

From Gender Studies to Biomedical and Health-Related Research:
A Critical Analysis of Gender Incorporation in the European Commission Framework
Programmes



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Abstract

The purpose of this paper is to analyze the increased focus on sex and gender in biomedical and health-related research funded by the European Commission Framework Programmes. This recent shift in policy and practice resulted in most part from the actions of a distinct group of reformers located at Maastricht University. In order to analyze and characterize these reformer's actions and the resulting outcomes, the concept of boundary movements as proposed by McCormick, Brown, and Zavestoski (2003) will be used. The structure of this paper is as follows: first a general introduction into the topic will be presented, followed by a literature review in Chapter 1. Chapter 2 then proceeds with an overview of the European Commission, its Framework Programmes, and the how sex and gender came to be incorporated in these institutions. Chapters 3 then provides an in depth analysis of how these actions can be seen as a boundary movement by zooming in on what is taken here as an exemplary continuant organization—namely the 'GenderBasic' project. Chapter 4 then looks at framing techniques used in all three projects. And finally, a conclusion summarizes the main findings and proposes possible areas of interest for future research. Such an analysis will not only illustrate how reforms came about in this specific context, but will also shed light on how new health social movements operate and create new relationships between science, society and public policy.

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Introduction

Attention to possible sex-differences, even in preclinical research, as well as to effects of gender, will lead to more adequate research data that serve the health of both men and women” (Bosch & Klinge, 2005, p.377)

Much work has been done since twenty-five years ago when neither the terms ‘gender’ and ‘science’ had been formally conjoined, nor had the implications of such a conjunction been subject to any kind of serious analytical or historical scrutiny (Keller, 2001, p.98). Today, not only has the study of gender become its own academic discipline and been taken up in fields such as cultural studies, psychology, anthropology, art history, film theory, sociology and science studies among many others, but increasingly, in the United States and the European Union, as the above epigraph suggests, sex and gender have come to be seen as invaluable dimensions of biomedical and health-related research. This may seem as a natural or even obvious development to some, but this development did not happen automatically; it took hard work and dedication, strategic framing, and boundary work in order to change the way that gender in science is conceptualized, analyzed and evaluated. Without this work, things would very likely have been otherwise.

It may seem hard to believe, but before the 1960’s, drugs were typically only tested on middle-aged white men (Schiebinger, 2008, p.16). It was assumed that the absence of other groups such as women, ethnic minorities, or individuals of different age groups did not matter much, because the findings from studying the ‘normative standard’ could simply be generalized to the entire population (Epstein, 2007, p.4). Not only have men at times been easier target groups to recruit—being physicians or men in the military, but they also do not have menstrual cycles or the ability to get pregnant. This means that they are ‘hormonally stable’—menstrual cycles will not confound data on drug effects in clinical trials. As well as this, without the possibility of pregnancy, drugs can be tested without concern that they may harm an unborn child. Although this may be true, and therefore testing on middle-aged white men may be easier, this type of medical practice is not only tremendously unfair but it is also extremely dangerous. One of the results of this ‘one-size fits all approach’ to medicine is that adverse drug reactions occur twice as often in women as in men (Schiebinger, 2008, p.16).

These obvious shortcomings, however, have not corrected themselves; it has taken hard work and dedication to make legislative changes both in the United States and the European Union. Since the mid-1980's a diverse assortment of reformers in the United States have protested against biomedical practices, "arguing that expert knowledge about human health is dangerously flawed and that health research practices are fundamentally unjust because of the inadequate representation of other groups in clinical trials" (Epstein, 2007, p.4). This diverse group of reformers, which included grassroots advocacy groups, clinicians, scientists, professional organizations, and government health officials (Epstein, 2007, p.4) managed to generate institutional reforms in the American biomedical sciences. The most pertinent victories were policy changes made within the National Institute of Health (NIH) and the Federal Drug Administration (FDA). In 1993, the NIH passed the Revitalization Act that legislated the mandatory inclusion of women and 'members of minority groups' as research subjects in NIH-funded studies (Epstein, 2007, p.82). And in the same year the FDA reversed their restriction of including women 'of childbearing potential' in trials of experimental drugs, out of concern for possible fetuses (Sismondo, 2010, p.5). And as for the pediatric population, they too became recognized as a crucial group of study in biomedicine: as of 1998 research funded by the NIH also had to include a description of how children would be included and studied, and if not, exactly why this was the case (Epstein, 2007, p.120).

In Europe we are seeing a similar trend, although the focus of reforms has been less on race and ethnicity as it has been in the United States, and more on woman and pediatric populations. As of 2006 the European Union has acknowledged through strict regulations that medicinal products currently used to treat pediatric populations remain understudied and unauthorized for such use. They have therefore imposed the requirement of a pediatric investigation plan in order to ensure that "the development of medicinal products that are potentially to be used for the pediatric population becomes an integral part of the development of medicinal products [and] integrated into the development programme for adults" (European Union, 2006, p.2). As for the inclusion of women, which will be the focus of this paper, "attention to sex and gender aspects in biomedical and health-related research has become a major initiative of the EU gender equality policy for research" (Klinge, 2008, p.183). Following the three-year lobbying actions of 'Women's International Studies Europe' (WISE), the European Commission requested a Gender Impact Assessment of their

Fifth Framework Programme in the year 2000. This unique opportunity was seized by a select group of social and natural scientists from Maastricht University who through their Gender Impact Assessment and successive involvement in the European Commission transformed the way that European research is conducted, theorized, and practiced. Differences between men and women are now taken into account in condition-specific aspects such as pathogenesis, patterns of symptoms and presentation of symptoms, treatment options and prognosis (Bosch & Klinge, 2005, p.379). And much like policy reforms within the NIH and FDA, studies that were funded under the 6th Framework Programme of the European Commission had to, according to policy regulation, pay explicit attention to sex and gender issues.

The purpose of this paper is to analyze these gender policy reforms in biomedical and health-related research funded under the European Commission's Framework Programmes. The reason that the focus of this paper will be on European and not American biomedical reforms is twofold. Firstly, as we will see in Chapter 1, other authors such as Steven Epstein (2007) and Londa Schiebinger (1999; 2008) have already written extensively on the topic of American biomedical reforms. And so American policy changes and analyses thereof will be used here as a point of departure and inspiration rather than as a focus of study. Secondly, not only has little work been written on European biomedical policy reforms (I. Klinge, personal communications, May 5, 2011) but Steven Epstein (2007) in his investigation even goes so far as to claim that policy changes emphasizing sex, race, ethnicity and age in biomedical research are a characteristically American development and have not occurred in Europe (p.7). So the hope here is partly to prove Epstein's claim wrong by presenting what has occurred within the European Commission, but also, to add to Epstein's research by analyzing these European reforms not as he does, in terms of a new 'biopolitical' paradigm, but rather, as a boundary movement in science, a concept that I take from McCormick, Brown & Zvestoski (2003) and explain in more detail in Chapter 1 and 3.

As for the choice to focus solely on issues of sex and gender, the reason for this is mostly pragmatic: I was able to come into close contact with a group of social and natural scientists from Maastricht University who played a central role in promoting and incorporating sex and gender issues in biomedical and health-related research funded by the European Commission. So whereas it would be equally interesting to look at the increased focus on pediatrics or to question why race and

ethnicity have not been emphasized to the same extent in European biomedical research as it has in the United States, the study here is limited to the issue of sex and gender, and more specifically to the sex and gender reforms that took place within the European Commission Framework Programmes starting from the year 1998.

Although we will be looking at this movement mainly through the concept of boundary movements, our analysis and thought process will be guided by a broader science and technology studies perspective (STS)—meaning that we will be viewing science, technology and society as mutually shaping and interrelated spheres open to the analysis of sociologists. From this perspective, neither science, technology, or society solely determines the course of history, nor do they develop in isolation. The development of new forms of science and new technologies are the outcome of negotiations, and could therefore have been otherwise. This is not to say that science and technology are no different from social processes or that scientific expertise is non-existent, but rather that there exists a variety of expertise (Bijker, 2001, p.31). So whereas we must accept a notion of obduracy, we must also acknowledge a notion of contingency.

In this way, the changes that have occurred in the European Commission are characteristic of such a perspective. These changes cannot be attributed purely to scientific discovery—it was not out of the blue that scientists in the laboratory discovered from nature that “biological and socio-cultural differences between women and men may result in different epidemiological patterns and effect modification of diagnostic, preventative and therapeutic interventions” (Klinge, 2008b, p.6). Nor can these changes be attributed purely to social activism or to an invasion of politics into scientific practice. Rather, this movement managed to maneuver between social worlds and realms of knowledge and in doing so blur the lines that demarcate science from non-science, experts from non-experts, and movement actors from non-movement actors. Through hard work and dedication, and strategic framing, this group of social and natural scientists from Maastricht University were able to appropriate and align categories of sex and gender with scientific excellence and European innovation.

By analyzing these reformer’s actions in terms of a boundary movement we will not only be evaluating the specific dynamics and strategies employed to promote sex and gender as scientifically relevant concepts in European biomedical research, but we will also, more generally, be shedding light on emergent social movements

that differ from the more traditional conceptions of social movements as being led by people “who lack regular access to institutions” (Tarrow, 1998, p.3). Much like the scientist-activists described in Scott Frickel’s book ‘Chemical Consequences’ (2004) this movement “... was not, primarily, a student-based or young professionals’ movement” (Frickel, 2004, p.82), rather it’s core activists “enjoyed relatively high status among their peers and secure employment” (Frickel, 2004, p.82). As well as this, those involved in these reforms would probably not call themselves activists. Yet their actions *were* a social movement, more specifically their actions were a boundary movement which involved a subtle yet successful form of contentious collective action—one that not only changed ideas, policies, and methodologies, but which re-drew the lines that demarcate science from non-science.

In order to make and support such claims, this paper is structured into the four following main chapters. First a literature review in which the necessary theoretical background along with relevant terminology and analytical concepts is presented in Chapter 1. Then Chapter 2 proceeds with an overview of the European Commission, its Framework Programmes, and how gender came to be incorporated in these institutions. Chapter 3 then provides an in-depth analysis of how these actions can be seen as a boundary movement by zooming in on what is taken here as an exemplary continuant organization—namely the ‘GenderBasic’ project funded by the European Commission from October 2005 to January 2008. Chapter 4 then looks at framing techniques used by this group of reformers. And finally the conclusion summarizes the main findings and proposes possible areas of interest for future research.

Chapter 1: Theorizing the Increased Focus on Sex and Gender in Biomedical and Health-Related Research

Most of what has been written about biomedical reforms mandating the inclusion of minority groups as research subjects has been limited to studies of the United States. In this chapter we will first describe and critically evaluate how some of these authors have theorized American biomedical reforms in terms of a ‘triumph for feminism’, and an ‘inclusion-and-difference paradigm’. We will then turn our attention to social movement theory, boundary work, boundary movements and framing—concepts that will be used in our analysis of European biomedical reforms. These concepts will be elaborated on here, their strengths and weaknesses will be assessed and the reasons for choosing them will be delineated. To avoid being repetitive—the concept of boundary movements is only briefly explained here and then in more detail in the analytical chapter that deals with GenderBasic—namely Chapter 3. And finally, this chapter ends with a methodology section providing the necessary information on how empirical work, presented in Chapters 2, 3, and 4 was carried out.

As a ‘Triumph for Feminism’

Just between 1990 and 1994 the U.S. Congress enacted “no fewer than twenty-five pieces of legislation to improve the health of American women, ranging from a requirement that women be included in clinical trials to new federal regulations for mammography” (Schiebinger, 1999, p.108). Historian of science Londa Schiebinger (1999) has described these reforms but also the founding of the NIH Office of Research on Women’s Health, and the Women’s Health Initiative of 1991 as a “triumph for feminism” (p.108). The reason that Schiebinger frames developments in this way can be seen as threefold. Firstly, if we look at the fact that scholars tend to make the distinction between getting women into science and changing scientific knowledge and that getting women into science is generally considered the easier of the two, then the advancement of opening up a certain part of scientific culture to gender analysis (Schiebinger, 1999, p.13) can certainly be seen as a triumph for feminism. A second reasoning may be that although American biomedical reforms eventually also came to mandate the inclusion and explicit attention to ethnic minorities and pediatric populations, it was, as Steven Epstein (2006) also acknowledges, the women’s health movements that set the ball rolling (p.331). Not only were women the largest social category invoked in these debates, but, in

addition, following the liberal feminist movements of the 1970's, women—at least in limited numbers—rose to positions of prominence in government, the medical profession, and the world of scientific research, and some of these women used these positions to push for reforms in biomedicine (Epstein, 2006, p.331). Once women were able to put forward their critiques, “they opened up a space of possibility that others could occupy—racial and ethnic minorities, for example, followed with arguments that they, too, were undeserved by modern medicine and underrepresented in study populations” (Epstein, 2006, p.331).

But Schiebinger's reasoning must also be seen in light of a third factor: the aim of her studies. In her two books 'Has Feminism Changed Science' (1999) and 'Gendered Innovations in Science and Engineering' (2008), Schiebinger takes the American biomedical reforms as an instructive example of how incorporating gender analysis in science is both possible and also extremely desirable. Though the focus of Schiebinger's two books differ slightly, they have in common her view that “for long enough we have asked what science is doing wrong”(Schiebinger, 1999, p.1-2) and that “it is time to look at what gender studies can offer in the form of new perspectives, new research projects and priorities” (Schiebinger, 1999, p.1-2). Schiebinger's (2008) goal is therefore to document how gender analysis, when turned to science or engineering, can profoundly enhance human knowledge (p.vii). According to her “this is where the action is today” (Schiebinger, 2008, preface). By evaluating the progress that feminism, “which defines a perspective, not a sex” (Schiebinger, 1999, p.16), has made over the years, Schiebinger (2008) hopes to elicit an understanding of how “removing gender bias has brought new insights to specific sciences and fields of engineering” (Schiebinger, 2008, p.4). In order to highlight this she elicits the field of biomedicine as exemplary for these aims.

Schiebinger's work is clearly important when we look back to the fact that twenty-five years ago the terms gender and science had not been formally conjoined nor critically analyzed in academic circles (Keller, 2001, p.98). In this context, the passing of the NIH Revitalization Act and the setting up of offices such as the Office of Research on Women's Health can certainly be seen as a milestone, if not, a triumph for feminism. One shortcoming of such an analysis, however, is that a more critical and in-depth discussion of how such reforms came about is left aside. Although Schiebinger (1999) states that “reforming aspects of medical research required new judgments about social worth and a new political will” (p.108), and not just the entry

of women into senior levels of scientific institutions and Congress (p.124), her analysis does little to further explain the actual process and work involved. By framing these reforms in terms of a ‘triumph for feminism’, Schiebinger largely ignores how these reforms came about, how they were opposed, and some of their ramifications—aspects dealt with more extensively in Steven Epstein’s analysis—one which we will turn to next.

As an ‘Inclusion-and-Difference Paradigm’

In contrast to Londa Schiebinger, sociologist Steven Epstein has characterized the increased attention to sex and gender in American biomedical and health-related research not in terms of a ‘triumph for feminism’ but rather as part of a bigger shift—what he coins the emergence of an ‘inclusion-and-difference paradigm’. In his 400-page book, ‘Inclusion: The Politics of Difference in Medical Research’, Epstein (2007) sets out to charter the origins, developments, challenges, and ramifications of a new wave of reforms in the United States where categories of sex, race, ethnicity and age, have come to be seen as defining differences for healthcare, pharmaceutical drug development and henceforth clinical trials. Epstein’s (2007) book is an impressive piece of work and a hallmark piece of reading on this topic. Not only is his work much more extensive and critical than that of Schiebinger, but his analysis brings to light important analytical concepts such as biopolitical paradigm, tacit coalition, framing, categorical alignment, and boundary work, concepts which we will delineate below.

Epstein’s overall analysis is guided by the concept of a biopolitical paradigm and more specifically, an ‘inclusion-and-difference paradigm’. Epstein (2007) defines this ‘inclusion-and-difference paradigm’ as “the research and policy focus on including diverse groups as participants in medical studies and in measuring differences across those groups” (p.17). The name ‘inclusion-and-difference’ underscores two central goals and achievements: the inclusion of “various groups generally considered to have been underrepresented previously as subjects in clinical studies, and the measurement of difference across groups with regard to treatment effects or biological disease processes”(Epstein, 2006, p.340). In order to clarify his use of the term paradigm, Epstein (2007) distinguishes it from Thomas Kuhn’s conception thereof. Epstein (2007) states that the ‘inclusion-and-difference paradigm’ is not a paradigm in the strict Kuhnian sense “because it does not constitute the

central set of assumptions guiding any scientific specialty group, nor is it restricted to any single such group” (p.17), but rather this ‘inclusion-and-difference’ paradigm is what Epstein (2007) terms a biopolitical paradigm—meaning a framework of “ideas, standards, formal procedures, and unarticulated understandings that specify how concerns about health, medicine, and the body are made the simultaneous focus of biomedicine and state policy” (p.18). The ‘inclusion-and-difference paradigm’ is a ‘biopolitical paradigm’ that traverses the boundaries between life sciences and state policymaking, simultaneously specifying goals, methods, and procedures for each. By adopting the language of paradigms, Epstein means to underscore the considerable degree of inertia that is in these regimes (Epstein, 2006, p.339-340).

We have now seen how Epstein’s general analysis is framed, in terms of a biopolitical ‘inclusion-and-difference paradigm’ but another important concept is that of a tacit coalition. As Epstein (2007) tells the story of how laws, regulations and bureaucratic offices were transformed in the United States through a diverse set of reformer’s actions, he refers to these reformers as a tacit coalition. What Epstein (2007) means with this term is that reformers were not one unified group of activists who set to the streets, but rather, they were individuals including ‘policy entrepreneurs’, politicians, interest groups, physicians, and members of congress (Epstein, 2006, p.330) who were “marked less by direct and sustained cooperation than by a certain unity of purpose” (Epstein, 2007, p.53). In other words, these reformers did not operate in formal unison, nor did they lack regular access to institutions—two common conceptions in social movement theory and analysis. By using the term tacit coalition, Epstein (2006) forces us to think critically and reflect upon some typical assumptions of how social movements bring about change (p.332)—a point we will turn to in the following section on social movements.

As for how these reformers were able to succeed, despite some opposition, Epstein deems this due to many factors, but most importantly due to categorical alignment, boundary work and framing. Categorical alignment refers to the “merging of social categories from the worlds of medicine, social movements, and state administration” (Epstein, 2007, p.13). Through categorical alignment, “proponents of inclusion were able to *act as if* the social movement identity labels, the biomedical terms, and the state-sanctioned categories were all one and the same set of classifications” (Epstein, 2006, p.337) and that therefore “political and biomedical remedies could be pursued simultaneously through a single project of reform”

(Epstein, 2006, p.338). Although this is where much of the reformers success lies, it is also where opponents and Epstein himself have been more critical. By making social categories seem the same as medically relevant ones “... such claims appear to divide the universe of human experience into two utterly separate camps, while thoroughly homogenizing all that which lies within each one” (Epstein, 2007, p.249). As well as making observations of some women true of all women, and therefore universalizing their experience, the use of categories such as race, age, and gender as defining social but also medical categories, marginalizes other possible determinants of health and illness such as behavior, social class or environmental living conditions (Tutton, 2009, p.793.) Dividing the human population into such categories serves to “reify and perpetuate a socially created dichotomy” (Epstein, 2007, p.251). As Epstein (2007) states: “the search for difference can help to create the differences; if you are looking for something you are likely to find it” (p.251). And so whereas Schiebinger has mostly framed these developments in a rather positive light, it is also important to note, as Epstein does, some of the ramifications of these reforms—that arguments used by reformers and the policy outcomes they achieves are equally constraining as they are enabling and in themselves hold various presumptions.

Besides the alignment of categories, reformers were also successful because of the way that they told their stories—in other words, the way that reformers were able to mobilize and motivate their social movement through the use of frames. The concept of framing was originally proposed by sociologist Erwing Goffman (1974), but has extensively been used since in social movement theory by authors such a Robert Benford and David Snow (2000). Frames are the stories used to mobilize and motivate social movements—they “call attention to the ways in which groups with political agendas actively seek to shape representations of reality and say what the world is like” (Epstein, 2007, p.58). Frames “provide a diagnosis of a social situation, they propose solutions, and they can serve as a call to arms” (Epstein, 2007, p.58) What framing processes address is what literature until the 1980’s mostly ignored, what Benford & Snow (2000) distinguish as meaning work—seeing the actors as active agents who are “engaged in the production and maintenance of meaning” (p.613).

In Epstein’s (2007) analysis of American biomedical reforms he characterizes this tacit coalition as using six main frames, namely—underrepresentation, misguided protectionism, false universalism, health disparities and biological differences. These

frames group the arguments of reformers and characterize why they were successful. Although these frames are particular to Epstein's analysis and to the American biomedical reforms that took place, the general use of the concept of frames is important and useful as it is a "central dynamic in understanding the character and course of social movements" (Benford & Snow, 2000, p.611). By looking at frames one can highlight how activists are able to mobilize others to join their movement, how they are able to articulate a problem and its solution, and how their stories, and not that of others, are able to resonate and diffuse. In our analysis of the boundary movement to incorporate sex and gender in the European Commission Framework Programmes we will also highlight framing techniques that were used (see Chapter 4).

And lastly Epstein uses the notion of boundary work. The concept of boundary work is taken from the work of Thomas Gieryn (1983). Gieryn (1983) proposed this concept in order to denote the practices and rhetoric by which 'science' is defined and distinguished from other things, such as 'politics' and 'religion' and by which professional autonomy is defended (Epstein, 2007, p.317). Epstein uses this terminology when analyzing the roles of employees at the Department of Health and Human Services (DHHS) in finding creative ways of institutionalizing the reform mandate of the NIH in order to meet requirements but also opponent's views that this was an infiltration of politics in science. Opponents included researchers, politicians, pharmaceutical companies, statisticians, and experts on clinical trials "who maintained that the policies made no medical sense and that reformers simply failed to comprehend the logic of scientific generalizations as employed in the arena of clinical research" (Epstein, 2007, p.14). They were successfully able to do both through boundary work: by "reestablishing an accepted divide between the realms of science and politics, with the new policies located on the 'science' side of the boundary" (Epstein, 2007, p.14). "This work was critical not only for the legitimacy of science, but also for the ability of DHHS [such as the FDA and NIH] agencies to defend their jurisdiction and autonomy" (Epstein, 2007, p.14). Boundary work, as we will see in Chapter 3, was also essential in European reforms—in which through their boundary movement they were able to redraw and blur the lines between science and non-science, activists and non-activists, and in doing so ensured that principles of gender and sex would not just be essential in social sciences but also in the life sciences—and more specifically in the field of biomedicine.

Epstein's (2007) book is extremely important in terms of what has been written about biomedical reforms mandating the inclusion not only of women but also of ethnic minorities and pediatric populations in American pharmacological drug development and henceforth, clinical trials. Not only does he provide a multifaceted coverage of the entire history and significance of these reforms (Brown & Senior, 2009, p.1708), but Epstein (2007) also makes important theoretical contributions by proposing and elaborating on concepts such as biopolitical paradigm, tacit coalition, framing, categorical alignment, and boundary work—some of which we will also use in our analysis of the European biomedical reforms. This being said however, Epstein's analysis of American biomedical reforms remains just that—limited to the United States. Although Epstein (2007) does acknowledge that “the evidence available to me suggests a limited, but perhaps increasing, spread of inclusionary goals—particularly with regard to women—from the United States to a number of Anglophone and European countries” (p.274), he retains that “this expression of an inclusionary intent mostly has not translated into a new regulatory framework, and formal policies with mechanisms of enforcement are mostly absent outside the United States” (Epstein, 2007, p.274). Of course his analysis cannot cover biomedical reforms attaining to gender, race, and age everywhere in the world—and hence his limitation of study to the United States, but his assertion that such reforms *have not* taken form in any regulatory framework outside the United States seems unsupported if one looks at our case study of the European Commission, but also a number of other initiatives and literature on this subject.

Not only has there been an increasing amount of academic literature published on the subject of increasing gender awareness in medical education and biomedical research¹ as well as an increasing focus on gender in medicine in institutions such as the Dutch Heart Foundation², the European Institute for Women's Health, the ICH and the European Medicines Agency³, but new regulatory frameworks and formal

¹ Wieringa, Hardon, Stronks, & M'Charek (2005); McDowell, Coleman, & Ferner (2006); Lagro-Janssen, Wong, Van Den Muijsenbergh (2008); Klinge, I., & Knijf, P. (2009); Verdonk, Benschop, de Haes, & Lagro-Janssen (2009); Çelik (2009); Celik, Lagro-Janssen, Klinge, van der Weijden, Widdershoven (2008).

² Read more about the Dutch Heart Foundations campaign ‘we hebben jouw hart nodig’ on <http://www.wehebbenjehartnodig.nl/> and the reasons for this campaign at: http://www.hartstichting.nl/hart_en_vaten/verschillen_mannen_vrouwen/ (texts in Dutch)

³ European Medicines Agency (2005); European Medicines Agency (2006)

policies are reforming the European Commission in terms of pediatrics⁴, and gender⁵. Although the issue of race and ethnicity in biomedical research have not extensively been addressed in Europe, with the exception of Wieringa, Hardon, Stronks, & M'Charek (2005), nor have these issues to this date been addressed in any policy documents mandating explicit attention to such categories, the issue of sex, gender and age have.

As we already mentioned earlier in this paper, the pediatric population has received increased attention in European biomedical research. It has been recognized by the European Union and the European Medicines Agency that “in the past, many medicines authorized in Europe were not studied adequately or authorized in children [which] caused difficulties for prescribers and pharmacists treating children, as well as for their patients and carers” (http://www.ema.europa.eu/ema/index.jsp?curl=pages/special_topics/general/general_content_000302.jsp&murl=menus/special_topics/special_topics.jsp&mid=WC0b01ac058002d4ea). To amend these shortcomings the European Union has set up the Pediatric Regulation to “stimulate research into the uses of medicines in children and to lead to their authorization in all ages” (http://www.ema.europa.eu/ema/index.jsp?curl=pages/special_topics/general/general_content_000302.jsp&murl=menus/special_topics/special_topics.jsp&mid=WC0b01ac058002d4ea). As well as this increased focus on pediatrics, the importance of gender in biomedical research has also moved center stage in Europe—initiatives to promote women’s health have been taken up by institutes such as the European Society of Cardiology in their ‘Women at Heart Initiative’ in which they highlight the growing burden of cardiovascular disease in women and promote improved treatment of women at risk of cardiovascular disease in clinical practice. But also the European Medicines Agency (2006) recognize the importance of sex differences for the manifestation and treatment of cardiovascular disease as they state that “the understanding of potential differences between men and women regarding the manifestation of [cardiovascular] disease is of importance for the improvement of the clinical management of [cardiovascular] diseases and has implications for the development of new cardiovascular drugs” (p. 3). Not only in cardiovascular disease

⁴ European Union (2006)

⁵ See appendix 1 which is a copy of the form that all applicants had to fill out when applying for funding under the European Commission’s Sixth Framework Programme.

but also in the manifestation and treatment of things like asthma, diabetes, depression, anxiety disorders and obesity have sex differences been emphasized (Klinge, 2007).

These initiatives do not necessarily contradict Epstein as they can still be seen in light of what he characterizes as “perhaps [an] increasing spread of inclusionary goals—particularly with regard to women—from the United States to a number of Anglophone and European countries” (p.274). But what does contradict Epstein’s analysis of international inclusionary policy trends is that a number of these initiatives, contrary to what Epstein states, have in fact been implemented in formal policies with regulatory power. For example the recognition that pediatrics remain an understudied group in biomedicine has led to the formation of the Pediatrics Committee on the 26th January 2007 whose role it is to enforce the mandatory pediatric investigation plan which ensures that “the development of medicinal products that are potentially to be used for the pediatric population becomes an integral part of the development of medicinal products [and] integrated into the development programme for adults” (European Union, 2006, p.2). As well as this, a number of European countries, such as Sweden, have made increasing the number of women along with integrating gender analysis into research design part of their national science policy.” (Schiebinger, 2008, p.21). And lastly, as we will also see throughout this paper, the European Commission, under their Sixth Framework Programme, mandate that project design address “systematically whether, and in what sense, sex and gender are relevant in the objectives and methodologies of projects” (European Commission, 2006). So although we must recognize that these policies do not so much address race and ethnicity, nor can they be said to on the same scale as the the NIH and FDA (for reasons we will see later on), it would be wrong to write these changes off completely by stating “inclusionary intent... has not translated into a new regulatory framework, and formal policies...” (p.274) outside the United States.

This can be seen as one reason that the present study focuses on the European Commission—to highlight that inclusionary policies have found their way into European regulatory frameworks, contrary to what Epstein claims. But our study at hand aims to do more than that—by analyzing these European reforms in terms of a boundary movement and looking at the boundary work and framing practices that were key to these reformers success, we will not only highlight that these reforms occurred but also *why* and *how* they occurred. Through our analysis we will not only

emphasize how sex and gender came to be incorporated in European biomedical research but our analysis will also provide important insights into common conceptions of social movement theory and the making of science and public policy. These gender reforms in the European Commission highlight the dynamic relationship between science and society. These reforms cannot be attributed purely to scientific discovery, nor can they be attributed purely to social activism or the invasion of politics into science—this movement managed to maneuver between social worlds and realms of knowledge and in doing so blurred the lines that demarcated science from non-science, experts from non-experts, and movement actors from non-movement actors. Through hard work and dedication, and strategic framing, this group of social and natural scientists from Maastricht University were able to appropriate and align categories of sex and gender with scientific excellence and European innovation. With this in mind we will now turn to an overview of concepts that will be used throughout our analysis—namely social movement theory, boundary work, boundary movements, and framing, and lastly we will turn to our methodology section.

As a Social Movement

In contrast to Schiebinger and Epstein, but still drawing on their insights, we will be analyzing biomedical gender reforms in the European Commission Framework Programmes as a type of social movement but more specifically a boundary movement. Boundary movements are a particular form of social movement—movements that blur the boundaries between science and non-science, experts and non-experts, movement actors and non-movement actors. But before we turn to the concept of boundary movements, it is important here to clarify why we will be analyzing European biomedical reforms in the European Commission Framework Programmes in terms of a social movement but also distinguish our conception of what makes up a social movement based on Steven Epstein and Scott Frickel's insights.

By analyzing these reforms as a social movement, and more specifically as a boundary movement, we will not only best be able to evaluate the specific dynamics and strategies employed to promote sex and gender as scientifically relevant concepts in European biomedical research, but we will also be drawing on insights from Altman, Brown, Mayer, McCormick, Morello-Frosch and Zavestoski (2004), Steven

Epstein (2007), and Scott Frickel (2004). Although our analysis of European biomedical gender reforms in terms of a boundary movement is one of a kind, analyzing these types of reforms in terms of a social movement is not completely out of context. Altman, Brown, Mayer, McCormick, Morello-Frosch and Zavestoski (2004) have characterized American biomedical reforms that pay explicit attention to race, ethnicity, gender and age as a social movement, and more specifically as a type of health social movement that they call ‘constituency based health movements’ (p.53). These constituency based health movements address what are experienced by reformers as inappropriate outcomes and oversights by the scientific community (Altman, Brown, Mayer, McCormick, Morello-Frosch & Zavestoski, 2004, p.50). Although their article is not actually dedicated to exploring ‘constituency based health movements’ but rather ‘embodied health movements’, both of which fall under what they call ‘health social movements’, their article provides a gateway for the way in which we will be theorizing European biomedical reforms: in terms of a social movement.

Similar to Altman, Brown, Mayer, McCormick, Morello-Frosch and Zavestoski’s (2004) we will be analyzing European biomedical reforms as a social movement. But this is not only grounded in the fact that Altman, Brown, Mayer, McCormick, Morello-Frosch and Zavestoski (2004) have done so for American biomedical reforms, it is also drawing on Steven Epstein’s (2007) concept of a tacit coalition and Scott Frickel’s (2004) conception of scientist-activists. As described above, Epstein (2007) saw American biomedical reformers as a tacit coalition: meaning that these reformers did not operate in formal unison, nor did they lack regular access to institutions—two common conceptions in social movement theory and analysis. This tacit coalition was not a typical grassroots movement, nor was it a movement that lacked access to institutions. Rather, “the reform coalition spilled across the normally recognized divides between experts and the laity, science and politics, and the powerful and disenfranchised” (Epstein, 2006, p.332), demonstrating the ‘fuzzy and permeable boundary between institutionalized and non-institutionalized politics and underscor[ing] the risk ‘[of assuming that] social movements are discrete entities that exist *outside* of government’ (Epstein, 2006, p.333).

This conception of a tacit coalition and the insights it carries is extremely important for our analysis of reformer’s actions from Maastricht University who

managed to change the way that European biomedical research funded under the European Commission Framework Programmes was conducted. Drawing on Epstein's conception of a tacit coalition, our analysis also highlights that "social movements are sometimes inside as well as outside state agencies" (Epstein, 2006, p.332). These reformers, as we shall see in Chapters 2 and 3, did not comprise a social movement in the traditional sense. As well as this, those involved in the movement would probably not call themselves activists. Yet their actions were a social movement, more specifically they comprised a boundary movement which involved a subtle yet successful form of contentious collective action—one that not only changed ideas, policies, and methodologies, but which re-drew the line that demarcates science from non-science.

These insights are also strengthened by Scott Frickel's (2004) findings and analysis on the rise of genetic toxicology. In his analysis of the rise of genetic toxicology, Frickel (2004) argues that "genetic toxicology was ushered in by a scientists' social movement" (p.12). Yet the people that he characterizes as scientist-activists and what he characterizes as a social movement do not necessarily adhere to traditional assumptions and distinctions of social movement theory. An example of this is that "social movements are typically defined as contentious collective action which become contentious when people who lack regular access to institutions...act in the name of new or unaccepted claims... and...behave in ways that fundamentally challenge others or authorities" (Tarrow, 1993, cited in Frickel, 2004, p.15). Yet in Frickel's (2004) analysis, the scientist-activists he described not only had access to institutions, enjoyed a relatively high status among their peers, and were not a student based movement, but they also generated transformative changes in science through normative actions (Frickel, 2004, p.142). And even so "this was a reform movement" (Frickel, 2004, p.142)—"it elaborated a social critique of the disciplinary organization of science and sought to create a new way of ordering environmental knowledge...(Frickel, 2004, p.12).

Why Frickel (2004) argues that this was a social movement is based on at least two reasons: firstly that advocating for interdisciplinary knowledge is a political act and secondly because "it involved a redistribution of disciplinary power...it gave new cultural and technical meanings to mutagenic agents, and it perforated institutional and ideological barriers that separated experimental work in genetics from public health and environmental politics" (Frickel, 2004, p.16). What Frickel's case

exemplifies is that we should not only question some of the traditional distinctions made in social movement theory—that social movements necessarily take place outside of formal institutions and by people who lack regular access to such institutions, but also the relationship between science and politics. As Frickel (2004) elaborates: “among other things, this undercover approach to environmental politics suggests that science activism is not ephemeral to scientific practice. Rather, it reinforces science studies scholars’ contention that environmental knowledge politics and practice are mutually constituted” (Frickel, 2004, p.142)—something that our analysis of the European Commission gender reforms will also highlight.

As Scott Frickel underscores: “too often, discussions of the relationship between science and social movements are based on undertheorized perceptions of the two as organizationally and epistemologically distinct phenomena. It is only recently that science scholars have begun to examine systematically how social movements and science interconnect, and to date there are very few studies that take scientist activism itself as a topic for serious analysis” (Frickel, 2004, p.142). This is where our research hopes to contribute. By studying the gender reforms in European biomedicine as a social movement and more particularly a boundary movement we will not only highlight that in order for something to be a social movement it does not necessarily mean that actors need to take to the streets, lack institutional access, or be young activists, but also, that science and social movements cannot and should not always be seen as two distinct phenomenon- they co-shape one another. How exactly they do so will be shown in our analysis of the European Commission reformers strategies but also by our choice to use the concept of boundary movements—as we will see in the following section.

As a Boundary Movement & Through Boundary Work

Before we turn to the concept of a boundary movement, let us first turn back to the concept of boundary work proposed by Gieryn (1983) but also used by Steven Epstein. The reason that we are turning back to this concept is to clarify what is meant by the blurring and crossing of boundaries in McCormick, Brown, and Zavestoski’s (2003) conception of boundary movements. Although they state that boundary movements cross and blur the boundaries between science and non-science—this is not to mean that these two are distinct entities in nature. These boundaries are constructed and negotiated and change through time.

Gieryn (1983) made this notion clear in his article ‘Boundary Work and the Demarcation of Science from Non-Science’ (1983). In this article, Gieryn (1983) set out to understand what creates epistemic authority—meaning why certain claims are seen as truthful and others are not and what gives science its authority. Philosophers of Science have long dealt with this question of demarcation yet their answers have been very different. Philosopher of Science Karl Popper proposed the idea of falsifiability to explain what distinguished science from non-science and Robert Merton proposed that science had inherent and distinct social norms—namely communism, universalism, disinterestedness and organized skepticism. Yet these ideas lent the authority of science to some innate, self-regulating characteristics. In contrast, Gieryn (1983) set out to restate the problem of demarcation by examining the characteristics of science not as inherent or possibly unique, but rather, as part of ideological efforts *by scientists* to distinguish their work and its products from non-scientific intellectual activities”(Gieryn, 1983, p.782). These boundaries are not constant nor does the epistemic authority of science exist in ether (Gieryn, 1999, p.15), but rather they are fought over, negotiated, and redrawn—this is what the GenderBasic project did, and this is what boundary movements are all about.

The concept of boundary movements was proposed by Sabrina McCormick, Phil Brown, and Stephen Zavestoski (2003) in order to analyze what they call the environmental breast cancer movement that arose in the early 1990’s in the United States. This movement reframed the successes of the broader breast cancer movement in order to focus on health effects of environmental toxins and potential environmental causes of breast cancer (McCormick, Brown, and Zavestoski, 2003 p.550). In order to analyze this movement, McCormick, Brown, and Zavestoski provide a social-movement case study of how three different locales, namely Long Island, Massachusetts, and the San Francisco bay area took up this movement, and in doing so, propose and outline their new analytical concept of a boundary movement.

McCormick, Brown, and Zavestoski (2003) define boundary movements as social movements and their constituent organizations that attempt to reconstruct the lines that demarcate science from non-science and in doing so blur traditional distinctions such as those between movement and non-movement actors, and between laypeople and professionals (p.547). This concept was proposed in order to characterize “the distinctive growth and strategies of movements involving citizen/science alliances to contend with environmentally related illnesses”

(McCormick, Brown, and Zavestoski, 2003, p.545). Although this concept was proposed to address the environmental breast cancer movement specifically and to characterize movements involving citizen/science alliances rather than other alliances such as social scientists/natural scientists, it is still an extremely useful approach for our case study of the gender sensitive biomedical reforms that took place in the European Commission Framework Programmes.

As McCormick, Brown, and Zavestoski (2003) point out, conceiving of a movement as a boundary movement helps explain its unique features”(p.549), but it also suggests approaches to analyzing other hybrid social movements (p.549). They find that their examination of the environmental breast cancer movement provides important lessons about the mechanisms, strategies and nature of social movements in general (McCormick, Brown, and Zavestoski , 2003, p.572-573) and predict that “future social movements, especially...involving health and environmental issues, will arise in similar boundary-crossing fashions” (McCormick, Brown, and Zavestoski, 2003, p.572). In general, their concept is a new conceptual framework to social movements theory that illustrates how social movements, especially dealing with health, can change scientific processes and agendas, as well as policy outcomes (McCormick, Brown, and Zavestoski, 2003, p.546).

Clearly their approach was not just meant for the analysis of the environmental breast cancer movement, but was proposed in order to provide an analytical basis for other such similar cases. As we will come to see in Chapter 3, the concept of a boundary movement best describes reforms and reformers actions within the European Commission Framework Programmes, but also helps exemplify insights gained from Epstein and Frickel on what can constitute as a social movement and that science and social movements should not always be seen as two distinct phenomenon. The strength of this approach is not only that it is based on a strong empirical case study done on the environmental breast cancer movement, but also that this analytical concept puts insights such as those of Epstein and Frickel into a clear analytical framework—one that we will use in our study. Although McCormick, Brown, and Zavestoski, (2003) go on in their theoretical description of boundary movements to highlight five main characteristics that constitute a boundary movement, for the sake of not being repetitious—we will delineate, adapt, and apply these more distinct characteristics in Chapter 3 when we analyze what is taken as an exemplary constituent organization of the boundary movement as a whole—namely the

GenderBasic project. We will now turn our attention to the concept of framing which will also be used our analytical Chapter 4.

Through the Concept of Framing

The concept of framing, or more specifically collective action frames and framing processes, have increasingly been used in relation to social movements and has come to be seen as a “central dynamic in understanding the character and course of social movements” (Benford & Snow, 2000, p.611). In their review article, Benford & Snow, who themselves have also written extensively on the subject elsewhere (Benford 1993a; Benford 1993b; Benford 1997; Snow 1988; Snow 2000), claim that “framing processes have come to be regarded, alongside resource mobilization and political opportunity processes, as a central dynamic in understanding the character and course of social movements” (Benford & Snow, 2000, p.612). What framing processes address is what literature until the 1980’s mostly ignored, what Benford & Snow (2000) distinguish as meaning work—seeing the actors as active agents who are “engaged in the production and maintenance of meaning” (p.613).

The concept of frames is derived primarily from the work of Goffman (1974) in which he analyzed framing as a way of organizing our everyday experiences. So for example we need the frame of play fighting in order to know not to punch someone really hard as one would do in a real fight. In this sense frame analysis is the study of the organization of experience. For Goffman (1974), frames were a “schemata of interpretation” that allow individuals “to locate, perceive, identify, and label” events within their world and the world at large (p.21). Since the work of Goffman (1974), however, the concept of framing “has been augmented by a rising interest across the social sciences in the narrative, discursive, and textual dimensions of human behavior, which in turn has opened up a rich seam for the interpretation of political action” (Jasanoff, 2005, p.23). As well as this, the concept of framing has been taken up in an increasing number of academic disciplines ranging from social movement theory, to science and technology studies to cognitive psychology as each of these disciplines acknowledge that “representations matter as much as whatever we may choose to call reality in shaping social behavior” (Jasanoff, 2005, p.25).

Authors such as Benford & Snow (2000) have redefined collective action frames as “action-orientated sets of beliefs and meanings that inspire and legitimate the activities and campaigns of a social movement organization” (p.614). Collective

action frames are constructed “in part as movement adherents negotiate a shared understanding of some problematic condition or situation they define as in need of change, make attributions regarding who or what is to blame, articulate an alternative set of arrangements, and urge other to act in concert to affect change” (Benford & Snow, 2000, p.615). Benford & Snow (2000) define these core action frames as diagnostic framing, prognostic framing and motivational framing. These three core action frames help us understand how activists are able to mobilize others to join their movement, how they frame a problem and its solution, and how their frames are able to resonate and diffuse. Diagnostic framing refers to the problem identification and attributions—so in other words, how does the movement’s actors diagnose the problem that needs a remedy? As for prognostic framing this refers to the “articulation of a proposed solution to the problem, or at least a plan of attack, and the strategies for carrying out the plan” (Benford & Snow, 2000, p.616). And lastly motivational frames “provide a ‘call to arms’ or rationale for engaging in ameliorative collective action, including the construction of appropriate vocabularies of motive” (Benford & Snow, 2000, p.617). How these are developed, generated and elaborated come down to discursive processes, strategic processes and contested processes.

Clearly this concept is relevant for our analysis, not only because it is a crucial concept for analyzing social movements, but also because, as Steven Epstein and Shiela Jasanoff exemplify, framing is extremely valuable for understanding how and why reformers actions are able to mobilize and motivate individuals into action and with that also disseminate their ideas. Now that we have outlined the concept of framing which we will use in our analytical Chapter 4, let us now turn our attention to our methodology in order to highlight how empirical research for the case study presented and analyzed in Chapters 2, 3 and 4 was carried out.

Methodology

The findings and analysis presented in the following two chapters are the culmination of on an extensive literature search, analysis of policy documents, journal articles, government reports, conference proceedings and project websites, but also the outcome of several semi-structured interviews. Interviews were held with Ineke Klinge (co-author of the Gender Impact Assessment, project leader of GenderBasic and co-project leader of Gendered Innovations), Mineke Bosch (co-author of the ETAN report, co-author of the Gender Impact Assessment, and member of the

GenderBasic project), Madelief Bertens (post graduate research assistant for the GenderBasic project), and finally Margit van der Steen (Coordinator of the Women's International Studies Europe lobby). One to two hour interviews were held over the phone with Mineke Bosch (June 23rd, 2011), Madelief Bertens (June 6th, 2011) and Margit van der Steen (July 6th, 2011). Extensive notes were taken on all three interviews, and with the permission of the interviewees, two of the interviews were taped. As for Ineke Klinge, we met in person on three occasions (May 5th, 2011; May 30th, 2011; June 6th, 2011/) in which I was able to conduct 1-2 hour interviews with extensive notes and tape recorded with Klinge's permission. All interviewees have been asked for and have granted permission to be cited throughout this paper.

These interviews were invaluable resources for gaining insight into the key historical events in European biomedical gender reforms, but also in providing access to and contextualizing seminal texts, government reports, and policy documents. Interviewees helped suggest reading various texts that in the end have been crucial to this analysis. As well as this, speaking to these individuals led to the development of new leads and new lines of questioning—which in the case of Ineke Klinge allowed for two one-hour follow up interviews. Without the help of these individuals it would have been very hard to conduct the research presented here.

The greatest challenge faced when collecting data was the complexity of the European Commission. This complexity can be attributed to two main things: their 'controlled vocabulary' (Parto, 2010, p.3), and their sheer volume of published articles. Although all documents can theoretically be accessed on the European Commission's website, finding relevant documents through key terms such as 'sex', 'gender', or 'framework programmes' proved impossible. This means that most documents provided were recommended or given to me directly by the individuals that I interviewed. Although this was extremely helpful, I am also aware that this means that much of my literature search was limited through what these individuals saw as relevant. I have tried my best to gain a multifaceted picture of what has occurred but this has not always been possible—I was not able to speak to everyone involved in these reforms, nor was I able to read or access all documents. The second difficulty, although this was to some extent overcome again through the help of interviewees, was the European Commission's controlled vocabulary. Projects funded or coordinated by the European Commission are labeled and presented in policy reports according to various 'work packages', 'work programmes', 'action

programmes', communications' and 'framework programmes'—but it was not clear, as an outsider, what most of these terms denoted. In general however, with these constraints in mind, and with the allocated time for this project, the findings here should be rather complete and should shed light on the chosen empirical study.

Chapter 2: Gender in European Biomedical and Health-Related Research

Now that we have clarified how others have theorized the increased focus on sex and gender in biomedical and health-related research, but also how we here will theorize these reforms in Europe in terms of a boundary movement, we will now turn to the reforms and reformers actions in the European Commission Framework Programmes. In order to do this, we will first start with an overview of the European Union and the role of the European Commission—in order to get a better understanding of the institution that is the main focus of our study but also the institution that was the main focus of reformers actions. We will then turn to a brief explanation of what the European Commission Framework Programmes are. And finally we will turn to three main projects led by the group of reformers from Maastricht University—namely the Gender Impact Assessments, the GenderBasic Project and finally the Gendered Innovations Project in order to highlight just what changes this group sought and achieved.

The European Union and the Role of the European Commission

The European Union is rather unique in that it is not a federation like the United States, nor is it an organization for co-operation between governments like the United Nations (http://europa.eu/about-eu/institutions-bodies/index_en.htm). What the European Union consists of today, is 27 member states⁶ who each remain independently sovereign but pool their sovereignty by delegating some of their decision-making power to the shared institutions that they have created which include the European Parliament, The Council of the European Union, and the European Commission (http://europa.eu/about-eu/institutions-bodies/index_en.htm). The European Parliament represents the EU citizens and is directly elected by them, the Council of the European Union represents the individual member states, and finally the European Commission seeks to uphold the interests of the Union as a whole (http://europa.eu/about-eu/institutions-bodies/index_en.htm). The mission of the European Commission as stated in its Governance Statement (2007) is “to promote the general interest of the European Union... by participating in the decision-making

⁶ Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxemburg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden and the United Kingdom (http://europa.eu/about-eu/countries/index_en.htm).

process, in particular by presenting proposals for European law, by overseeing the correct implementation of the Treaties and European law, and by carrying out common policies and managing funds” (p.2). It is the European Commission who has the ‘right of initiative’ in that it can propose new laws “to protect the interests of the EU and its citizens” (http://europa.eu/about-eu/institutions-bodies/european-commission/index_en.htm). It is then the European Parliament and Council which adopts them, but the European Commission who proposes new laws, implements them, and sees that they are properly taken on board (http://europa.eu/about-eu/institutions-bodies/index_en.htm).

The European Commission is based in Brussels and Luxemburg but has offices in every EU country and delegations in capital cities around the world. The Commission's leadership is comprised of 27 Commissioners, one from each of the member state countries. The Commissioners, who are allocated a 5-year term, make up the Commission's political leadership (http://europa.eu/about-eu/institutions-bodies/european-commission/index_en.htm). The president, who as of 2010 is José Manuel Barroso, is responsible for assigning each of the Commissioners responsibility for a specific policy area. The appointment of all Commissioner's including the President, is subject to approval by the Parliament. As for the day-to-day functions of the Commission, this is taken care of by the Commission staff who include administrators, lawyers, translators, interpreters, and secretarial staff among others, who are organized into departments known as Directorates-General (DG's) (http://europa.eu/about-eu/institutions-bodies/european-commission/index_en.htm).

The way that the Commission upholds EU policies and interests can be seen along four main levels: proposing new laws to the European Parliament and Council, managing the EU budget and allocated funding, enforcing EU law together with the court of justice, and finally representing the EU internationally by for example negotiating agreements between the EU and other countries (http://europa.eu/about-eu/institutions-bodies/european-commission/index_en.htm).

The Framework Programmes

Over the past decades the European Commission has implemented a series of five-year planning programmes that set the agenda for major research developments in a wide range of scientific and scholarly disciplines (Hoogland, 1999, p.5). These five-year planning programmes are what the European Commission has come to call its

Framework Programmes. The set up of so-called Framework Programmes “is the EU's main instrument for funding research and development activities covering almost all scientific disciplines” (http://cordis.europa.eu/guidance/helpdesk/faq_en.html). These Framework Programmes have to serve two main functions: strengthen the scientific and technological bases of industry and, secondly, encourage its international competitiveness while promoting research activities in support of other EU policies (European Commission, 2002, p.1). In this way, not only do the Framework Programmes set the agenda for European funded research, but they are also seen by the European Commission to be “vital for keeping Europe globally competitive” (http://europa.eu/pol/financ/index_en.htm).

To this date there have been seven Framework Programmes set up by the European Commission. For the purpose of our study, we will be focusing on the fifth, sixth, and seventh as this is where reformers which we will be analyzing prompted, developed, and fought for an explicit focus on sex and gender issues in biomedical and health-related research. But before we delve into the projects that reformers led in each of these Framework Programmes—we will first start with a general overview of each Framework Programme.

The Fifth Framework Programme funded by the European Commission ran from 1988-2002 and was “designed to help solve problems and to respond to major socio-economic challenges facing the European Union” (Laurila & Young, 200, p.7). On a budget of 14 960 million Euros the Fifth Framework Programme worked around the set up of 23 ‘key actions’ which were meant to focus Europe’s research efforts on 23 major social and economic problems over the next five years (<http://ec.europa.eu/research/rtdinf21/en/key/why.html>). These priorities included improvement of the economic competitiveness of the EU and its member states, expansion of the export market for EU products and services, globalization of the labour/job market, strengthening the EU’s position in International research, and maximization of the EU’s research potential.

What is also important is that the European Commission’s Proposal for the Fifth Framework Programme included a specific note on women and research, stating that “a special effort will be made to increase the participation of women in all activities of the Framework Programme and boost, through these activities, the place and role of women in science and research in Europe” (quoted in Laurila & Young,

2007, p.7). Although this is what the European Commission promised, these promises did in many ways not materialize and was therefore highly criticized by many including the Women's Association: 'Women's International Studies Europe' (WISE) who conducted a three year lobby for this reason. Their lobby was very successful (Margit van der Steen, personal communications, July 6th, 2011) and led to many changes in the remaining years of the Fifth Framework Programme. Most likely following their lobby actions, various goals and action plans were set up by the Commission to address gender issues. The Commission came to recognize that ““women's participation in research must be encouraged” (Laurila & Young, 2007, p.9) and that this must be achieved through research *by* women, research *for* women, and research *about* women (Laurila & Young, 2007, p.9). Following this they set up a Gender Watch System. This Gender Watch System “set a representation based target of 40% participation of women at all levels of the FP [framework programme] and calls for this to be monitored” (European Commission, 2009, p.5) Part of the Gender Watch System was the call for tender to conduct the Gender Impact Assessments of the Fifth Framework Programme in the year 2000—the assessments pivotal to reformers actions in our boundary movement.

As for the Sixth Framework Programme which ran from 2002-2006, it also aimed to strengthen the scientific and technological bases of Community industry and encourage competitiveness of the European Union (Laurila & Young, 2007, p.7) but was structured around three specific targets: integrating European research, structuring the European Research Area, and strengthening the foundations of the European Research Area. But more specifically, based on recommendations made from the Gender Impact Assessments in the Fifth Framework Programme, a number of specific steps were taken to improve gender issues in the Sixth Framework Programme including expanding the 40% target to all groups, panels and committees associated with the Framework Programme, introducing Gender Action Plans, and finally collecting better sex-disaggregated data in all areas of the framework programme (European Commission, 2009, p.5). Paying attention to issues of sex and gender in European research is said to have reached a high point in the Sixth Framework Programme (Ineke Klinge, personal communications, May 30th, 2011). This is also where the GenderBasic project that ran from October 2005 to January 2008 fits in—the project that is taken as an exemplary constituent organization of our boundary movement.

And finally the Seventh Framework Programme which was initiated in 2007 and is currently still running, has seen quite some scaling down in mandates for research to pay explicit attention to sex and gender issues in contrast to the enormous impetus in the Sixth Framework Program (Klinge, personal communications, May 30th, 2011). The main reasons for this, as explained by Klinge (personal communications, June 30th, 2011) was that there had been some resistance in the research community that applying for European funding had become too bureaucratic—too much paper work and too many extra things in their head next to their core business research. And so the Commission decided to scale down and simplify their funding procedures. However, this being said, in January this year, the European Commission has funded the Expert Group Innovation through Gender, or Gendered Innovations Project, which has re-phrased the issue of gender not as gender bias but rather what gender studies can offer in the forms of creativity and new research questions. Headed by Ineke Klinge and Londa Schiebinger, this project, as we will see below, will likely form the next core step for our boundary movement.

Reformers Actions—Key Moments in the Boundary Movement

The Gender Impact Assessment

In the year 2000 the European Commission asked for a Gender Impact Assessment (GIA) of their Fifth Framework Programme. Seven studies were carried out, each one focusing on one specific programme or sub-programme of the Fifth Framework Programme. It is here that Ineke Klinge and Mineke Bosch, two key reformers in our boundary movement, came to be involved in promoting sex and gender issues in biomedical and health-related research funded by the European Commission Framework Programmes. Ineke Klinge is an immunologist by training but also has a second specialization in Gender Studies. She works as an assistant professor in Gender Studies in Health Sciences at the Faculty of Faculty of Health, Medicine and Life Sciences at Maastricht University. As for Mineke Bosch, she is a historian by training but is specialized in the field of women, gender, and science. She also works at Maastricht University but rather at the center for Gender and Diversity. Through a call for tender, Ineke Klinge and Mineke Bosch were granted the GIA for the life sciences known as the ‘Quality of Life and Management of Living Resources’. A large part of

the programme that they were assigned to assess in their GIA comprised health related research.

Although the beginnings of social movements are notoriously difficult to pin down (Frickel, 2004, p.67), and this boundary movement is no different in that sense, this assessment provided a unique opportunity to frame the necessity of focusing on sex and gender in biomedicine and is therefore taken as the moment where our boundary movement begins. As Bosch and Klinge (2006) stated “carrying out such a GIA offered a unique opportunity for taking a significant step forward in translating feminist insights into the life sciences and health research” (Bosch & Klinge, 2005, p.379). Already in this statement here we see remnants of a boundary movement—their aim was not just to promote the use of sex and gender from feminist theory, but to *translate* it—to make it ‘scientific’. Through this Gender Impact Assessment, Klinge and Bosch were given a chance to criticize current forms of biomedical research and to transform them. They set out “based on and backed by a wealth of evidence from existing research” (Bosch & Klinge, 2005, p.379) to “transform... the ‘traditional’ life sciences and health related research methodology into a gender-sensitive one” (Bosch & Klinge, 2005, p.379) defined by them as “renewed attention to sex differences (without falling into essentialist traps), together with an awareness of possible gender effects” (Bosch & Klinge, 2005, p.379).

But they didn’t just do this in any way—they were particular in how they went about it. Not only was their GIA study carried out in close collaboration between the research team and the scientific staff of the Commission (Bosch & Klinge, 2005, p.386), forming a kind of social scientist/life scientist alliance, but they were also extremely careful in how they phrased and put forth their ideas. As Bosch & Klinge (2005) state: “we became convinced that careful building of a dialogue between the two parties involved, the gender experts and scientists (committed scientific officers and policy-makers), was vital for the acceptance and, by implication, for the future effect of our work— thus, as gender experts, we adopted an ‘educational style’ and invested in the development of a clear, acceptable vocabulary for both parties” (Bosch & Klinge, 2005, p.386). This is indicative not only of a social scientist/life scientist alliance, but one could also see this acceptable vocabulary as a boundary object—a key characteristic of a boundary movement.

Sex was distinguished as a biological quality and gender as a sociocultural process, “both of equal importance in relation to health-related research” (Bosch &

Klinge, 2005, p.386). This decision can be seen as one made in order for their movement to be successful, for these concepts to function as boundary objects in that they would then overlap different social worlds and be malleable enough to be used by both parties—namely the social scientists and life scientists Bosch & Klinge state that “although we are fully aware of ongoing debates within feminist theory questioning the distinction between sex and gender, for disciplines like biomedicine and health sciences this conceptual difference is necessary” (Bosch & Klinge, 2005, p.386).

These actions which can definitely be seen as a boundary movement were successful in the sense that following their Gender Impact Assessment Report new guidelines were introduced for applicants submitting proposals in the Sixth Framework Programme. Individuals applying for funding under the Sixth Framework Programme had to “answer a set of specific questions as regards to integration of the *gender dimension*” (Klinge, 2008b, p.6) and “Integrated Projects and Networks of Excellence also had to write a Gender Action Plan” (Klinge, 2008b, p.6).

The GenderBasic Project

Following the success of the Gender Impact Assessment that Ineke Klinge and Mineke Bosch completed in 2001, they applied for funding for the ‘GenderBasic’ project. The main aim of the GenderBasic project was to “provide scientists involved in health-related research (with a focus on basic and clinical research) funded by the EU Framework Programmes with practical tools, relevant examples, and best practices regarding sex and gender differences in the content of their research” (Klinge, 2007, p.S61).

Now that applicants for funding under the Sixth Framework Programme had to explain how they would study issues of sex and gender it became evident that many researchers did not know how to do this. According to Klinge (2008b) researchers were not unwilling to take sex and gender into account, but were facing difficulties (p.6). This observation was based on problems put forth at the meeting of the Commission Network on Gender Aspects in Food Quality and Safety Research (GENDFOODSAFE) in which researchers put forth questions such as ‘why is integration of the gender dimension a good thing to do?’ and ‘what is the theoretical basis for including gender?’ (Klinge, 2008b, p.7). As well as this, researchers expressed concerns that they would encounter methodological, financial and practical

issues in focusing on gender (Klinge, 2008b, p.7). And so it seemed that although the Gender Impact Assessments had managed to create policy changes—a great success for this boundary movement, these policy mandates did not seem easily understood by those who were supposed to implement them. As Klinge (2007, S.60) put it: “it appeared that applying the top-down guidelines to biomedical and health-related research was not without difficulty and posed various challenges (practical, methodological, conceptual, ethnical, and financial) to basic, transnational, clinical and public health research” (Klinge, 2007, p.S60). And this is where GenderBasic came in: to translate these top-down requirements into practical tools for life scientists—the next step in this boundary movement.

The GenderBasic Project continued with the ‘educational style’ of the GIA but did not just produce a final report for the European Commission, but also produced a supplement issue in the academic journal ‘Gender Medicine’⁷ in which eighteen social scientists and life scientists, referred to in the report as “high-profile international experts” (p.S59), were recruited to write up state of the art reviews on integrating sex and gender in six conditions: anxiety disorders (Marrie Bekker and Janeke van Mens-Verhulst), asthma (Dirkje Postma), the metabolic syndrome (Vera Regitz-Zagrosek et.al), nutrigenomics (Jose Ordovas), osteoporosis (Piet Geusens and GeertJan Dinant), and work-related health (Anne Hammarstrom). This can in some ways be seen not only as a gender expert/science alliance but also as a call to arms. Besides this publication, there was also an expert meeting held in Maastricht on January 26-27th, 2007 in these papers were discussed and peer reviewed. And finally a website was set up with general information on the project, links to the expert meeting proceedings, and other relevant documents (<http://www.genderbasic.nl/>), and was based on the following actions.

Besides these recruited ‘experts’, the project was coordinated by Ineke Klinge, who herself is a biologist by training, specialized in immunology, but also has a second specialization in Gender Studies in Science. Also working on the project were professor Mineke Bosch, a historian by training specialized in women, gender and science, professor Rein Vos, who was Chair of the Department of Health, Ethics & Society of the Faculty of Health, Medicine and Life Sciences at Maastricht

⁷ Klinge et.al (2007). GenderBasic: Promoting Integration of Sex and Gender Aspects in Biomedical and Health-Related Research. *Gender Medicine*. 4(Supplement B), S59-S178.

University, and finally Madelief Bertens, who was hired as a post-graduate assistant. University of Maastricht at the and Madelief Bertens.

What is interesting, especially when we move to the next key project: Gendered Innovations, is that Londa Schiebinger's aim of extracting analytical tools from gender studies in forms of showing what gender studies can offer in the form of new perspectives, new research projects and priorities in 'Has Feminism Changed Science' (1999) chimes very closely with the GenderBasic project who's "main objective was to provide scientists involved in health-related research (with a focus on basic and clinical research) funded by the EU Framework Programmes with practical tools, relevant examples, and best practices regarding sex and gender differences in the content of their research" (Klinge, 2008a, p.184). This project can be seen as a kind of translation process of EU guidelines to research practitioners, but also a translation of what it means to study sex and gender, two concepts deriving from the social sciences, in life science research—and specifically biomedical and health related research. Their actions are clearly a boundary movement but also lie on the advocacy-oriented side of Altman, Brown, Mayer, McCormick, Morello-Frosch & Zavestoski (2004) continuum being a group that works "within the existing system and biomedical model, use tactics other than direct, disruptive action (*e.g.* education), and tend not to push for lay knowledge to be inserted into expert knowledge systems" (p.53).

Gendered Innovations Project

Although there was some scaling down in the Seventh Framework Programme, in January 2011 the European Commission funded the Expert Group Innovation through Gender for the duration of two years. This project, also known as 'Genderd Innovations' is based on an expert contract which has been given to Londa Schiebinger, John Hinds and Ineke Klinge. The Gendered Innovations Project employs sex and gender analysis to create new knowledge and stimulate novel design. The project develops methods of sex and gender analysis for basic and applied research in science, medicine and engineering and provides concrete examples, or case studies, to show how sex and gender analysis lead to innovation.

Moving from first pointing out that sex and gender issues were not being addressed in biomedical research through the GIA, to then providing a document of best practices in the GenderBasic project, the Genderd Innovations can be seen as the

latest development in this boundary movement. Their main aim is to launch a ‘smart’ website in which case studies are available, definitions of concepts such as sex and gender, a timeline of gender reforms in biomedical research in the United States and Europe amongst other things. The website is to be launched in November 2011 and will be open for the general public at that time. The website URL is: <http://genderedinnovations.stanford.edu/index.html>.

Much like Londa Schiebinger’s books discussed in chapter 1, the gendered innovations project aims show that including sex and gender analysis in research and design can spark creativity by offering new perspectives, posing new questions, and opening new fields for development. According to the internal postings about this project on CAPRI “Gender theory has had enormous impact in the humanities and social sciences over the past thirty years and is increasingly being integrated into medicine and the life sciences. What is needed now is to translate these often complex insights into methods readily useful to scientists and engineers. There is a need to develop internationally agreed upon methods of sex and gender analysis”. This is the problem the Gendered Innovations project seeks to solve. The goals of the EU/US Gendered Innovations in Science, Medicine and Engineering project is to provide scientists (physical and life scientists), biomedical and public health researchers, engineers, and technology designers with practical methods for sex and gender analysis. To achieve these goals, the GI project will produce a website which will highlight methods, terminology and case studies.

These gender reforms were prompted and advanced by a select few following the lobbying actions of the women’s studies association: ‘Women’s International Studies Europe’ (WISE). Had it not been for WISE, the window of opportunity to emphasize sex and gender in European biomedical and health-related research may never have arisen, but it was this select group of social and natural scientists from Maastricht University, and not WISE, who eventually changed and transformed policies and practices within the European Commission. It was this group that was able to blur and then redraw the lines between science and non-science, between medical practices and politics, between experts and non-experts; and in doing so, succeeded in making the issues of sex and gender not only medically relevant but also an integral part of European innovation. It is for this reason that their actions will be analyzed here as a boundary movement, a concept that I take from McCormick, Brown & Zavestoski (2003) and explain in more detail in chapter 1.

Chapter 3: European Gender Reforms as a Boundary Movement: The case of 'GenderBasic'

Although the entire process of incorporating sex and gender into biomedical research funded by the European Commission Framework Programmes as described above comprises a boundary movement, the 'GenderBasic' project can be seen as an exemplary constituent organization of the boundary movement as a whole. In order to highlight more clearly how these reformers actions constitute a boundary movement, the 'GenderBasic' project will be analyzed in depth here in terms of the five main characteristics that according to McCormick, Brown, and Zavestoski (2003) comprise a boundary movement.

GenderBasic as a Boundary Movement

Generally, boundary movements are “social movements and their constituent organizations that move between social worlds and realms of knowledge” and in doing so, blur traditional distinctions such as those between laypeople and professionals and between movement and non-movement actors (McCormick, Brown, and Zavestoski, 2003, p.547). But more specifically, boundary movements are constituted through five main characteristics. The first of such characteristics as defined by McCormick, Brown, and Zavestoski (2003) is that boundary movements “attempt to reconstruct the lines that demarcate science from non-science” (McCormick, Brown, and Zavestoski, p.547). Reformers in a boundary movement “push science in new directions and participate in scientific processes as a means of bringing previously unaddressed issues and concerns to the attention of the clinical and bench scientists” (McCormick, Brown & Zavestoski, 2003, p.547). This first feature will not be adopted for our purposes, as it is characteristic of reformers from Maastricht University and the changes they ensued within the European Commission.

This first characteristic clearly captures how reformers in GenderBasic were able to promote concepts of sex and gender as scientific concepts and more specifically as biomedical concepts crucial for scientific excellence. GenderBasic can almost be seen as a kind of appropriation process (Rogers, 2006) and translation project (Latour, 1987) as reformers took social science concepts of sex and gender and appropriated and translated them into biomedical concepts. Through their work—the experts meetings and the 10 review articles that were conducted, the GenderBasic

project inscribed the notion that gender sensitivity is relevant to the medical sciences, and placed the concept of gender on the science side of the boundary—hence blurring the boundary between gender studies and the natural sciences. As for pushing science “in new directions and participat[ing] in scientific processes as a means of bringing previously unaddressed issues and concerns to the attention of the clinical and bench scientists” (McCormick, Brown & Zavestoski, 2003, p.547)—this was also clearly the case in GenderBasic as they addressed six medical conditions—namely anxiety disorders, asthma, the metabolic syndrome, nutrigenomics, osteoporosis and work-related health, and pushed these established medical arena’s into gender sensitive directions. Like Epstein concept of categorical alignment, “proponents of inclusion were able to *act as if* the social movement identity labels, the biomedical terms, and the state-sanctioned categories were all one and the same set of classifications” (Epstein, 2006, p.337).

As for the second characteristic that McCormick, Brown, and Zavestoski (2003) outline, boundary movements “blur the boundary between expert and laypeople” (p.547). They do this by becoming either informal or legitimate experts. Some activists may become informal experts on the topic at hand by using the Internet or other resources to gain medical and scientific knowledge (McCormick, Brown, and Zavestoski, 2003, p.547). They can then use this knowledge to legitimate their claims when in conflict with medical care providers or other professionals (McCormick, Brown, and Zavestoski, 2003, p.547). Other activists may even become legitimate experts “by working with scientists and medical experts to gain a better level of understanding of the science underlying their disease” (p.547). According to McCormick, Brown, and Zavestoski (2003) this is where “boundary organizations gain power and authority by obscuring the boundary between experts and layperson” (McCormick, Brown & Zavestoski, 2003, p.547).

This second feature also bears very close to the power, authority, and success of reformers in the European Commission, however with one key difference: activists in this case were not laypeople but rather social scientists—more specifically, they were gender studies scholars. Therefore, for our purposes here, we will replace McCormick, Brown, and Zavestoski’s distinction of laypeople and professionals with that of gender experts and natural scientists. Although one may think that gender experts are already professionals, and that therefore our distinction does not bear the same oppositional power as that of McCormick, Brown, and Zavestoski, natural

scientists have long fought to distinguish their discipline from that of the social sciences—demarcating their practice as ‘hard science’ and the social sciences, at best, as ‘soft science’. So whereas these social scientists may be considered professionals in their own academic discipline, they, just like the laypeople described in McCormick, Brown, and Zavestoski’s text, had to become formal and informal experts in order to blur the boundaries between gender studies (social sciences) and medicine (life sciences).

This blurring of the distinction between gender experts and natural scientists is definitely where the GenderBasic project gained much of its power and authority. Ineke Klinge, the project leader of GenderBasic, but also co-author of the GIA and currently co-project leader of Gendered Innovations, plays a key role in this boundary movement. She is herself a natural scientist specialized in immunology but also has a second specialization in gender studies. Through her unique position as a social scientist and natural scientist, Ineke Klinge, was able to ‘translate’ social science concepts of sex and gender into natural science concepts crucial for conducting biomedical and health-related research. As she herself said “I was able to speak their [natural scientists] language and this helped a lot” (personal communications, June 15th, 2011). Not only could she communicate between both ‘cultures’, but she knew what laboratory life looked like, the methodologies that were involved in the natural sciences, but also how to conduct valid scientific experiments. In this way she was on level ground between the natural scientists and life scientists—respected by both sides—blurring the lines between science and non-science, but also between natural scientists and social scientists, specifically gender experts. Her motives were as a social scientist but her life science background gave her the ability to constantly switch sides and speak their language—she became an expert in both. This unique position and perspective allowed the members of GenderBasic, and particularly project coordinator Ineke Klinge, to maneuver between realms of knowledge—particularly the realms of natural sciences, social sciences, and policy making—characterizing a gender expert/natural scientist alliance.

The third distinguishing feature of boundary movements as explained by McCormick, Brown, and Zavestoski (2003) is that “boundary movements transcend the traditional conceptions (i.e. boundaries) of what is or is not a social movement” (p.547). They state that activists transcend traditional conceptions of what is and what is not a social movement by “by moving fluidly between lay and experts identities,

and across various organizational forms” (p.547). Reformers of a boundary movement are able to “move in and out of organizations and institutions in ways that traditional social-movement activists do not.” (p.547). In GenderBasic this was also clearly the case and also a large part of its success. Not only were members of the GenderBasic project employed at different and multiple institutions, but these institutions were sometimes even located around the globe. The project coordinator Ineke Klinge was herself an employed professor at the Faculty of Health, Medicine and Life Sciences at Maastricht University, but also worked in close coordination with the European Commission as they employed her for the GIA in 2000 and were funding her GenderBasic project, but on top of that, she also in 2004 joined the Maastricht Center for Gender and Diversity. Ineke Klinge when necessary could switch between the organization of Maastricht University, the European Commission, but also switched roles between gender expert, immunologist, activist and non-activist. In this way, Klinge was able to move fluidly between her expert identity as a life scientist at the Faculty of Health, Medicine, and Life Sciences, and her lay identity as a gender expert at the Center for Gender and Diversity, or her other powerful position as being backed by the European Commission.

As for other members of the GenderBasic project, particularly those writing the ten review articles for ‘Gender Medicine’, they were internationally renowned natural scientists and social scientists—representing not only diverse disciplines but also diverse international institutions ranging from the Imperial College in London (medical doctor Anita Holdcroft), to the Center for Cardiovascular Research in Berlin (Jorg Isensee), to the Department of Vertebrate Genomics in Berlin (PhD Patricia Ruiz Noppinger), to the Center for Public Health (Kitty Lawrence)—just to name a few examples. So not only was Klinge able to fluidly move between various lay and expert identities and various organizational forms, but so were the other members who came from not only various countries but also various academic disciplines—blurring conceptions of what is and what is not a social movement. This blurring was of course also helped by the fact that the European Commission funded the GenderBasic project. Since the GenderBasic project was funded by the European Commission it meant that to a certain extent that they not only supported but also sanctioned the project’s aim to “provide scientists involved in health-related research (with a focus on basic and clinical research) funded by the EU Framework Programmes with practical tools, relevant examples, and best practices regarding sex

and gender differences in the content of their research” (Klinge, 2007, p.S61). This also meant that Klinge and other project members could act as though, if necessary, that they were working on behalf of the European Commission’s policy implementations.

The fourth characteristic of a boundary movement is that they make use of ‘boundary objects’. This notion of boundary objects was originally proposed by Susan Star and James Griesemer (1989), but is also used by McCormick, Brown & Zavestoski in order to characterize how boundary movements work. McCormick, Brown & Zavestoski (2003) define boundary objects as objects that “overlap different social worlds and are malleable enough to be used by different parties” (p.547). In their case study of the environmental breast cancer movement, boundary objects included mammography machines, genetic testing for breast cancer, patents on the BRCA-1 sequence, pharmaceuticals, Breast Cancer Awareness Month and Avons ‘Breast Cancer Walk’ (McCormick, Brown & Zavestoski, 2004, p.2). Whereas Star and Griesemer’s notion of boundary objects mostly pertains to tangible objects or technological artifacts, McCormick, Brown & Zavestoski, as seen above, also include activities as boundary objects. Their definition of boundary objects is therefore more flexible than that of Star and Griesemer (1989)—as is also indicated by the fact that they place ‘objects’ in quotation marks. Therefore we find it suitable that boundary objects in our analysis can also comprise concepts. The concept of sex, although more like a boundary concept, can be seen as something that had been understood by both scientists and gender experts—therefore “maintaining enough similarity in each to create coherence... while at the same time being used distinctly in each one” (McCormick, Brown & Zavestoski, 2004, p.2).

As Klinge explained to me in our interview (June 15th, 2011), it was by starting with the concept of sex that she was able to start talks about gender with the natural scientists. According to Klinge (personal communications, June 15th, 2011), the concept of sex could be used as a leverage point to move on to the importance of gender. She would start by describing sex differences—that biological processes run differently in a female or in a male body, and they accepted that. This acceptance according to Klinge (personal communications, June 15th, 2011) merely stems from differences in reproductive biology- that’s clear, that’s been taught in medical school. But that these differences also hold for a number of common diseases, and so a heart is a heart so to say, and so is a female heart different from a male heart- well yes, and

that was new for them. But this kind of un-awakened acceptance of biological differences is one, and that was used as a leverage to introduce differences as a result of gender. And the best example to convince them was to give an example of how gender and gender roles can be harmful for ones own health- especially for men. And even our first meeting with some rather conservative scientists, this example of how gender role behavior is deleterious for a man's own health, individual health, was really convincing to the male colleagues there. Because they all recognized it, they all were nodding, so 'okay yes it's true, I don't go to the doctor' and then they became, I think, advocates of it. Really preaching. They became converted men. And a converted man is a *very strong* ally. And they were converted by this reference to their individual health. And this role of male gender role behavior, very good work has been done in the years after that by the men's health movement.

The fifth and final characteristic is that boundary movements cross "two or more social movements, while blurring the boundaries of those separate movements" (McCormick, Brown & Zavestoski, 2003, p.547). In their text, McCormick, Brown & Zavestoski (2003) describe the environmental breast cancer movement as crossing over, blurring, and utilizing the AIDS movement, the women's health movement, and toxics activists (McCormick, Brown & Zavestoski, 2004, p.2). They then further this characteristic by describing "the fluidity with which these groups can move back and forth between organizational cultures, and between the roles of activists and experts" (McCormick, Brown & Zavestoski, 2004, p.2). So not only do reformers in a boundary movement cross over and blur the lines between one social movement and another, but they themselves, are able to "play varying roles over time, occasionally being part of the movement as either members or 'advocacy scientists', other times being somewhat detached scientists, and other times being uninvolved" (McCormick, Brown & Zavestoski, 2004, p.2). In our case of European biomedical reformers, they did not cross as many social movements, but they did draw on the broader women's movement which did not just adhere to biomedicine but also to equal opportunity and gender mainstreaming in all European research. What they definitely did do was move between organizational cultures and the roles of experts, activists and scientists. It is by and crossing these cultural and analytical spaces that boundary movements are able to negotiate and challenge the acceptable definitions of scientific practices and products (McCormick, Brown & Zavestoski, 2003, p.547).

The GenderBasic project was a crucial element in the boundary movement that was able to re-align certain aspects of gender studies, usually seen as non-scientific, on the science side of the boundary. They were able to move the boundaries and re-draw the lines between science and non-science because of the way that they spoke—they framed their convictions in the rhetorics of science—using their language to disguise the politics and they also framed it in terms of the European Commission get support and funding. Now that we have analyzed this gender move in European Commission funded research in terms of a boundary movement, we will now turn our focus to the framing techniques that were used in the boundary movement as a whole.

Chapter 4: The Process of Framing Sex and Gender in the European Commission Framework Programme Reforms

Part of the success of the Maastricht reformers boundary movement was also due to the frames that they incorporated. The purpose of this chapter is to analyze these frames in each of the mentioned projects in Chapter 2: the GIA assessment, the GenderBaic project and the Gendered Innovations project. As was seen in Chapter 1, frames are the stories that social movement actors tell in order to inspire and legitimate their activities and campaigns but also to mobilize support for such a movement (Benford & Snow, 2000, p.614). They negotiate a shared understanding of some problematic condition or situation they define as in need of change, make attributions regarding who or what is to blame, articulate an alternative set of arrangements, and urge others to act in concert to affect change” (Benford & Snow, 2000, p.615). Frames offer “rich resources for interpretive analysis” (Jasanoff, 2005, p.25) and will be used here to highlight how this group of Maastricht reformers were able to mobilize others to join their movement, frame a problem and its solution, and how these frames were then able to resonate and diffuse.

The Gender Impact Assessments

The Gender Impact Assessment that was conducted by Ineke Klinge and Mineke Bosch in 2000 was so successful in part due to the frame that they employed. Working with the window of opportunity that was provided by the lobbying actions of Wise, the Gender Mainstreaming Policy of European Commission and the final report of the Helsinki Group, Klinge and Bosch (2000) set out to frame current biomedical and health-related research funded under the European Commission Fifth Framework Programme as being under-representative of sex and gender aspects. Although their aims were clearly political as they Bosch and Klinge (2006) stated that “carrying out such a GIA offered a unique opportunity for taking a significant step forward in translating feminist insights into the life sciences and health research” (Bosch & Klinge, 2005, p.379), they knew that they had to frame their motives in a careful way.

Through this Gender Impact Assessment, Klinge and Bosch were given a chance to criticize current forms of biomedical research and to transform them. They set out “based on and backed by a wealth of evidence from existing research” (Bosch & Klinge, 2005, p.379) to “transform... the ‘traditional’ life sciences and health

related research methodology into a gender-sensitive one” (Bosch & Klinge, 2005, p.379) defined by them as “renewed attention to sex differences (without falling into essentialist traps), together with an awareness of possible gender effects” (Bosch & Klinge, 2005, p.379). But they didn’t just do this in any way—they were particular in how they went about it. Not only was their GIA study carried out in close collaboration between the research team and the scientific staff of the Commission (Bosch & Klinge, 2005, p.386), forming a kind of social scientist/life scientist alliance, but they were also extremely careful in how they phrased and put forth their ideas. As Bosch & Klinge (2005) state: “we became convinced that careful building of a dialogue between the two parties involved, the gender experts and scientists (committed scientific officers and policy-makers), was vital for the acceptance and, by implication, for the future effect of our work— thus, as gender experts, we adopted an ‘educational style’ and invested in the development of a clear, acceptable vocabulary for both parties” (Bosch & Klinge, 2005, p.386). This is indicative not only of a social scientist/life scientist alliance, but one could also see this acceptable vocabulary as a boundary object—a key characteristic of a boundary movement.

By framing their criticisms in an educational style and working in close collaboration with scientists, the GIA assessments were successful because they in some sense seemed less threatening. As well as this, the way that Klinge and Bosch (2000) backed up their literature, they did not so much say that the concepts of sex and gender were from the social sciences, but they much more profited from the work of the early feminist biologists who had already imported sex and gender- they gave all the quotes from Blijer, Fausto-Sterling, Londa Schiebinger—really knowledgeable biologists. And this was definitely successful in the sense that following their Gender Impact Assessment Report new guidelines were introduced for applicants submitting proposals in the Sixth Framework Programme. Individuals applying for funding under the Sixth Framework Programme had to “answer a set of specific questions as regards to integration of the *gender dimension*” (Klinge, 2008b, p.6) and “Integrated Projects and Networks of Excellence also had to write a Gender Action Plan” (Klinge, 2008b, p.6).

The GenderBasic Project

As for the GenderBasic project, reformers educational frame was replaced by a ‘scientific excellence’ frame. It was no longer as much a question of convincing

others that sex and gender were medically relevant concepts, but it was now more a question of convincing practitioners that these concepts were also practical and necessary in order to pursue scientific excellence. Now that applicants for funding under the Sixth Framework Programme had to explain how they would study issues of sex and gender (see appendix 1), it became evident that many researchers did not know how to do this. According to Klinge (2008b) researchers were not unwilling to take sex and gender into account, but were facing difficulties (p.6). And so this is where GenderBasic came in: to translate these top-down requirements into practical tools for life scientists—in terms of methodologically sound concepts that would lead to scientific excellence. This project can be seen as a kind of translation of what it means to study sex and gender, two concepts deriving from the social sciences, in life science research—and specifically biomedical and health related research. The GenderBasic project “focused on the interaction of sex and gender at all levels, from the sub-cellular (molecular/genetic) to the societal (population)” (Klinge, 2007, p.S62). Studies such as the ones conducted by Anita Holdcroft (2007) provided “evidence that sex and gender are determinants of many outcomes in life science research” (p.S64)—and so framing the issue of sex and gender as crucial for scientific excellence. And as for the study conducted as part of the GenderBasic project by Kitty Lawrence and Anita Rieder (2007), they criticized the fact that “women were found to be underrepresented in ethics committees, which lack clear guidance, particularly in the European Union, to ensure the inclusion of gender issues in public health research” (p.S96)—therefore diagnosing the problem, and then proposing a solution including “establishing guidelines for researchers on how to incorporate gender in health research, ensuring that the composition of ethics committees is more representative of society, and recommending that data collection systems or bodies ensure that data are desegregated by sex and include socioeconomic aspects” (p.S96).

The Gendered Innovations Project

Unfortunately the Sixth Framework Programme was, until now the high point of gender reforms in the European Commission. After the 6th Framework Programme, the explicit requirement to indicate how issues of sex and gender would be addressed in biomedical and health-related research funded by the European Commission Framework Programmes (see appendix 1) were scaled down. As Klinge states “there was this enormous impetus in the 6th framework program where it was at its

maximum and then it has been scaled down, so to say, in the 7th framework program... because of some resistance in the research community, that applying for European project had become too bureaucratic, too much work, too much paper work, too much extra things in their head next to their core business research” (personal communications, May 30th, 2011). So whereas reformers had the idea that “if we had identified the problem with the research community then you should invest more in making it more clear to the research community instead of scaling it down” (Klinge, personal communications, May 30th, 2011), this was not the case.

However not all hope is lost—with the framing of issues of sex and gender in terms of innovations, as has been done in the current Gendered Innovations project, reformers have slightly shifted but aligned their social cause with the European Commission’s goal for the next ten years—namely ‘innovation’. In The Gendered Innovations Project, reformers employ sex and gender analysis to create new knowledge and stimulate novel design. The project develops methods of sex and gender analysis for basic and applied research in science, medicine and engineering and provides concrete examples, or case studies, to show how sex and gender analysis lead to innovation.

So moving from first pointing out that sex and gender issues were not being addressed in biomedical research through the GIA’s ‘educatiol frame’, to then providing best practices and framing sex and gender as necessary concepts for scientific excellence in the GenderBasic project, the Genderd Innovations can be seen as the latest frame in this boundary movement. Their main aim is to launch a ‘smart’ website in which case studies will be made available, definitions of concepts such as sex and gender will be given, and in general in which examples of gendered innovations are a click away for scientists all around the world. Much like Londa Schiebinger’s books discussed in Chapter 1, the gendered innovations project aims at showing that including sex and gender analysis in research and design can spark creativity by offering new perspectives, posing new questions, and opening new fields for development. The goals of the European Union and United States co-funded Gendered Innovations in Science, Medicine and Engineering project is to provide scientists (physical and life scientists), biomedical and public health researchers, engineers, and technology designers with practical methods for sex and gender analysis. To achieve these goals, the Gendered Innovations project will highlight

methods, terminology and case studies that frame gender incorporation in terms of scientific innovation.

Conclusion

Biomedical and health-related research in both the United States and the European Union have been transformed over the past decade to encompass and explicitly focus on a distinct set of groups who are said to be biologically different. Whereas in Europe the focus has come to be on sex, gender and age, NIH and FDA policies in the United States have also mandated the inclusion of racial and ethnic minorities. Authors such as Londa Schiebinger and Steven Epstein have analyzed biomedical reforms in the United States in terms of a ‘triumph for feminism’ and an ‘inclusion-and-difference paradigm’ respectively. Drawing on Steven Epstein’s notion of a tacit coalition and Scott Frickel’s notion of scientist-activists, we have shown here that the gender reforms in biomedical research funded under the European Commission Framework Programmes can be seen as a social movement and more specifically, as a boundary movement. Through operating within the European Commission, adopting their language, and forming alliances with scientists, a distinct group of intellectual activists from Maastricht University were able to transform European biomedical research funded by the European Commission Framework Programmes into a gender sensitive one. They were able to blur and redraw the lines between science and non-science—situating gender studies on the science side of the boundary. This did not happen easily, it took distinct strategies and ways of framing—they had to adopt and ‘speak the language’ of life scientists and the European Commission.

What we hope to have highlighted here is not only that biomedical reforms mandating the inclusion of underrepresented groups has occurred in Europe, in contrast to what Epstein claims, but also how these reforms took place and the strategies that were employed. By analyzing the gender reforms in the European Commission Framework Programmes in terms of a boundary movement we have shown how activists managed to blur and redraw the boundaries between science and non-science, natural scientists and social scientists, and movement and non-movement actors. This empirical case shows that social movements should not be assumed to be led by people lacking institutional power or by young professionals protesting in the streets—this was a group of intellectual activists, who through blurring their roles as social scientists, natural scientists, activists, and non-activists and through adopting a distinct frame and style of language were able to transform European biomedical research funded under the European Commission Framework Programmes to one that

emphasized sex and gender as relevant, if not essential categories for biomedical research practices and scientific excellence.

As for the future, it will be interesting to see what it holds. Although these reformers were extremely successful, especially in the Sixth Framework Programme, we must remember that their successes are not permanent. This boundary movement was able to blur and redraw the lines between science and non-science by situating and translating principles from gender studies to medically relevant, and therefore scientifically sound concepts. However, as Gieryn (1999) points out, boundaries are never permanent and are constantly re-negotiated. Although in the Sixth Framework Programme and during GenderBasic, this group of reformers were able to place their claims on the science side of the boundary, it seems that they were once again pushed back to the other side in the Seventh Framework Programme as the policy mandating explicit attention to sex and gender in biomedical research was turned to more of a recommendation. Life scientists had started to complain that sex and gender requirements were “too much burden from Brussels” (Klinge, personal communications, May 30th, 2011) and it did not seem that the infrastructure or necessary trained gender experts were in place to evaluate attention to sex and gender issues. However armed with a new frame—‘Gendered Innovations’, reformer Ineke Klinge hopes to revamp things again by working with American historian of science and gender studies scholar Londa Schiebinger. Although we have focused on only one group operating within the European Commission our findings should be applicable to other health social movements as well. We have shown like Brown, Morello-Frosch & Zavestoski that science, activism, and policy are not separate issues (<http://www.ucpress.edu/book.php?isbn=9780520270213>).

What would be interesting for future research would be to question whether the increased focus on pediatric populations in European biomedical research could be analyzed in a similar fashion—namely through the concept of a boundary movement. As well as this, it would be interesting to investigate why race and ethnicity have not been emphasized to the same extent in European biomedical research as it has been in the United States. If we look back at Epstein’s analysis of reforms in the United States—he argues that although American biomedical reforms eventually also came to mandate the inclusion and explicit attention to ethnic minorities and pediatric populations, it was, the women’s health movements that set the ball rolling (p.331). Once women were able to put forward their critiques, “they opened up a space of

possibility that others could occupy—racial and ethnic minorities, for example, followed with arguments that they, too, were undeserved by modern medicine and underrepresented in study populations” (Epstein, 2006, p.331).

Although individuals that I have spoken to, including clinical researcher Jean-Claude Ansquer (personal communications, May 5th, 2011) and race and ethnicity expert Alana Proctor (personal communications, May 9th, 2011) say that it is unlikely that race and ethnicity will gain the same prominence in European biomedical research as it has in the United States, it would be interesting to see whether this is really the case. When I asked individuals in my preliminary research stage whether issues of race and ethnicity would likely be raised in European biomedical research, a response I often received was that race and ethnicity are simply not an issue in Europe. I find this hard to believe—and for this reason this would provide an interesting case study for future research. As well as this I could suspect, if we follow Epstein’s logic, that the space opened up by the sex and gender reforms in the European Commission Framework Programmes would lead other categories, such as race and ethnicity, to gain similar importance.

Appendix 1: Mandatory Inclusion of Sex and Gender in Biomedical Research Funded
Under European Commission's 6th Framework Programme

**GENDER ACTION PLAN (GAP)
FINAL IMPLEMENTATION REPORT**

This GAP implementation report is part of the final reporting to be completed by the project coordinator and each contractor of IPs and NoEs as indicated. It details the activities undertaken and assesses the progress made in implementing a Gender Action Plan for the project.

1. GENERAL INFORMATION

1.1. Contract No.:

1.2. Thematic priority:

1.3. Instrument:

1.4. Project Acronym:¹

1.5. Period covered (Start Date – End Date)¹

1.6. Name and title of co-ordinator¹:

1.7. Name and title of contractor:

3. SCIENTIFIC LEADERSHIP AND MANAGEMENT, AND WORKFORCE STATISTICS FOR THE PROJECT TO BE COMPLETED BY CONTRACTORS

Please indicate in the table below on a headcount basis, how the scientific management and workforce was distributed at the end of the project (Previously supplied data will be inserted automatically)

The first headcount of May 2006 demonstrated that the Europrevall workforce met the 40-60% equality range, therefore no more headcounts on the full workforces were made. However a number of additional headcounts was made on 1) Participation of women and men in the first 4 conferences (May 2007) and 2) attendance of the Prague conference (October 2008) and 3) representation of male/female PhD's in Europrevall (Fall 2008).

Type of Position	Number of Women	Number of Men	Total	% Women	% Men
Scientific manager					
Scientific team leader / work package manager					
Experienced researcher (> 4 years)					
Early researcher (<= 4 years)					
PhD students					
Technical staff					
Other					

¹ Pre filled when applicable

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