-genetic-risk' subject, when empowered through genetic knowledge and education, is expected to act responsibly and follow a specific set of ethical practices. These expectations stem from above and below: that is they are individual (personal fight against the disease), collective (moral acceptance of the membership to the previvor/survivor collective), and institutional (responsibility of self-care and preservation of the body).

Therefore, neoliberal governance restricts certain freedoms and choices, which is contradictory with its initial promise of freedom. These restrictions are put in place in order to enable specific forms of moral autonomy, under the banner of the empowerment discourse. As Trnka and Trundle (2014, p. 140) put it: "the same neoliberal processes that highlight the importance of granting individual freedom, choice, and autonomy thus simultaneously constitute new relations and dependencies". A choice is never entirely free, as it is always delineated by the dominating modes of validation of the decision (Laclau, 1996), which are in this case biomedical rationalities and neoliberal governance. Another misfire of neoliberal governance discourse is located within individual autonomy and the construction of a rational/logic choice framed within biomedical discourses. Biosocial communities such as FORCE constitute a form of collective social responsibility, where individuals who share similar faulty genes, or similar conceptualisation of high risk for HBOC, support and educate each other. These collectives engage in attributing responsibility to each other, therefore reinforcing the neo-liberal self-governance discourse (and thereby constituting an additional layer of the modes of accountability), but also attributing blame and responsibility back to the state and science where there are instances of limitation of science (case of *uninformatives* for example), difficulties of access to preventive solution (case of genetic test pricing due to the patenting), or discrepancies within the prescriptions of different experts (case of contradictory advice from oncologists and geneticists for instance). These collectives construct new spaces and forms of social inclusion (Epstein, 1998) that both reinforce and resist responsabilisation as a form of governance. Nevertheless, in the case of FORCE, the overall genetic determinism tamed the resistance, as notions of individualisation were

intertwined with the members understanding of their bodies. The resistance manifested primarily when the neoliberal form was clashing with other forms of responsibility.

The next section concludes this chapter by scrutinising the competition between the different forms of responsibility, as well as discussing the performative effects of tension and conflict.

8.5. Competing forms of responsibility:

Within the responsabilisation framework of care, the logic of choice is based on biomedical expertise; therefore positioning the biological as the ultimate value of life. The biological determines the interventions, as well as their course of action: saving the body by reducing the risk through preventive surgery, then reconstructing the heteronormative female body through plastic surgery. However, throughout my dataset the responsibility of self-care was co-existing, and sometimes challenged by other modes of responsibility.

The most frequent instances of tension and resistance were the cases where there were social interactions, with family members or medical staff for example. While value of life is maximised within the biomedical frame, through the preservation and survival of individual bodies, the FORCE contributors described sometimes a meaningful life as social and moral beings emphasising the importance of social interaction with their family and children for example. Instances of resistance and conflict with neoliberal governance includes where family members were not understanding of the decision making to undertake a double mastectomy or hysterectomy on a still-healthy-yet-pre-ill body. There were other instances of resistance where the care of dependents such as children prevailed, particularly with the concern of not being emotionally and physically available for their care after the post-surgery induced menopause effects. On the other hand, there were other occasions where responsibility and risk were interwoven with sexist ideologies of the ideal female body; paving the way for practices such as the reconstructive surgery,

that re-enacts the heteronormative female body, to be appointed as an 'empowering' tool.

Ultimately, and as Jacques Derrida notes, responsibility is infinite, which determines its existence as a concept. As he put it "if you give up the infinitude of responsibility there is no responsibility (...) there are only moral and political problems, and everything that follows from this, from the moment when responsibility is not limitable" (Derrida, 1996, p. 86). This view entails an understanding of choice making as continuously inhabited by tensions and conflict, as deciding on an option essentially entails some sort of exclusion. Thus, one can never state that they have fully assumed their responsibilities, because such an utterance (with a conceptualisation of responsibility as finite through the use of 'fully') represents basically an act of reference to the hegemonic forms of responsibilities (with specific performative effects that are context dependent), rather than an actual discussion of responsibility. The decision (or consensus when a collective is involved) represents a temporary stabilisation resulting from a provisional hegemony (Mouffe, 1996). However, the *undecidability* (Derrida, for eg. 1981) does not end when the decision is taken. The undecidability "continues to inhabit the decision" (Derrida, 1996, p. 87), and constitutes a condition of politicisation. The very existence of the political and ethical is a result of the permanent existence of undecidability. Even when a decision (or temporary stabilisation) is taken, undecidability does not come to an end. It is "not a moment to be traversed and overcome" (Derrida, 1996, p.86-87). Because the discourses excluded through the decision do not vanish after the choice making, the traces of their moral locations continue to conflict with the adopted subject position. Therefore, the study of tensions and conflict should not be limited to documenting them, or using them as explanatory resources. Indeed, they are integral parts of the acts of politicisation and ethicisation, and do not necessarily represent a 'negative thing'. Tension and conflict are necessary for the deconstruction and the destabilisation of provisional hegemonies, when this destabilisation is deemed as an ethically appropriate decision. Drawing on Derrida's view on chaos and instability, I argue that the performative effects of tension and conflict constitute not only a risk but also a chance to destabilise.

FORCE forum contributors were often shifting subject positions when interacting with each other, particularly when there were clashes between the responsibility of self-care and the social context. Every shift of subject position involved a movement within the moral location (as discussed in the previous chapters). To each location was ascribed a set of rights and duties that drew on different, and sometimes competing, modes of responsibility. In addition, the subject position always carries the traces of the dislocation from the other available moral locations (Laclau, 1996). While these locations, dislocations, and relocations resulted sometimes in further uncertainty and conflict within their choice making, there were occasions where these modes of responsibility co-existed synergically. These instances of synergy occurred when and where there was an overlapping of ethical domains such as the case of the breast reconstruction surgery discussed above, where there was a fulfilment of both the need to reduce the HBOC risk (within a biomedical rationale) and conform to heteronormative conceptualisations of the body.

To say that the subject position has a moral location entails that the subject position cannot exist without an association to a moral order. Therefore, the decision precedes the subject position, as the decision represents an ethical and political ordering of the unstable. As Derrida (1996, p. 84) put it: “if there is a decision, it presupposes that the subject of the decision does not yet exist and neither does the object”. However, for the decision to materialise, there is a need for an individual to take the subject position which it constitutes. In other terms, the ‘subject’ represents the bridge between the undecidability and the decision (Laclau 1990). Nevertheless, it is important to stress the ephemeral and exclusionist character of these decisions and subject positions. Again, tensions come at work here when the universal character of the choice⁷ encounters the singular character of the individual adopting a subject

⁷ This universal character includes for instance options deriving from biomedical rationalities. Biomedical rationalisation represents an effort to stabilise and organise an essentially chaotic understanding of the human body. Provided the hegemony of scientific reasoning and scientific methods to theorise the body, biomedical rationalities can delineate options that possess a universal character. Even the so-called personalised medicine (Tutton, 2012, discussed in chapter three), is located within the realm of the universal, as it groups patients under a group of biomarkers.

position. This is what Laclau explain (1996, p.59, emphasis added) as the “*constitutive split* between *singularity* and *universality* (...) [a] tendency of a signifier to evade its strict attachment to a signified while keeping a ghostly relation to it”. This supports the above argument concerning the undecidability constantly inhabiting the decision.

Beyond the bringing into being of an ontological entity that is the consumer of prevention, the various processes I discussed in this chapter inscribe self-care as the dominant way of life within this entity and its practices; which positions the *consumer-entrepreneur of self-preservation and survival* as a more suitable label. However, self-care is in constant interaction and sometimes competition with other modes of responsibility; thereby creating tensions and misfires.

I have stressed at the beginning of this work the importance of Derrida’s *iterability* in studying the politics of performativity (discussed in chapter two), and supplemented as the thesis unfolded with other Derridean concepts such as *différance* and *usure* that are equally important for the politicisation of the performativity thesis within market studies. These concepts (or in Derrida’s (1974) terms *quasi-transcendental logics*) form as an ensemble the terrain of the undecidables (Laclau, 1996); which are essential to the existence of the political and the ethical.

The next and final chapter will present an overview of the contributions I presented in this thesis, as well as avenues for future research.

Chapter 9: Summary of contributions and research agenda

“Conflicts of duty – and there is only duty in conflict – are interminable and even when I take my decision to do something, undecidability is not at an end. I know that I have not done enough and it is in this way that morality continues, that history and politics continue. There is politicization or ethicization because undecidability is not simply a moment to be overcome by the occurrence of the decision. Undecidability continues to inhabit the decision and the latter does not close itself off from the former. The relation to the other does not close itself off, and it is because of this that there is history and one tries to act politically”

(Derrida, in *Remarks on Deconstruction and Pragmatism*, 1996, p.87)

This thesis started by addressing some critics that pointed out the apolitical aspect that characterised a lot of work within market studies, particularly with its domestication of the concept of performativity. I have stressed the importance of scrutinising the perlocutionary effects of performatives in order to connect the economic and the political, and demonstrated that throughout the presentation of the case, and its analysis and discussion. This helped move beyond a superficial focus on stabilisation processes of ontological entities, and engage with the ideological, the moral, as well as the multiplicity of scenarios of tension, conflict and disruption. By the same token, it re-established the importance of considering the intimate relation between the political and the economic (Polanyi, 1944).

This final chapter is structured as follows. First, I summarise the contributions of this research, and present them as elements of answer to this thesis' research questions. Following that, I present the methodological contributions, as well as potential

methodological avenues for future research. Finally, I present a research agenda for market studies, focusing on the performativity thesis, and modes of responsibility; as well as some concluding thoughts.

9.1. Summary of contributions:

9.1.1. Research Question 1:

How does scientific knowledge participate in performing new subjectivities and forms of consumption of prevention? And what are the effects of this performativity?

- The interactions between the discourses of genetics, cancer survivorship, and neoliberal governance, bring into being an entity that is necessary for the sustention of the market of preventive solutions for HBOC; and which I call here the ***consumer-entrepreneur of self-preservation and survival***.
- For this ontological entity to exist, there is a prior requirement of the mainstreaming to the pre-ill of biomedical rationalities, as well as neoliberal ideologies of responsabilisation and self-care (Beckhman, 2013). This is facilitated by the provision of the subject position, 'empowered', with all the set of rights and duties attached to its moral location. The consumption of prevention constitutes both a right and a duty, as it represents an essential requirement in order to fulfil the responsibility to preserve the body. Therefore, the act of consumption results from the temporary stabilisation of subject positions; as they make a set of rights and duties, rationalities and practices available for individuals.
- The subject position has a moral location, where a set of rights and duties are ascribed. These subject positions are both ephemeral and exclusionist, as each location entails the exclusion of the 'other'. In addition, the individual carries traces of the dislocations from previously inhabited moral locations. These locations, dislocations, and relocations can result in tensions, when the various

ethical domains conflict, as well as when the singular character of the practice clashes with the universal character of the moral order.

- Self-care is realised through the scrupulous following of a set of ethical practices and the consumption of preventive solution; therefore allowing to fulfil the duties of a good biological citizen. However, responsabilisation is not the sole mode of responsibility, and does not exist in isolation of the other modes. Tension and misfires occur when moral locations conflict between different subject positions associated with 'opposing' modes of responsibility. This is particularly the case when 'self-care' clashes at the same time and space with 'care for the other'.
- Tensions and conflict are necessary for the deconstruction and the destabilisation of provisional hegemonies. Thus, their performative effects constitute both a risk and a chance to destabilise.

9.1.2. Research Question 2:

How are the responsibilities of the at-genetic-risk subject negotiated in everyday practice?

- Moral responsibility is located within subject positions. Their location are indexed in speech primarily through the use of pronouns, in order to associate subjectivities to individuals. Having a sense of self is having a sense of moral location, and thereby a sense of responsibility. This sense of self and responsibility is often consciously or unconsciously referred through the use of the pronoun 'I'. The moral positioning through the use of 'I' involves a triadic relation between the speaker, the storyline which the utterance contributes to, and the utterance's illocutionary force.
- The self, the collective, the other, the expert (amongst other actors) are all located rhetorically in speech. Each subject position has a moral location, which is associated to a set of rights and duties. These rights and duties are ideologically constructed. Through the provision of the 'pre-ill' subject

position, genetics discourse attribute responsibility to patients before the beginning of the disease; making the 'the duty to get better' shifts to 'the duty to stay healthy' (Greco, 1993). Staying healthy, by preventing disease, becomes an auditing tool, which monitors the individual's responsibility of self-care.

- The individualisation of the body and responsibility, through genetic deterministic and neoliberal governance discourse, adds a political layer to practices such as advice giving and seeking, as well as the legitimisation of hesitations and doubt, amongst individuals of the same biosocial community. There are different 'modes of accountability', whereby audit, surveillance and expectations stem from above, below and within: these are institutional (responsibility of self-care and preservation of the body following a set of ethical practices mapped by biomedical discourses), collective (moral acceptance of the category membership to the previvor/survivor collective), and individual (personal fight against the pre-disease).
- The responsibility is therefore negotiated (1) ideologically, ranging from biomedical rationalities to neoliberal self-governance to commonsensicalities; and (2) in interaction, through the legitimisation of category membership, hesitations and doubts, as well as advice giving through the use of modality and script formulations.
- The discourse of empowerment acts as a glossed form of responsabilisation, stripped from aspects of guilt that can be attached to responsibility, and promoting self-realisation, self-reliance and self-care. Empowerment has a co-constitutive relationship with responsabilisation, as it constructs responsibility not only as an ability that can and should be acquired, but also as the ultimate way for emancipation. In this case, not doing anything to prevent HBOC occurrence is not an option.
- The subject position 'at-genetic risk' locates the subject within the domain of the biological and the individual, which competes sometimes with other moral domain where the responsibility for the other is at play (such as care for children or the inclusion of family and friends in the decision making).The

encounter between 'self-care' and the 'care for the other' creates tensions and sometimes misfires as the moral locations conflict.

9.1.3. Research Question 3:

How does the translation of genetics and risk knowledges by lay population shape their practices? And how does this knowledge interact with other moral domains throughout the decision making process?

- Biomedical knowledges shape the relationship of individuals with their bodies. As such, genetics, risk and cancer transform the body into a highly quantifiable and segmented one. The intertwining of these discourses constructs prevention as an extension of survival; thereby positioning the practices of risk reduction and preservation of the body as central to the category membership of survivor/previvor. The objectification of this process enables the rationalisation of choice making process, which is made from a set of ethical procedures geared towards the preservation of the body.
- On the other hand, the cases of non-quantifiable evaluations of risk lead to tensions and confusion within the decision making process. It also lead to the attribution of responsibility back at the state and science; often blaming the limitation of science, lack of research funding, or incompetence of the medical staff.
- Genetics discourse participates strongly in the individualisation of the body and the logic of choice. This is performed through obvious devices such disease redefinition, but also undercover devices such as metaphors of the body as a container of mutations (metaphor of carriage for example), or the metaphors of movement and war which redefine the biological enemy as within. The devices operate in interaction with other rhetorical and moral systems, and shape not only the set of ethical practices to preserve the body, but also the attribution work of accountability and responsibility.

- The choice making is entangled with (1) a complex weaving of the positions/locations that are within the various discourses, and (2) the moral structure that establish the legitimacy of those choices. These positions do not only constitute the speakers and their audience in certain ways; they also represent resources through which they negotiate new positions. Nevertheless, these positions have different moral locations that may conflict, particularly between the domains of 'self-care' versus the 'care of the other'.

In the next section, I summarise the methodological contributions, as well as potential methodological avenues to be explored by market studies.

9.2. Methodological contributions:

While discussions on responsabilisation have mostly focused on theorising self-governance as a technology of self; my analytical framework, combining three tools from discursive psychology (discourse action model, ideological dilemmas, and positioning theory), helped scrutinising the practices of the responsabilised citizen, and how they enacted, negotiated, or resisted this mode of responsibility. Furthermore, it unravelled the politics of category membership with the case of previvors, as well as the movements of responsibility from the individual to the collective. Furthermore, it helped connect individual and collective practices to wider ideologies, without jumping too quickly to grandiose discourses, through the use of Billig's ideological dilemmas (Billig et al. 1988), and the function of indexicality from positioning theory (Davies and Harré, 1990). Finally, adopting an incremental process and engaging with the effects of performativity helped avoiding the trap of equating performativity to some magical effects, which has been the object of some critiques of the performativity thesis.

Another contribution can be located in the choice of the dataset. The use of computer-mediated communication as research data is still relatively rare in market studies and marketing scholarship in general, especially when coupled with a linguistics focus. As

I have argued previously, the incredible wealth of research material available in the internet makes it a promising avenue to explore. There is room for new research methods to be developed within the virtual realm, especially with the fast-paced growth of technology. Research methods will need to be tailored in order to fully exploit the potential of the multiplicity of synchronous, asynchronous, and hybrid data out there. There are also potentialities for developing new understandings of online ethics and privacy, as it still represents a tricky area within computer-mediated research (as discussed in chapter six). Considering that the material constitutes the medium for the discursive in the case of computer-mediated communication, market studies appears to be an ideal venue for exploring the construction of market actors and practices within the virtual realm, and developing new research methods.

The virtual world does not operate in isolation from the physical world, and the movement of economic materialities and discourses between the two realms could also constitute a potential avenue of research for market studies.

9.3. Directions for future research:

I start this section with a brief summary of the key findings of this thesis, and build the directions for future research from there.

In order to become empowered through the freedom of choice, individuals need to engage in consumption processes in the first place. On the other hand, this choice is entangled with a set of rationalities and calculation processes (quantifications and evaluation of the risk to develop a disease in this case); meaning also that the freedom in this context alludes to a freeing from previous ideological system, rather than an absolute freedom. This moves us beyond a description of 'homo economicus' as a calculating agent, to a discussion on the ideologies that not only bring this entity into being but also the effects of this performativity on the practices of healthcare. When care is reconfigured as individual, and in purely biological and economic rationalities, competition with other modes of responsibility is evident.

Under these circumstances, certain movements of activism are reconfigured through the lens of the ethics of self-government, where the critique is turned inward. For these strands of activism, the key to mobilise actors around a cause is to formulate their argument around what can be detrimental to the wellbeing of one-self, whether it constitutes a risk to affect individuals directly or indirectly. This contrasts with alternative understandings of care such as 'relations of care' (Mol, 2008).

Recent developments within anthropology have proposed frameworks for new conceptualisations of responsibility that could challenge the dominance of responsabilisation (Mol, 2008; Ferguson, 2012; Trnka and Trundle, 2014). In the case I presented within this study, the social actors faced various limitation in enacting the different forms of duties as responsabilised individuals. There is a need for a framework for conceptualising responsibility, which places responsabilisation alongside other modes of responsibility such as relations of care (Mol, 2008); as opposed to a narrow focus on self-care. While this study has focused on the responsibility of individuals, the new frameworks need, in order to include relations of care, to connect these modes of responsibility with the responsibility of the state, as well as the responsibility of corporations. In the context of genomics, this is particularly relevant with the development of personalised genetics products, including potential future developments of one stop personal genomic shops (Molteni, 2017) that could reconfigure the logic of choice through further geneticization of human behaviour.

Some of the key elements that needs to be reconfigured within the developments of a concept of responsibility are the state responsibility, as well as economic assemblages; with a framework that moves beyond the individualising and isolating notion of corporate social responsibility when considering the responsibility of corporations. The future frameworks should take into consideration the interconnectedness of the various actors, while also considering the multiplicity of modes of responsibility and accountability, and how they work with each other, rather than a focus on measuring and allocating blame. Because it focuses on how the interconnectedness of various discursive and material resources can bring things into being, market studies appears to be a great avenue for developing such frameworks.

Annemarie Mol's relations of care (2008) constitute an excellent starting points as it focuses on aspects that are very much devalued by neoliberal ideology such as dependency, interdependency and recognition. Contrasting the logics of 'choice' and 'care', Mol argues to consider 'relationships of care' as a means to conceptualise and policy responsibility alongside 'individual choice'. 'Relations of care' take into account the interactivity and messiness of these relations and the power relations involved; thus displacing autonomy and independence from their places as the sole locus of responsibility. Such a perspective destabilises an understanding of self-care and care for the other as dichotomous, and requires us to locate the historical development of this dualism in order to deconstruct it. As Mouffe (1996, p. 3) states: "it is only in a rationalistic world (.....) that the demands of self-realization and those of human solidarity could be so neatly differentiated". This urges us to challenge the understanding of responsibility as localised within a dualism, but in interaction, negotiation and movement.

These pioneering works in anthropology could constitute the first steps for new developments within market studies that conceptualise new modes of responsibility and governance. The first milestones of this research agenda will be a performativity programme that connects with the politics, in order to better understand the current forms of governance and their effects, and will constitute the building block for new ways of governing to emerge.

9.4. Concluding thoughts:

As the Latin proverb states '*ordo ab chaos*', which means order out of chaos, order and stability are not natural, they are efforts to temporarily stabilise the chaotic (Derrida, 1996). However, chaos does not end when order starts – chaos continues to inhabit the order, as the natural always exists. Therefore, stabilisation and chaos (instability, destabilisation) are not discrete domains, as is sometimes depicted in the performativity thesis within market studies. Instability does not end when stabilisation happens; it continues to inhabit the temporal order. The act of organising

consists of attempts of temporal stabilisations of something “essentially unstable and chaotic” (Derrida, 1996, p. 83).

This thesis started with considering the critiques of market studies and ANT, accusing its apolitical character. So, is market studies apolitical? Well, the answer is both yes and no.

By focusing on stabilisation processes, market studies has not neglected the political. It documented political efforts of organisation. However, the tendency to focus on thick descriptions confined it within the activity of documenting the political, rather than engaging with it; which ultimately lead its critics to accuse market studies of being apolitical.

For market studies to connect with the political, it needs to move from a description of performativity, to act as a performative problematisation of the distinction between chaos and organisation, and recognise the forms of exclusions that the acts of organising and stabilising embody. This is because the very act of deciding on a particular method of organising and stabilising entails the repression of alternative ways. In this effort of performative problematisation, market studies needs to deconstruct the rationalisation and moralisation strategies, which can function as devices to hide the forms of exclusion that stabilisation embodies. The tensions and conflict occurring throughout and beyond these stabilisations can be not only a risk but also a chance to destabilise.

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Appendix A: My medical choice by Angelina Jolie - Letter to The New York Times

OP-ED CONTRIBUTOR
My Medical Choice

By ANGELINA JOLIE
Published: May 14, 2013 | 1712 Comments

LOS ANGELES

 Enlarge This Image



Loren Capelli

MY MOTHER fought cancer for almost a decade and died at 56. She held out long enough to meet the first of her grandchildren and to hold them in her arms. But my other children will never have the chance to know her and experience how loving and gracious she was.









We often speak of “Mommy’s mommy,” and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a “faulty” gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.

My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman.

Only a fraction of breast cancers result from an inherited gene mutation. Those with a defect in BRCA1 have a 65 percent risk of getting it, on average.

Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventive double mastectomy. I started with the breasts, as my risk of breast cancer is higher than my risk of ovarian cancer, and the surgery is more complex.

On April 27, I finished the three months of medical procedures that the mastectomies involved. During that time I have been able to keep this private and to carry on

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Figure 28: My Medical by Angelina Jolie, Part I (Copyright © The New York Times)

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with my work.

But I am writing about it now because I hope that other women can benefit from my experience. Cancer is still a word that strikes fear into people's hearts, producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action.

My own process began on Feb. 2 with a procedure known as a "nipple delay," which rules out disease in the breast ducts behind the nipple and draws extra blood flow to the area. This causes some pain and a lot of bruising, but it increases the chance of saving the nipple.

Two weeks later I had the major surgery, where the breast tissue is removed and temporary fillers are put in place. The operation can take eight hours. You wake up with drain tubes and expanders in your breasts. It does feel like a scene out of a science-fiction film. But days after surgery you can be back to a normal life.

Nine weeks later, the final surgery is completed with the reconstruction of the breasts with an implant. There have been many advances in this procedure in the last few years, and the results can be beautiful.

I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don't need to fear they will lose me to breast cancer.

It is reassuring that they see nothing that makes them uncomfortable. They can see my small scars and that's it. Everything else is just Mommy, the same as she always was. And they know that I love them and will do anything to be with them as long as I can. On a personal note, I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity.

I am fortunate to have a partner, Brad Pitt, who is so loving and supportive. So to anyone who has a wife or girlfriend going through this, know that you are a very important part of the transition. Brad was at the [Pink Lotus Breast Center](#), where I was treated, for every minute of the surgeries. We managed to find moments to laugh together. We knew this was the right thing to do for our family and that it would bring us closer. And it has.

For any woman reading this, I hope it helps you to know you have options. I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices.

I acknowledge that there are many wonderful holistic doctors working on alternatives to surgery. My own regimen will be posted in due course on the Web site of the Pink Lotus Breast Center. I hope that this will be helpful to other women.

Breast cancer alone kills some 458,000 people each year, according to the World Health Organization, mainly in low- and middle-income countries. It has got to be a priority to ensure that more women can access gene testing and lifesaving preventive treatment, whatever their means and background, wherever they live. The cost of testing for BRCA1 and BRCA2, at more than \$3,000 in the United States, remains an obstacle for many women.

I choose not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer. It is my hope that they, too, will be





Figure 29: *My Medical* by Angelina Jolie, Part II (Copyright © The New York Times)

able to get gene tested, and that if they have a high risk they, too, will know that they have strong options.

Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of.

Angelina Jolie is an actress and director.

A version of this op-ed appeared in print on May 14, 2013, on page A25 of the New York edition with the headline: My Medical Choice.

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Figure 30: My Medical by Angelina Jolie, Part III (Copyright © The New York Times)

Appendix B: Ethics approval documentation

Doctoral Research Request - Experiences of the at-risk breast cancer patients

Cheded, Mohammed

To: suefriedman@facingourrisk.org

08 May 2015 17:42

Dear Dr. Friedman,

Hope this e-mail will find you well.

I am writing you to ask your consent to use some the discussions from the message board in FORCE website as data for my PhD research.

My name is Mohammed Cheded, and I am a Marketing PhD student at Lancaster University UK. The provisional title of the doctoral thesis I am currently undertaking is: 'Risk Narratives and the Shaping of Markets: Story of a body, a pill, and a market'.

The research looks at how stories and narratives, surrounding risk, shape diagnostic practice and patient-consumer 'at risk' identities. It will explore the experiences of women, categorised at high risk of developing breast cancer, and how they are affected by the debates around BRCA screening. I am interested in how women talk, communicate, react, and make sense of their experience of being at high-risk of developing breast cancer. It is motivated by the lack of research in new categories of 'at-risk' patients that can be understood from a market perspective - that is as the 'at-risk' patient as one actor amongst others operating in a medico-economic arena. This would help us better understand the 'at-risk' patient identity as an actor operating in the marketplace, as well the impact of the genetic predisposition discourse on their experiences.

I intend to collect the data unobtrusively. Confidentiality will be ensured by anonymising patient profile (including usernames and pseudonyms which will be treated with the same respect as for a person's real name). Particular precautions will be taken to reduce the level of risk and safeguard the confidentiality of data. In line with the British Psychological Society and the strictest Ethics Guidelines for internet-mediated research projects which we are working with here at Lancaster University, specific strategies to ensure maximal anonymisation will be implemented such as paraphrasing or combining traceable quotes (after the data analysis stage). This is to reduce the risk of patients being identified, if quotes are being traced to source (through a google search for example).

Lancaster University is home to the UK's very first Marketing department, ranked in the top two in the Complete University Guide for the last three years, and with a substantial strength in researching how new markets are made.

My research is supervised by Dr. Gillian Hopkinson (Marketing Department, Lancaster University, g.hopkinson@lancaster.ac.uk), and Dr. Alan Gilchrist (Marketing Department, Lancaster University, a.gilchrist@lancaster.ac.uk).

Looking forward to hearing from you.

Kind regards,

Mohammed.

Mohammed Cheded
Marketing PhD Student
Department of Marketing
Lancaster University Management School, D44, Lancaster, LA1 4YX
E-mail: m.cheded@lancaster.ac.uk

Figure 31: Informed Consent Letter

Source: Screenshot from my e-mail box (m.cheded@lancaster.ac.uk)

Ethics application approved UREC REFERENCE:RS2014/5

Ethics (RSO) Enquiries

To: [Cheded, Mohammed](#)
Cc: [Hopkinson, Gillian; Gilchrist, Alan](#)

20 July 2015 09:30

Dear Mohammed

Thank you for submitting your completed stage 1 self assessment form and additional information for **Risk Narratives and the shaping of markets: Story of a body, a pill and a market**. The Part B information has been reviewed by members of the University Research Ethics Committee and I can confirm that approval has been granted for this project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress) to the Research Ethics Officer;
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (ethics@lancaster.ac.uk 01542 592605) if you have any queries or require further information.

Kind regards,

Debbie

Debbie Knight | Research Ethics Officer | Email: ethics@lancaster.ac.uk | Phone (01524) 592605 | Research Support Office, B58 Bowland Main, Lancaster University, LA1 4YT

Web: Ethical Research at Lancaster: <http://www.lancaster.ac.uk/depts/research/ethics.html>



www.lancaster.ac.uk/50

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Figure 32: Ethics application approval
Source: Screenshot from my e-mail box (m.cheded@lancaster.ac.uk)