

**Issues of Autonomy and Agency in Oncofertility:
A Socio-Bioethical Exploration of British Adult
Female Cancer Patients Making
Oncofertility Decisions**

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Abstract

This thesis examines from a socio-bioethical perspective British premenopausal cancer patients' experiences with making oncofertility decisions. It uses original empirical research into the experiences of a small group of patients to address social, clinical and ethical concerns about how patients make decisions in the medical context. Several North American studies have noted that the ways in which cancer and fertility concerns are addressed in the medical context may affect patient decision-making. This thesis focuses specifically on how these experiences are influenced by the medical encounters in the UK, by exploring how female cancer patients make decisions about their future fertility. The thesis also examines whether social and bioethical theories of autonomy and agency adequately capture how decisions are made in practice, using empirical data to interrogate existing theory. To address these questions, semi-structured interviews were conducted with premenopausal cancer patients. Data from the interviews were analysed using sociological and bioethical theories in order to improve understandings of how this patient group makes decisions, and how they feel this experience could be improved. This research therefore contributes to the growing body of literature seeking to identify how patients make decisions within the medical context and what types of support are necessary to address the needs identified by patients. Furthermore, the thesis demonstrates how sociology as a discipline can be seen as a constitutive part of bioethics, with this project serving as an example of one way that bioethical research can be conducted through a sociological lens.

Dedication

This thesis is dedicated to the eleven women who kindly trusted me with their stories.

Thank you.

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There are several people who were integral to helping me finish this thesis and I would like to acknowledge and give thanks to them here.

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List of Abbreviations

A and E	Accident and Emergency department
GP	General Practitioner
HCPs	Healthcare professionals
HIV	Human Immunodeficiency Virus
IRAS	Integrated Research Application System
IVF	<i>In Vitro</i> Fertilisation
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRES	National Research Ethics Service
PI	Principal Investigator
R and D	NHS Research and Development department
REC	NHS Research Ethics Committee
UK	United Kingdom
US	United States of America

Chapter 1

Introduction

As cancer patient survivorship rises, so do the concerns about those patients' lives after cancer. The fertility of cancer patients is a growing clinical concern, and the two clinical fields of oncology and fertility medicine are now being considered together as 'oncofertility'. Oncofertility is an emerging field of medicine and as such remains an under-researched area of interest. As separate clinical fields, cancer and fertility have long been areas of interest in both sociology and bioethics, but few studies have focused solely on the clinical field of oncofertility. Several North American studies in the last decade have noted that the ways in which cancer and fertility concerns are addressed in the medical context may affect how patients make decisions. In this thesis I focus on these issues in the UK, exploring how female cancer patients make decisions about their future fertility. Using original empirical research I explore the experiences of a small group of British patients in order to address social, clinical and ethical concerns about how patients make decisions in the medical context. I also examine whether existing theoretical frameworks for patient decision-making adequately capture the experiences described in my data. I then use this analysis to suggest ways in which understandings of how this patient group makes decisions could be improved. This research therefore contributes to the growing body of literature seeking to identify: how patients make decisions within the medical context; how patients define their needs; and the types of support necessary to address these needs. Through my analysis I demonstrate and explore theoretically how sociology as a discipline can be seen as a constitutive part of the multidisciplinary field of bioethics.

In this introductory chapter I explain why I chose oncofertility as the focus of the research, why I conducted the research through the sociological lens, and why researching this topic in this way can be considered timely. I also outline the structure of the thesis, as it differs in some ways from more traditional structures, partly because it has multiple foci; it is not just about oncofertility, not just about decision-making and not just about bioethics. Instead, I undertook multiple strands of inquiry and research which require individual explorations before being brought together. By briefly explaining the thesis structure here I hope to offer the reader some signposts of what to expect in the following chapters.

1.1 The Importance of this Research

In the last 10 years oncofertility for women has undergone a number of changes due to the development of more successful forms of fertility preservation like egg freezing (Jadoul et al., 2010). Previously women could only preserve their fertility through drugs and/or embryo freezing. Additionally, women without a partner had to use sperm donation if they wanted to freeze embryos (see chapter 2). However, current research into ovary freezing (Wallace and Barr, 2010) and experimental work on reproductive technology more generally, have changed the landscape of oncofertility options (both treatment and eligibility) dramatically in a short period of time. The field of oncofertility has also changed owing to the advances in cancer treatment and an increase in survival rates for women to 50% in the last 40 years (Cancer Research UK, 2014). As screening programmes improve and cancer survivorship grows, life after cancer has become an important consideration for patients, with fertility a part of this consideration (Quinn et al., 2007).

Oncofertility presents an interesting area within which to examine decisions in the medical encounter for several reasons. Oncofertility decisions are simultaneously decisions for the present and the future. Restoration of fertility after cancer treatment cannot be predicted, and not all oncofertility treatments are compatible with the best course of cancer treatment advised. As a result, oncofertility decisions are unique as optimal survival and optimal fertility have to be valued against each other. Decisions about cancer treatment result in lost fertility options in the future, and decisions to undertake oncofertility techniques can limit the availability and efficacy of certain cancer treatments. While many decisions made in the healthcare context are difficult, oncofertility patients must make related and important choices about their health and future lives, amidst the uncertainty of their survival and their fertility post-cancer. Exploring how and why patients make oncofertility decisions also provides a new perspective on decisions in medicine from an emerging field, examining how current practice affects those decisions, and how future practice might be changed to better reflect patient needs.

1.2 The Advantages of this Approach

As I explain in the theoretical framework (chapter 3), this thesis examines two distinct, but important phenomena: how and why female patients make oncofertility decisions, but also how the concept of autonomy is understood in the medical encounter (in this case the medical encounter being oncofertility). I am bringing these two phenomena together in order to examine autonomy in the context that decisions are made. I argue that both research goals are best reached by taking a sociological approach, which allows access to patients' accounts of their lived experiences through the sociological theory, methodology and methods laid out in the theoretical framework and methodology chapters. Examining phenomena in the world through qualitative methods, like face-to-face interviews, is both an essential part of the interpretative methodology and analysis underlying this research (Brewer, 2000), and also represents a newer way of conducting bioethical inquiry (Haimés, 2002; Hedgecoe, 2004).

Using the sociological analysis of empirical data to reflect on the accuracy of bioethical theories is still considered by some academics to be unorthodox.¹ The use of sociological epistemologies to examine bioethical problems is part of what some academics have called the “empirical turn” in bioethics (Borry et al., 2005). The research I describe in this thesis is therefore not only situated in the field of sociology, but also within an ongoing debate about the role of bioethics and the constitutive fields of bioethics. Following Haimés (2002), Hedgecoe (2004), and others, I approach this research through a sociological bioethics, which is defended in the theoretical framework. By taking a sociological approach to explore how autonomy is manifest in practice, this thesis provides an example of how bioethics can be “done” through fields other than philosophy, theology and law. It therefore contributes to wider academic debates.

1.3 The Timeliness of this Research

Sociological bioethics is part of a growing trend of examining bioethical theories in practice. In the substantive fields of patient decision-making and oncofertility,

¹ There have been several special issues on the subject of how to “do” bioethics, the most recent of which were published in 2009 and 2010 by *Bioethics*. I give a full account of the debate in chapter three.

examinations of practice have dominated current research. In particular psycho-social and clinical research on decision-making (critically reviewed in chapter 2) in the last five years has focused on the limited efficacy of decision-making models in the clinical context, but little work has been done to change these models. Similarly much has been said about the relevance of bioethical theories to current medical practice. Again, few studies have commented on what needs to change or how to implement those changes such that bioethical theories are more relevant. The emerging field of oncofertility is still evolving, however early examinations of the clinical context have already raised concerns from researchers about how patient decisions may be affected negatively by oncofertility practices (see chapter 2 for a full account).

This thesis is timely as it speaks to a number of gaps that have emerged in the literature. Most research on patients making decisions has been through applied philosophical bioethics or psychosocial clinical work. Given the growing support for sociological bioethics, it is time to take a sociobioethical approach to the examination of the theories, and the medical encounter. Oncofertility is an appropriate field in which to conduct this examination as it is both emerging and fast-paced, changing as important technical milestones, like viable egg freezing, are met, thus making decisions more acute and immediate for patients as the nature of available options continues to change.

1.4 The Structure of this Thesis

As I am examining two related, but distinct substantive fields, oncofertility and decision-making, I begin with a critical examination of these fields in order to situate the research within existing debates and scholarship. The literature review chapter (chapter 2) examines current research in the field of oncofertility, as well as sociological research on cancer, fertility, the medical encounter and patient decision-making. The literature on bioethical theories of autonomy, sociological theories of agency, and critiques of sociological bioethics are reviewed in the theoretical framework (chapter 3). In this chapter I build on and critique existing theories of autonomy and agency in order to construct the theoretical framework for this thesis. Separating the substantive fields from the theoretical background of the research highlights how the fields of oncofertility and patient decision-making are not only the focus of this research, but are also the lens through which I show that bioethics can be “done” through, and with, sociology. In the

theoretical framework I also emphasise how the field of bioethics can and does benefit from the recognition of the role that sociological theory, methodology and methods play in constituting bioethical examination and inquiry.

The use of sociological methodology and methods is highlighted and explained in the methodology section (chapter 4). I outline how the research questions are best addressed through an empirical investigation of the British adult premenopausal cancer patient's experiences with oncofertility decisions. In this chapter I also explain how the research was designed, and describe and explain setbacks and changes to the research that occurred along the way. I then examine the data collected in three chapters that outline and analyse the main themes from the research: Time; Information and Understanding; and Being Guided (chapters 5–7). Within each main theme I discuss a number of sub-themes in order to show the nuanced nature of the themes, and also highlight their interconnectedness.

In the final two chapters I bring the substantive interests and the theoretical interests together. I address what can be learnt from the sociological analysis of the empirical data to better inform bioethical theories of autonomy and decision-making, and evaluate the strengths and limitations of my own work. In these chapters I also comment on how those theories may be developed so that they better reflect how decisions are made and influenced in the medical encounter. Finally I present an outline of a new conception of autonomy, Facilitated Autonomy, which builds on previous bioethical theories (in particular Relational Autonomy), while also incorporating theory from sociology and the empirically identified needs of the interviewees from this study. I end this thesis with a reflection on how Facilitated Autonomy may help address the concerns raised by patients in this study, and in the wider literature, before suggesting what future research, conducted through a sociological bioethics, is needed to further understand how patients make decisions. I also suggest future research questions in the fields of oncofertility and patient decision-making more generally, in order to improve understanding of these two important areas.

Chapter 2

Literature Review

In this thesis I draw from the scholarly work in both the substantive fields of oncofertility and patient decision-making, and from the wider areas of study that surround those fields, namely sociological work on cancer, (in)fertility and the medical encounter.² This chapter is divided in two; in the first half I examine the work in sociology on cancer and (in)fertility more generally before focusing on a critical account of current oncofertility research. In the second half I review contemporary and classic sociological literature on the medical encounter before examining current sociological/psychosocial research on patient decision-making within the medical encounter. I end this chapter with a discussion of the gaps in the literature and how this thesis will address some of these gaps. The reader will note that one rather large focus of the thesis is deliberately missing from this chapter: that of bioethical accounts of patient autonomy, and sociological accounts of agency. A critical review of this literature can be found in the following chapter where I outline the theoretical framework, as this literature is essential to understanding the theory that informs the research.

2.1 Sociological Research on Cancer

Oncofertility is a relatively new field of medicine, and as a result there is little research to be found on the sociology of oncofertility. There is, however, a history of sociological research into the two areas that make up oncofertility: cancer and (in)fertility. I would like to briefly address these two areas of research in order to outline where oncofertility fits into the literature, as well as highlight those areas where this thesis seeks to fill a gap in current knowledge.

² I have decided not to include a literature review of bioethical research on cancer and (in)fertility as both areas are very wide ranging, including everything from research ethics, pro-life versus abortion debates, disability ethics and end-of-life/palliative care debates. I am also less interested in whether oncofertility as a whole field is “ethical”, but rather how decisions are made and what influences these decisions in oncofertility. It is the bioethical theories of autonomy that are of interest to me, not the bioethics debates about cancer treatments and infertility techniques.

A literature search for sociological work on cancer³ revealed that the focus of that research is predominantly on studying accounts of risk, cancer stories/narratives from patients and family, looking at biographical disruption and identity issues for cancer patients, examining the effects of cancer diagnosis/screening on patients, and work on embodiment and gender issues in cancer. Research done in sociology that is specifically on cancer patient decision-making has been more difficult to find. Much of the literature on that subject has been from a clinical or psychosocial point of view, and within that literature there has been a focus on developing models for decision-making that can be implemented by physicians. One study in 1998 however bears a closer look as it is the first instance of work on cancer and patient choice that I could identify that was from a sociological perspective. It is also interesting to note that it is written by the same authors who figure prominently in the research on shared decision-making, which is reviewed later in this chapter.

The 1998 study by Charles *et al.* explored the “experience of treatment decision-making as seen through the patient’s eyes” (73). It was a prospective study of breast cancer patients who had just been diagnosed and were presented with their treatment options by their doctors. The study found that doctors reported presenting what they felt were two distinct sets of options: treatment versus non-treatment options (Charles *et al.*, 1998, 77). However, patients did not consider these options to be of equal value, and so the choice between what the study patients called “doing nothing” versus “doing something” was not perceived to be a “meaningful choice” (Charles *et al.*, 1998, 77). This was because patients were particularly attuned to risk and how risk could be interpreted from the survival rates that each treatment style offered. As a result patients identified “doing nothing” and “doing something” as carrying a set of risk statistics that the patients had to choose between. For this group of patients there were “right” and “wrong” choices that could be made, where “right” choices were those choices that carried the least risk of blame to the patient should the cancer recur (Charles *et al.*, 1998, 79). In this 1998 paper Charles *et al.* echo their 1997 paper by advocating a shared decision-making style approach to help alleviate the stress caused to the patient by having to determine the “right” decision to make (Charles *et al.*, 1998, 90). The authors conclude by arguing for an “interpretive model” of information transfer between

³ This search was conducted through database searches of books and journals using a combination of the search terms: cancer, sociology, empirical research, oncology, medical sociology, and sociology of health and illness. It was supplemented by searching online for the same search terms, and then repeated when looking for sociological work on (in)fertility.

patient and physician whereby the physician and patient work together to come to a treatment decision, thus alleviating the stress of the decision (Charles *et al.*, 1998, 88).

While this study is worth discussing here because this thesis (coincidentally) has similar research interests (and design), its conclusions are necessarily dated. The interpretive model that the authors advocate relies on a poorly explained middle step of physician–patient communication that later research (see section 2.5) has identified as a major stumbling block for patient decision-making. Further studies on the efficacy of shared decision-making (again see section 2.5) have identified that it rarely occurs in practice, despite the contemporary rhetoric surrounding its importance in the clinical setting. Charles *et al.*'s research is also 16 years old and many of the treatment options have changed since the article was written. Interestingly, much of the academic work on patient decision-making (cancer and other specialities alike) has since shifted to being published in clinical or psychosocial journals (with the focus on decision-making models and whether they work), or applied bioethics journals (with the focus on patient autonomy and the right to decision-making). Whether this has to do with the clinical focus of social science research in medicine, or because patient decision-making has been a major focus of contemporary studies of the medical encounter is difficult to ascertain. What is clear is that not much work has used sociological analysis to examine current cancer patients' decision-making experiences.

2.2 Sociological Research on Infertility

Research on infertility has been similarly split between two different research tracks: on the one side clinically-based, on the other a more sociological approach. In a review of the past 10 years of social science research into infertility Greil *et al.* found that there are currently two main streams of research (2010, 140):

- 1) Quantitative work to improve service delivery and assess the need for psychological counselling (identified by Greil *et al.* as clinical research).
- 2) Qualitative work to capture the experience of infertility and “the social context that shapes it”. This work takes a sociological approach informed by social science work and theory on illness experience, gender, the body and stigma.

Greil *et al.* argue that the two streams do not communicate with each other, and that despite research “moving towards situating infertility in the social context” the clinical research/focus still dominates the literature (2010, 142). The situation has not changed much since 2010, and I share Greil *et al.*’s concern that the continued focus of research on clinically based studies limits what can be known about infertility, as clinical studies only conduct research with those women who present themselves for treatment (Greil *et al.*, 2010, 142). Little is known about the infertile individual (male or female) who does not seek treatment. Finally research into infertility (sociological and clinical) has been mostly confined to *in vitro* fertilisation (IVF) patients in developed countries, though more research is now being done on the infertility experience in developing countries (Greil *et al.*, 2010, 146–156).

2.3 The Substantive Field: What is Oncofertility?

In the last forty years cancer survival rates in the UK have doubled to 50% (Cancer Research UK, 2014). Women in the UK have high chances of both five (56%) and ten (52%) year survival rates as well (Cancer Research UK, 2011). As a result of this increased survival, the future fertility of oncology patients has become a vital consideration (Quinn *et al.*, 2007, 146). The nature of oncology treatments necessitates that conversations about future fertility occur prior to cancer treatments, making the clinical need for information and decision-making in oncofertility uniformly urgent (Meneses *et al.*, 2010, 1112). While exact infertility rates due to cancer treatments are unclear, as fertility potential is currently not measured prior to cancer treatment, it is known that women who receive chemotherapy or radiotherapy during their reproductive years have a 40–80% chance of becoming infertile after treatment (Quinn *et al.*, 2007, 147). By comparison, men have a 30–70% chance of infertility as a result of cancer treatments (Quinn *et al.*, 2007, 147). Successful fertility preservation relies heavily on a variety of factors such as patient age, gender, treatments used, cancer diagnosis, and non-clinical factors such as socio-economic background and access to medical resources (Quinn *et al.*, 2007, 147). However fertility preservation is not an exact science; the ability to preserve fertility, and the range of infertility prevalence after treatment, depend on the same list of factors above, making overall success difficult to predict.

Due to these complexities, medical research has been exploring the relationship between cancer treatment and infertility in detail since the 1970s. By the 1990s young people with Wilms' tumours,⁴ lymphomas,⁵ acute lymphocytic leukaemia⁶ and brain tumours, among others, were surviving due to higher radiation doses, which adversely affected fertility (Jacobs *et al.*, 2009; Wallace and Barr, 2010). It was also found that patients treated with chemotherapy drugs such as alkylating agents were at risk of infertility (Anchan and Ginsburg, 2010, 176). Chemotherapy drugs disrupt the cell cycle of all proliferating cells in the body and cannot distinguish between a neoplastic cell (a cancer cell) and a germinal cell (eggs and sperm) (Anchan and Ginsburg, 2010, 177), destroying germinal cells along with the cancerous cells, frequently causing infertility. In women, the extent of the damage depends on the patient's age (younger women have a larger ovarian reserve), duration of treatment, and treatment dosage. However the effect of chemotherapy is potent: roughly 40% of women under the age of 40 report chemotherapy related amenorrhea⁷ (Anchan and Ginsburg, 2010, 177).

2.3.1 Oncofertility in Practice

Oncofertility treatments (also referred to as fertility preservation techniques) have developed alongside advances in cancer treatments. For men the favoured fertility preservation techniques are sperm cryopreservation and gonadal shielding during radiotherapy (Lee *et al.*, 2006, 2922). For female oncology patients, the three established fertility preservation techniques are embryo cryopreservation, conservative gynaecologic surgery⁸ and oophoropexy⁹ (Quinn *et al.*, 2007, 147; Jadoul *et al.*, 2010, 619). Experimental fertility preservation techniques for women can include everything from egg freezing to ovary transplant, while male experimental techniques are less widely explored owing to the extremely high success rate of sperm cryopreservation. In recent years there has been some success with ovarian cryopreservation in women (Wallace and Barr, 2010; Jadoul *et al.*, 2010). In most cases fertility preservation must occur before treatment starts (Lee *et al.*, 2006; Wallace and Barr, 2010), and it is argued that patient education and understanding about the effects of cancer treatment on

⁴ Childhood kidney cancer.

⁵ Tumours found in the lymphatic system.

⁶ The rapid multiplication of cancer cells that replace normal blood cells in the body.

⁷ Amenorrhea is the absence of a menstrual period in women of reproductive age.

⁸ For example: a trachelectomy, which is the surgical removal of the cervix.

⁹ Moving the ovary so that it is not in the radiation field.

fertility should be an essential part of the communication between oncology clinician and patient during diagnosis and treatment (Quinn *et al.*, 2007; Schover, 1999; Schover *et al.*, 1999, 2002a, 2002b).

– ***The lack of knowledge about oncofertility*** –

Given that cancer treatment is, for the most part, protocol driven¹⁰ the knowledge that treatment affects fertility necessitates the need to inform survivors, as well as newly diagnosed patients, about the likelihood of infertility due to their cancer treatment. However, despite available fertility preservation techniques, there is evidence that, in the US at least, fewer than 50% of adult patients of childbearing age receive “adequate or appropriate education, counselling, and resources about reproductive decisions prior to their cancer treatment” (Quinn *et al.*, 2007, 147; see also Schover, 1999; Schover *et al.*, 1999, 2002a, 2002b). For example, in an older American study of treatment knowledge in young male oncology survivors, 25% cited lack of information as the reason why they did not bank sperm prior to treatment (Schover *et al.*, 2002a, 1881). Some studies have attempted to explore this reported breakdown of communication by directly asking the healthcare professionals (HCPs) involved. Most HCPs in the US-based studies said that they did not have the clinical information they needed, or wanted, in order to have an in-depth conversation about fertility preservation with patients (Cope, 2002; Reebals *et al.*, 2006; Goodwin *et al.*, 2007; Clayton *et al.*, 2008; Quinn *et al.*, 2007). One study found that “knowledge appears to be a key factor in determining whether and how physicians discussed fertility preservation with oncology patients” (Quinn *et al.*, 2007, 151) as how informed the physicians felt about oncofertility translated into how comfortable they felt discussing it with patients. In particular, American HCPs were unsure of which fertility preservation techniques exist, what resources were available to patients, and where to refer patients who have chosen to pursue fertility preservation prior to treatment (Cope, 2002; Reebals *et al.*, 2006; Goodwin *et al.*, 2007; Clayton *et al.*, 2008; King *et al.*, 2008; Quinn *et al.*, 2007). American nurses reported feeling that they did not have any practical information to disseminate to their patients, such as pamphlets on nearby fertility clinics, and found it difficult to determine whether fertility preservation was an option for their patients and to whom to refer their patients (King *et al.*, 2008, 470). This inexperience, coupled with a lack of familiarity with, and/or lack of access to, appropriate information stopped

¹⁰ Meaning that most cancers have a set of corresponding treatments that normally occur in a specific order: for example surgery is often done before chemotherapy in breast and cervical cancer.

many HCPs from having discussions with patients about fertility preservation techniques (King *et al.*, 2008, 470). In one study it was found that 91% of physicians felt sperm banking should be offered, but only 10% reported feeling comfortable enough with their knowledge of oncofertility techniques to offer it (Cope, 2002, 294). With respect to female treatment a 2007 study found that roughly half of the HCPs surveyed felt they needed to know more about female fertility preservation (Goodwin *et al.*, 2007, 84).

Those HCPs who were aware of fertility preservation techniques reported making individual judgement calls on which of their patients they inform about these techniques (Cope, 2002, 294). HCPs offered a number of varied reasons unrelated to health for the criteria they used when deciding whether to inform a patient about fertility preservation. Examples include: whether the patient already has children, whether the patient shows interest in fertility preservation, and if the patient is married or in a long term relationship (Cope, 2002, 294–295). Reasons given as to why HCPs may choose not to have a fertility preservation discussion were individual to the HCP and hinged on their own beliefs about who would want to know about fertility preservation. Some examples of reasons why HCPs choose not to speak to their patient about fertility preservation include: the patient is a homosexual (Cope, 2002, 294), the patient has HIV (Cope, 2002, 294), the patient's financial situation (Goodwin *et al.*, 2007, 82; Quinn and Vadaparampil, 2009, 397) and the sex of the patient (Goodwin *et al.*, 2007, 82; Wilkes *et al.*, 2010, 155). These examples illustrate how choices made by HCPs about which patients they inform about oncofertility treatment can greatly affect the patient's future choices. This suggests that those patients who HCPs choose not to inform are missing crucial information about their disease and treatment that might otherwise change the decisions a patient would make about their healthcare. In addition, by holding back information HCPs may inadvertently be limiting not only information, but treatment options available to patients, thus limiting patients' abilities to exercise their ability to choose the medical course of action best suited to their values and beliefs. As the reasons given above are based on assumptions and prejudices held by the HCPs, the HCPs are potentially discriminating against patients unjustly.

It can be argued that, by limiting these options and choices, HCPs are restricting patient decision-making and not respecting patient autonomy. This is a strong claim, however it can also be argued that fertility preservation for cancer patients is ultimately choice

preservation for patients' future selves. By preserving their fertility patients can put off the choice to have children to a future date when they feel ready to make that decision. Therefore the management of fertility preservation discussions by HCPs must be comprehensive and accurate as fertility preservation can be part of a patient's life plan after cancer. This need is strengthened when the HCP's beliefs about who is interested in fertility preservation are compared with the beliefs of the patients. For example, many HCPs choose not to bring up fertility preservation because they judge it an awkward topic for the patients (Quinn and Vadaparampil, 2009, 397). However, little research has been done to confirm that patients actually feel embarrassed by these conversations (Quinn and Vadaparampil, 2009, 399), meaning that many patients miss out on an important conversation about fertility preservation due to HCPs' conjecture about what patient's find awkward to discuss.

The mismatch between patient needs and HCPs' assumptions of patient needs, combined with the HCPs self-reported desire for further education on oncofertility techniques, is problematic as it is not just information about the patient's present physical condition that must be considered when treating them. Nisker *et al.* argue that not only do physical harms associated with fertility preservation have to be mapped out and discussed with the patient, but the potential psychological effects have to be considered too (Nisker *et al.*, 2006, 1688). They write that "to make an informed choice about something that will have a significant impact on one's future, one must know what the future will hold if one chooses that thing or does not choose it" (Nisker *et al.*, 2006, 1688). Wilkes *et al.* (2010, 156) argue similarly, having found that patients want discussions about possible future outcomes, and courses of action regarding fertility preservation, to come from their HCPs so that they can make informed decisions about their future.

– *The lack of time to discuss oncofertility* –

In addition to feeling ill-informed, HCPs in the studies reviewed also cited a lack of time as the reason why fertility preservation conversations do not happen, or happen later on during the treatment course (Cope, 2002; King *et al.*, 2008; Quinn *et al.*, 2007). As it appears that fertility preservation is mostly confined to the small window of time between cancer diagnosis and the beginning of treatment (King *et al.*, 2008, 474), timing is actually an important part of oncofertility success. If this window is passed, the 'choice' of fertility preservation is often lost to the patient forever, meaning that

when a conversation happens matters just as much as *the content* of the conversation. Patients who miss, or are unaware of, this narrow window of time are left with fewer options, and thus it could be argued that they have restricted choice with regards to their future fertility.

2.3.2 Studies in the United Kingdom

Outside of the US, research into oncofertility experiences has been patchy (see table 2.1 below); however, recent studies in the UK mirror the conclusions from the American studies, suggesting that patient experiences in the field of oncofertility may require further research.

Of the 331,000 cancer diagnoses per year in the UK, 1 in 20 diagnoses occur in women under 50 years old; roughly spanning the fertile age-range for women (Cancer Research UK, 2014). While the 2013 NICE guidelines state that sperm and embryo preservation should be offered where appropriate (NICE, 2013),¹¹ there remains no national funding policy for fertility preservation, and the provision of fertility services is unevenly spread across the country (Wilkes *et al.*, 2010, 152). Where oncofertility is concerned, “little is known about the extent to which fertility preservation advice is given at or around the time of diagnosis or its quality or impact on patients’ lives” (Wilkes *et al.*, 2010, 152).

A recent study on the experience of fertility preservation among cancer patients in the UK diagnosed at a young age revealed similarities to the previous studies conducted in the US (Wilkes *et al.*, 2010). This retrospective UK study reported that fertility advice was offered to some patients, however patients (or in the case of childhood cancers the parents of patients) were “universally focused on survival at the point of receiving a cancer diagnosis” (Wilkes *et al.*, 2010, 154). Wilkes *et al.* found that only three of the eighteen survivors interviewed had been offered and accepted fertility preservation; all three were male (Wilkes *et al.*, 2010, 154).¹² In all cases, immediate cancer treatment was advocated and patients, or their parents, accepted this without question (Wilkes *et al.*, 2010, 154). However, priorities and needs changed once treatment started, with

¹¹ NICE guideline 1.16.1.2 states: “At diagnosis, the impact of the cancer and its treatment on future fertility should be discussed between the person diagnosed with cancer and their cancer team” (NICE, 2013).

¹² The study had no focus on one particular type of cancer and the diagnosis of the patients was diverse. See Table II in Wilkes *et al.* (2010) for a full breakdown of participant cancer types and age.

patients realising that fertility was a significant concern. For example, one participant of a 2010 study stated: “I was more upset about the fact that I was never going to have any more children than having the cancer” (Wilkes *et al.*, 2010, 154). This sentiment is echoed in similar international studies on life after cancer (Schover, 1999; Tshudin and Bitzer, 2009).

Region/Country of Research	Number of Studies	Number of Studies Focused SOLELY on Adult Women
NORTH AMERICA	28	7 (25%)
United States	25	5
Canada	3	2
EUROPE	11	2 (18%)
United Kingdom	7	0
Netherlands	2	0
Italy	1	1
Switzerland	1	1
ASIA	1	0 (0%)
Japan	1	0
AUSTRALIA AND OCEANIA	4	4 (100%)
Australia	4	4
TOTAL	44	13 (29%)

Table 2.1: Psychosocial research worldwide on patient experiences with cancer and fertility¹³

¹³ Table accurate as of April 2014. This literature survey used only those papers published in English using the criteria set out by Tschudin and Bitzer (2009). It built on the survey of research conducted by Tschudin and Bitzer (2009) on patient experiences with cancer and fertility over a decade (1998–2008) looking at psychological and sociological research. Twenty-four studies were identified as relevant, of those studies three were conducted in the UK and six of the worldwide studies were focused solely on adult women. Following the criteria set out in Tschudin and Bitzer (2009), a further literature search was done to cover the period between 2008 and 2013, where a further 20 studies were identified, four of which were studies done in the UK, and a further eight were worldwide studies on adult women.

– *Male patient studies* –

As with the American studies, male survivors in the UK had more positive reactions. This is most likely due to fertility preservation being simpler and less time consuming for males (Chapple *et al.*, 2007; Wilkes *et al.*, 2010). Male fertility preservation has become part of the treatment process and many male cancer patients felt that there was no decision made about fertility preservation; instead they were just “going with the flow” of the treatment (Wilkes *et al.*, 2010, 154; see also Crawshaw *et al.*, 2009). None of the male patients in a 2010 UK study knew the consequences that chemotherapy would have at this point in their lives, so did not think to ask about fertility preservation (Wilkes *et al.*, 2010, 154). They were all pleased that fertility preservation was part of the treatment process and that they had done it (Wilkes *et al.*, 2010, 154). It has been reported, however, that further work is needed on improving protocols and liaison systems between oncology departments and sperm banks (Chapple *et al.*, 2007, 73).

– *Female patient studies* –

To date I have found only two UK-based studies that have included adult female patients. However these were not focused solely on adult females, as they also included children, adolescents and male patients (Crawshaw *et al.*, 2009; Wilkes *et al.*, 2010). The experiences of adult female cancer patients are considerably under-represented and, at the time of writing, no studies focusing solely on female patients in the UK have been reported (see table 2.1). The focus of previous research, like the US studies, has been primarily on paediatric and adult male patients. The two UK studies that explored patient experiences did look partially at the young female patient, reporting that female patients often felt “brushed aside” and that a more detailed explanation of the effects of treatment on fertility was needed (Wilkes *et al.*, 2010, 154; see also Crawshaw *et al.*, 2009). Female patients felt that “more complex information was required and comprehension was less successfully achieved” with current standards (Crawshaw *et al.*, 2009, 385). Consequently, one patient went so far as to say that she “felt that she had not been able to make an informed decision” as she felt fertility discussions with her clinicians were insufficient to necessitate her understanding of the effects of cancer on fertility (Wilkes *et al.*, 2010, 154).

Some research has looked more closely at the needs of patients when making decisions in the oncofertility setting, and both female and male patients reported a need for increased support in the form of leaflets, website suggestions and access to fertility

specialists which they felt may help with making decisions about fertility preservation (Crawshaw *et al.*, 2009; Wilkes *et al.*, 2010). Patients also added that this support should be offered as soon as possible, and should continue to be available throughout the treatment process and in aftercare (Crawshaw *et al.*, 2009; Wilkes *et al.*, 2010).

The few UK studies have made it clear that more research needs to be done, particularly with regard to understanding the perspectives of adult female patients, as “gender-related differences clearly warrant fuller attention, and have not been reported elsewhere” (Crawshaw *et al.*, 2009, 386).

2.4 Sociology of the Medical Encounter

The concerns outlined by recent research on oncofertility have less to do with actual oncofertility (i.e. concerns about the techniques and treatments) and more to do with what oncofertility patients experience in the medical encounter and the influence of that medical encounter (i.e. concerns about communication with HCPs, lack of training for oncology HCPs about oncofertility etc.). There has been a lot of sociological work done on examining and understanding the medical encounter, in particular through work in medical sociology.

Sociological work on the medical encounter has focused largely on two aspects:

- 1) The patient–professional relationship
- 2) Decision-making within the medical encounter

I would like to provide a brief overview of the sociological work done in these two areas so as to better situate my research within the established debates.

2.4.1 *The Patient–Professional Relationship*

Nettleton argues that sociological analysis of what she calls the “lay–professional interaction” is either from a macro or micro approach (2013, 123). Macro approaches take a structuralist-functionalist or structural-conflict view of these interactions, while

micro approaches focus on the characteristics of the interactions themselves (Nettleton, 2013, 123). I will focus more on analysis done on the micro level, as this is where a number of significant changes to practice have occurred since the late 20th century, and is the most relevant to this study.

The relationship between the patient and physician has changed as we shift from an “industrial age medicine” to “information age health care” (Nettleton, 2013, 124). With the rise of chronic illness diagnoses, the contemporary patient–professional relationship is now characterised as a ‘meeting of experts’ (Tucket *et al.*, 1985) as patients are “encouraged to take responsibility for their own health and are more knowledgeable about factors which influence their health status” (Nettleton, 2013, 124). Information and transparency are part of the contemporary medical encounter, or at least they are supposed to be. With this transparency comes a responsibility from physicians to be more aware of their limitations, communicating areas of doubt and soliciting information from their patients as expert equals (Annandale, 1998, 264; Horton, 2003, 40).

However the ‘meeting of experts’ is a misnomer, as it assumes an equality between patient and professional that has yet to be seen in contemporary practice (Nettleton, 2013, 126). Nettleton argues that the relationship between doctor and patient tends to “reflect and reinforce wider social relations and structural inequalities” like gender, race and class (2013, 123). As a result within these interactions physicians have neglected, and continue to neglect, patients’ views in the clinical encounter. Further, the patient–physician interaction within which this ‘meeting of experts’ is supposed to occur is in doubt, as the shift towards drop-in appointments and one-off consultations has prompted some to argue that the patient–physician relationship is better characterised as a patient–physician encounter (Potter and McKinlay, 2005, 476).

Regardless of whether it is an ‘encounter’ or a ‘relationship’, patient–physician interactions are not just the meeting of two individuals (experts or not). These interactions are also where the beliefs and norms of the society within which they take place are reproduced (for example Strong’s 1979 discovery of the ritual and ceremony of the medical encounter). Some academics, such as Waitzkin, argue that because of these beliefs and norms, medicine can be viewed as a type of social control (Waitzkin, 2000, 124). As a result it can be difficult to understand how the contemporary patient

manages to meet as an expert with their doctor, given the dominant social authority conferred on the physician. Nettleton argues that there is no space in the medical encounter for the patient to explain and justify the choices they make, only room for the doctor to do so (2013, 130). While this is not always the case, it does place more value on the doctor's reasoning and choice than on the patient's. In the "information age health care" this is problematic as "the effective communication and exchange of true, rather than ideological, information can take place only in a context where both parties are equal" (Nettleton, 2013, 131). It is unsurprising then that contemporary work on the medical encounter has focused intensively on the patient-physician relationship within which this communication takes place.

Sociological work on the medical encounter has not just been confined to identifying the negatives. As medicine has shifted towards a patient-centred care approach (Mead and Bower, 2000), sociological analysis of the medical encounter has reflected these changes as well, placing increased emphasis on the importance of patients as "active participants in the process of health care work" (Nettleton, 2013, 136).

The change from the use of the term compliance to the use of the term concordance is a good example of this shift. Earlier work on the patient-physician relationship focused on patient compliance, and non-compliance, to treatment prescribed. Non-compliance carries with it ideas of blame and moral disapproval, however once non-compliance was seen as having as much to do with poor medical practice (in particular poor communication) as it was with "recalcitrant patients", efforts were made to decrease non-compliance by examining why and how it occurs (Nettleton, 2013, 132). As a result new terms are used in the patient-centred care approach that remove the normativity of non-compliance (now called non-adherence), while also pushing the active patient/patient-centred care agenda with a new understanding of compliance; now called concordance. Concordance builds on the idea of the active patient and is understood as "an open exchange of beliefs about medicine about which prescribing and medicine decisions may then be based" (Marinker *et al.*, 1997 as cited in Nettleton, 2013, 133).

While concordance is about moving towards the "meeting of experts" ideal, this ideal is still beating against older norms that remain operational in the medical encounter. Active patients who challenge the doctor's authority may still be viewed as they were in Strong's 1979 work: as challenging the ritual and ceremony of the established social

encounter. One area where there has been a more concerted push to move away from these older norms is in the area of patient decision-making, and I would like to turn to research in that area now.

2.4.2 Patient Decision-Making

The increased focus on patient decision-making has coincided with an increasing emphasis on patient-centred care. Annandale argues that the move towards patient-centred care is due to beliefs in contemporary society which place a high value on the “authority of the self amid competing ideas about how illness should be understood and treated” (Annandale, 1998, 254). The contemporary medical encounter is shaped by the tension that is created between the importance of the self’s authority and personal choice, versus what Annandale calls “the moral responsibility to actually make these choices” within the “constraints that surround decision-making for both patients and health-care providers” (Annandale, 1998, 252). Changes in how hospitals are organised and staffed (for example the shift towards drop-in and one-off appointments identified by Nettleton) mean that the “individual patient, reconstructed as a decision-maker, is now at the centre of medical and research culture” (Annandale, 1998, 267). As a result much of the sociological work on patient decision-making focuses on *how* the patient makes decisions, and *experiences* decision-making in the contemporary medical encounter.

However, despite medical culture placing the patient “at the centre of decision-making” (Annandale, 1998, 271), this has not been translated into practice any more than the ideal of the active patient described by Nettleton. Thus the idea that “any decision to be made is the prerogative of the patient [...] is far from being the case” (Annandale, 1998, 273). Instead clinical decision-making remains “strongly marked by moral discourse” in particular with regards to the “tendency of power to remain with the doctor” (Annandale, 1998, 274). As a result the experience of the patient remains at odds with the so-called patient-centred care approach supposedly adopted by contemporary Western medicine. With this in mind I would now like to examine the substantive work that has been done in this area, with particular attention to the shared decision-making model that is the current focus of social science research in medicine, as it is relevant for my work in later chapters.

2.5 Framing Patient Decision-Making in the Wider Context

In many ways the concerns about knowledge, information and communication within the substantive literature are new to the field of oncofertility (which is itself new), but they are not new to medicine. While research on decision-making in oncofertility remains patchy, significant research in the social sciences has examined decision-making in other medical contexts, building on sociological research on the medical encounter. Research focused on patient-centred care has shed light on how patients make decisions, in particular looking at shared decision-making in practice, as well as the role of HCP–patient communication, and by extension the role of the HCP–patient relationship in decision-making.

Asking patients for treatment preferences is becoming one of “the most basic forms of patient involvement in medical care” (Zikmund-Fisher *et al.*, 2012, 198). The “best choice” for patients is no longer just about the best medical choice for their illness, but should also be grounded in “the preferences, values, and goals of the patient” (Zikmund-Fisher *et al.*, 2012, 198). This can be understood as a move away from older, paternalistic models of medical decision-making, and a move towards a more inclusive understanding of the process of decision-making itself. A number of models of decision-making were proposed 20 years ago (see Emanuel and Emanuel, 1992). Shared decision-making, in particular the Charles *et al.*, 1997/1999 version of it, has been the focus of recent research, perhaps because it embodies the patient-centred care ethos.¹⁴

2.5.1 Shared Decision-Making

Charles *et al.*’s shared decision-making model is closely linked to patient-centred care, embracing an informed choice approach to decision-making where shared decision-making is understood as “a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients’ information, sense of autonomy and/or control over treatment decisions that affect their well-being” (Charles *et al.*, 1997, 682). This process involves both patient *and* doctor, thus “sharing” the

¹⁴ While the Charles *et al.*, 1997 and 1999 papers are older, they are frequently referred to in later papers that reference the shared decision-making model originally proposed in these two papers, and so despite their age they are still very relevant when discussing contemporary decision-making research and literature.

decision made between them (Charles *et al.*, 1997, 685). Shared decision-making has been understood to occupy the middle ground between paternalism and consumer choice, and combines “patient values and preferences, as well as physician knowledge and recommendations” (McMullen, 2012, 238). Engaging in shared decision-making requires periodic checking in from both parties to ensure informed understanding of the options available, and mutual understanding of the values and preferences of the patient (McMullen, 2012, 238).

Despite the importance placed on the involvement of the patient in shared decision-making, patient involvement has not been observed in practice to the extent that shared decision-making theory would demand, leaving a gap between theory and practice. Instead “researchers widely acknowledge that an actual decision-making process rarely fits any of these idealised models” and empirical studies have shown that “shared decision-making does not often occur in practice” (McMullen, 2012, 238).

Recent studies have found that in practice HCPs struggle to incorporate patients’ values in shared decision-making (Towle *et al.*, 2006; McMullen, 2012). Similar to the oncofertility studies reviewed, doctors are communicating what they think the patient should know, not discussing what the patient wants to know, thereby shutting down possible options and effectively eliminating the possibility of informed choice. Both patients and HCPs are unsure of how and what to communicate. What has been observed is a rhetoric from HCPs that implies the patient holds the power of choice, while the HCP has only the power of persuasion (McMullen, 2012, 243–246). This understanding of patient decision-making assumes that the patient has the power to take or ignore the HCP’s advice (McMullen, 2012, 243), and discounts the strong influence of the HCP on the patient’s choice. Empirical work indicates that a more paternalistic model is still at work in clinical practice, and while HCPs may believe whole heartedly in the rhetoric of shared decision-making, they appear unaware that they are not actually engaging in it (McMullen, 2012, 244).

As I shall outline further in the theoretical framework (chapter 3), the gap between theory and practice for decision-making models is an example of how the traditional model of patient autonomy, i.e. patient-makes-decision-alone-after-dispassionate-explanation-of-options, is not what happens in practice. This gap flags up two important questions to be addressed:

- 1) Why does this gap between theory and practice exist?
- 2) What is happening in practice *and* theory that means there is a gap?

Researchers in the field (including myself, as this is partly what this thesis sets out to do) want to know how patients navigate decisions, if they feel they have at least some power of choice (as shared decision-making implies), and how the balance of power between patient and HCP influences decision-making (McMullen, 2012, 247). Research has so far been confined to the listing of problems with decision-making models, suggesting that further research may be necessary to determine how patients make decisions, and how existing theory can be informed and changed by research into current practice.

2.5.2 *Communication between Healthcare Professionals and Patients*

In an attempt to better understand how patients make decisions, research has focused on a few possible areas of concern for patient decision-making, one of which is communication between healthcare professionals and their patients. If patients are to determine their “preferences, values and goals” as outlined by the patient-centred care model and the shared decision-making model, they must also be “informed of (and understand) the pros and cons of each treatment choice” (Zikmund-Fisher *et al.*, 2012, 199). Studies examining patient–HCP interactions have shown that patients who have “effective communication” between themselves and their HCP have “greater satisfaction with their medical care, lower levels of anxiety and depression, higher levels of understanding about their condition, are more likely to adhere to treatment, and have higher overall levels of wellbeing and quality of life” (Siminoff, *et al.*, 2006, 356; see also Street *et al.*, 2007; Martinez *et al.*, 2009; Moreau *et al.*, 2012). Positive communication is referred to as “patient-centred” communication, where the patient is perceived of as “involved” in the discussion of options and the physician responds to this involvement by being “more informative, accommodating, and supportive” (Street *et al.*, 2007, 588–592). In addition, physicians are still viewed as “the most helpful resource in making a treatment decision” (Kim *et al.*, 2013, 99), linking communication and patient decision-making strongly in the wider literature. When this type of “communicative reciprocity” (Street *et al.*, 2007, 595) cannot be achieved it is difficult for patients to be informed so that they can make a decision with certainty. This is

problematic as one study found that “feeling informed” was one of the strongest indicators of patient satisfaction with their treatment decision (Martinez *et al.*, 2009, 388), indicating the importance patients place on being informed.

2.5.3 *The Healthcare Professional–Patient Relationship*

One of the reasons why communication between HCPs and patients has been examined with regards to decision-making is that the HCP–patient relationship is also influential in communication and therefore in decision-making. One North American study found that of all the factors that influenced how physicians communicated, the “physicians’ orientation to the doctor–patient relationship” was in the top three (Street *et al.*, 2007, 594). As demonstrated earlier in this chapter, examinations of the HCP–patient relationship have been prominent in the sociological literature, and the relationship between the two is often conceived of as “ideal types or categories arranged on a continuum from physician paternalism to patient autonomy” (McMullen, 2012, 238). Regardless of which category or type the relationship falls into, research in the wider literature remains clear that the relationship does influence patients’ decisions.

2.6 Filling the Gap

The literature reviewed in this chapter shares a point of commonality; that the patient’s own choices, beliefs etc. should be valued in the contemporary management and experience of illness, and it is within this landscape that I situate my own research. Part of how the patient’s choices are valued in the medical encounter is through supporting the patient’s decision-making, and so I am not just situating this thesis in the existing work on the sociology of the medical encounter, but also within the current body of sociological research that examines patient decision-making. However within the current literature there are some identifiable gaps that this thesis addresses; some from the substantive field of oncofertility, and some from the wider field of sociology.

The focus on patient decision-making is not in itself new. However, as I show here, current research suggests that decision-making models and theories do not accurately capture how patients make decisions in practice. Further research is needed to discover

what is happening, and what patients feel is necessary to make these decisions. In addition there is a gap in the substantive field; the British, premenopausal cancer patient's experience of making decisions about cancer and fertility. Problematically current research in oncofertility has suggested that the solution to this is to ensure that the management of fertility preservation discussions be comprehensive and accurate. This may be difficult to achieve as research indicates that communication between patients and doctors can be poor, and decision-making models such as shared decision-making, are rarely seen in practice. To address these concerns my research moves away from these models and focuses instead on the experiences of British premenopausal cancer patients when making decisions. Focusing on patient experience may shed more light on how and why patients make decisions in the medical setting, which could then be used to develop more accurate understandings of how patients make decisions. My research will also provide data on a previously under-researched patient group to contribute to current understandings of the oncofertility patient experience.

Finally the concerns raised by previous studies raise questions about the accuracy and legitimacy of theories of patient decision-making, autonomy and agency. I argue in this thesis that these concerns necessitate empirical research into the substantive field, but also a reflexive look at how the empirical and theoretical can be brought together. In the following chapter I therefore turn to an outline of what patient autonomy is commonly regarded to be; why autonomy is considered so important in the medical context; and why a lack of respect for it, and a lack of full awareness of what autonomy means, is problematic for both theory and practice.

Chapter 3

The Theoretical Framework for the Research

In this chapter I outline the theories that inform the theoretical framework of this thesis. I review and critique the existing theories on autonomy and agency, and provide an overview of the current debate on how to “do” bioethics. In the final pages I outline the analytical framework for the research, situating it within the sociological bioethics that I advocate for throughout the thesis.

3.1 Bioethics, Ethics and Philosophy

3.1.1 *Bioethical Traditions*

One of the more difficult things to define about bioethics is the term itself. One definition that comes close to capturing its complexity can be found in *The Encyclopedia of Bioethics*: “The systematic study of the moral dimensions—including moral vision, decisions, conduct and policies—of the life sciences and healthcare, employing a variety of ethical methodologies in an interdisciplinary setting” (Reich, 1995, xxi). This definition captures the complexity of bioethics as a discipline by outlining the numerous goals of bioethics, that of “moral vision, decisions, conduct and policies”, within a specific context, that of the “life sciences and healthcare”, and it brings to light the most complex aspect of bioethics as an interdisciplinary field, that of the “variety of ethical methodologies in an interdisciplinary setting”, which is a good way of capturing how various disciplines contribute to bioethics through their methodologies.¹⁵

A closer look at the history of bioethics reveals how certain disciplines became integral to the field. In his 1998 book *The Birth of Bioethics* Jonsen argues that bioethics has its roots in medical ethics (Jonsen, 1998, 3), as the Nuremberg Trials (and the resulting 1946 Nuremberg Code) are often seen as the beginning of bioethics as a discipline, because they “initiated an examination by professional persons in science, medicine and

¹⁵ It also leaves the door open for a more serious consideration of sociology as one of the “ethical methodologies” that bioethics uses. I will revisit this during my critique of traditional bioethics.

law of one of modern medicine's central features: scientific research" (Jonsen, 1998, xii). This is a distinctly American view, which is overly focused (in my opinion) on research ethics and law, however it is a distinct moment in time where what is recognised as bioethics today began being put into practice.

While the Nuremberg Code is an important part of the history of bioethics, I would like to focus on Jonsen's account of how bioethics has emerged from medical ethics (Jonsen, 1998, 3). Discussions of medical ethics are seen as early as the Hippocratic Oath, with more regular publications on its nature emerging in the 19th century with Thomas Percival's 1803 work *Medical Ethics* (Jonsen, 1998, 7). Jonsen argues that for over a century medical ethics was chiefly concerned with the physician, his [*sic*] behaviour, as well as his character and his duty/social responsibility to his patients (Jonsen, 1998, 6–8); what Jonsen describes as "an ethic of competence" (Jonsen, 1998, 8). This physician-centric medical ethics became increasingly challenged in the 1950s by significant medical and technological advances that Jonsen argues turned medicine from a straightforward face-to-face encounter into something more complicated and impersonal (Jonsen, 1998, 11). The advent of definitions like "brain death" and medical advances such as organ donation meant that the duty/responsibility of the physician to their patient (a focus of medical ethics) became more difficult to define; in particular new questions emerged about what was a medical benefit, what was medical harm and why that distinction mattered. The medical discipline turned to those academic disciplines that had traditionally answered these difficult ethical questions: namely theology, philosophy and law (Jonsen, 1998, 11).

For years these 'classical' disciplines dominated the bioethics scene, in part because, as Jonsen argues, they had gotten in on the ground floor and "these professional students of ethics moulded these conversations [about the life sciences and medicine] into a shape designed by their disciplines, their traditions, and their personalities" (Jonsen, 1998, 34). The hope was that these disciplines would be able to develop procedures that would help people reach decisions about difficult questions in medicine and the life sciences (Jonsen, 1998, 326). This meant that the way bioethics was "done" throughout the mid-20th century was distinctly philosophical in nature because, as Daniel Callahan argued in the first issue of the *Hastings Center Studies*, "the traditional methodologies of philosophy and theology are indispensable [to bioethics]" because they offer

“standards of rigor which can and should come into play, bearing on logic, consistency, careful analysis of terms, and the like” (Callahan, 1973, 71).

Jonsen’s account of the birth of bioethics is focused on the American birth of bioethics, and as a result it does not capture all the nuances of the development of the discipline internationally. However what Jonsen’s account does capture is the move from medical ethics to something broader, a moral inquiry into the practice of both medicine and science. As such the methodology of bioethics remained steadfastly philosophical for many years, with the social sciences haphazardly tacked on to the already “established” discipline of moral philosophy.¹⁶ Bioethics has been largely confined (especially in America) to philosophy, theology, law and medicine departments. Despite cautions that bioethics must consider the social, sociology has remained until very recently a marginalised resource with which to attack bioethical problems (Haimes, 2002; Hedgecoe, 2004). I examine the lack of sociology in bioethics, and how this can be resolved, later on in this chapter. For now I would like to give an account of how bioethics is traditionally done, focusing on some of the more prominent ‘ways’ of doing bioethics.

3.1.2 *Ethics and Bioethics*

To understand how traditional bioethical study is conducted, it is necessary first to understand what ethics is and how moral philosophical study is carried out, as the two share much of their methodology. Jonsen calls ethics the “rules, customs and beliefs of a society”, but also “the scholarly effort to articulate and analyse those rules, customs and beliefs” (Jonsen, 1998, 6). This is a useful way of understanding ethics as it justifies the use of “scholarly effort” other than philosophy by highlighting the link between ethics and society.

In the field of philosophy “ethics” is a wide term encompassing much more than the customs, rules and beliefs discussed above. The term ethics “is a generic term covering several different ways of examining and understanding the moral life” (Beauchamp and

¹⁶ Around the turn of the century and into the early 2000s social scientists such as Haimes (2002) and Hedgecoe (2004) became more vocal about the role of the social sciences. I will address this later on in the chapter, but have included a mention here to give an idea of the timeline between the Nuremberg Code of 1946 and the beginning of the recognition of the role that the social sciences play in bioethics.

Childress, 2009, 1). Bioethics specifically examines this moral life within the broad context of the life sciences and medicine. In recent years ‘bioethics’ and ‘medical ethics’ have often been conflated, however, I will distinguish between the two and define medical ethics as the ethical *practice* of medicine, and bioethics as the more general study of the morality of the life sciences and medicine. Applied ethics, often referred to as practical ethics (Beauchamp and Childress, 2009, 1) examines the “theoretical and practical moral issues involved in specific contexts” (Fisher, 2009, 4). When this “specific context” is medicine, applied ethics becomes applied biomedical ethics or applied bioethics,¹⁷ one of the more common ways of “doing” bioethics. A normative approach to ethical study, applied bioethics attempts to determine which moral norms should be used for guidance and evaluation of action with reference to the fields of the life sciences and medicine (Beauchamp and Childress, 2009, 2). Applied bioethics generates statements about what “ought to be” the case, thus conferring ethical value to certain actions over others (Beauchamp and Childress, 2009, 2). The conclusions reached by applied bioethicists are often in the form of action-guiding statements intended for use in public policy and clinical practice.

3.1.3 *Philosophical Bioethics: King of the Castle?*

Philosophical bioethics, or traditional bioethics as it is sometimes referred to, explores normative principles in the context of bioscience (Ives and Draper, 2009, 250). Philosophical theoretical frameworks for bioethics include forms of deontology, utilitarianism, consequentialism, virtue ethics (both ancient and modern), casuistic ethics and contractarian ethics (Scully, 2008, 39). Traditional bioethics retains much of its philosophical legacy in its methodology, and “is generally characterised by analytic methods rooted in philosophical arguments” (Ives and Dunn, 2010, 257). These analytic methods are used to proscribe or prohibit certain actions and problematize certain areas of science and/or medicine (Ives and Dunn, 2010, 257). Philosophical bioethical inquiry follows a rough pattern that “entails identifying an ethical problem and justifying a normative solution to that problem, of the kind: In circumstance C one ought to perform action A” (Ives and Draper, 2009, 250). In essence, philosophical bioethics applies a general norm (meaning a principle, rule, ideal, right etc.) to a clear case that falls under

¹⁷ The terms ‘bioethics’ and ‘biomedical ethics’ are synonymous. I will use the term bioethics throughout this thesis.

said norm (Beauchamp and Childress, 2009, 369). This is a top-down approach that defends rules and principles, which then give moral judgements based on an appeal to full ethical theory (Beauchamp and Childress, 2009, 370). Philosophical bioethicists appeal to abstract theoretical principles, rationality and logic in order to solve the bioethical conundrums that they encounter.

Ethical principlism, where ethical principles dictate when something is right or wrong, is one of the more prominent tools of the philosophical bioethicist (Parker, 2009, 202). Beauchamp and Childress' bioethical principles are perhaps the most well-known product of ethical principlism (Hoffmaster, 1994, 1155; Beauchamp and Childress, 2009). Beauchamp and Childress claim that applied bioethics assumes a common morality that is universal: an overarching set of norms that taken together are "applicable to all persons in all places, and we rightly judge all human conduct by its standards" (Beauchamp and Childress, 2009, 3). They argue that this common morality forms the basis of bioethical principlism, which can be understood as an analytical framework set within the general norms of common morality that can be universally applied (Beauchamp and Childress, 2009, 12). Bioethical principlism applies these norms to the life sciences and medicine, using four principles to help guide action and generate further specific rules of conduct: respect for autonomy (sometimes called respect for persons), justice, beneficence and non-maleficence (Beauchamp and Childress, 2009, 12). While the principles are supposed to carry equal weight, the principle of respect for autonomy has sparked academic and practical interest such that this principle almost eclipses the other three in the literature (Fox, 1996, 6; Jonsen, 1998, 334; Callahan, 1999, 277; Beauchamp and Childress, 2009, viii).

Using these principles, philosophical bioethics aims to analyse bioethical issues by conducting thought experiments, highlighting inconsistent reasoning and looking for logical fallacies, often developing ethical theories entirely without reference to (or investigation of) the activities in practice (Ives and Draper, 2009, 250; Kerr and Shakespeare, 2002, 188). This is because philosophical bioethics generally strives to achieve Nagel's 'view from nowhere' in order to access an unbiased truth about medicine and science, not unlike scientific investigation itself (Nagel, 1986),¹⁸ that emphasises a commitment to objective, transcendent knowledge and universalizability.

¹⁸ This is not to ignore the extensive debates about knowledge in science, however I will not be addressing these debates here.

These analyses give the philosophical bioethicist normative prescriptions (which some bioethicists might argue are “truths”) about the bioethical issue at hand. These prescriptions can then be carried forward as action guidance (applied bioethics) about choice and progress in medicine and science. They are often fed back into the theories from which they were produced to serve as reinforcing examples of that theory’s practicality.

3.1.4 *The Social Science Critique*

Recently there has been a move away from philosophical bioethics as sole arbiter of the ‘right and wrong’ of the life sciences and medicine. Hedgecoe and others, argue that there is a gap between bioethical theory and practice which “undermines the validity of [bioethical] claims, and reduces its contribution to policy debates surrounding bioethical issues” (Hedgecoe, 2004, 121). This criticism reflects the increased demand for more substantive, practical solutions to many current bioethics problems. In parallel to this call for substantive solutions, a number of concerns with philosophical bioethics have emerged, many of them culminating in a call for the increased use of social sciences in bioethics. I would like to address these concerns here.

Many of the critiques of traditional bioethics stem from its “grounding in applied philosophy and moral theory” (Hedgecoe, 2004, 123) which makes central to bioethics the view that “moral norms are binding or prescriptive solely in virtue of their rational justification” (Hoffmaster, 1994, 1155). Due to the influence of moral philosophy on bioethical inquiry, much of the emphasis has been on outlining “good moral practice in medicine [which] can be achieved by the application of pre-prepared ethical theories to specific situations—hence the ‘applied ethics model’” (Hedgecoe, 2004, 124). Critics of the traditional, philosophical bioethics model argue that it fails to provide guidance to real life situations (Hedgecoe, 2004, 125; Hoffmaster, 1994, 1156).¹⁹ This is problematic as the “real life situations” that Hedgecoe describes are the salient feature of bioethics: particular individuals, in a particular context that has been ignored by traditional bioethics due to its universal/generalizable orientation. Ives and Draper are quick to point out that “there is something lacking in an approach that appeals solely to

¹⁹ And also misses out on crucial aspects of moral life, as feminist bioethicists like Margaret Urban Walker argue.

abstract theoretical principles and rationality” (2009, 250), when the bioethical context is very much rooted in the real world practices of medicine and the life sciences. Charles Bosk offers a more scathing account of the same concerns arguing that “there are not many areas where we equate theoretical and practical wisdom [...] the idea that moral theory can be used to solve practical problems cuts against so many beliefs prevalent in the medical, academic, or larger political culture that we might wonder about its certainty to the bioethics enterprise” (Bosk, 1999, 55).

Bosk argues that the philosophical origins of bioethics put undue emphasis on discovering a “single, correct solution for each ethical problem, which is largely independent of person, place and time” (Bosk, 1999, 62). The push from traditional bioethics on universal ethical principles (such as Beauchamp and Childress’ four principles) leaves little room for this “real world” and instead “champions” universal ethical principles, which ignore social/cultural factors, viewing them as unimportant “epiphenomena” (Hedgecoe, 2004, 125).²⁰ The lack of emphasis that traditional bioethics places on empirical evidence and social phenomena is problematic given that “what counts as an ethical problem in the first place, prior to the application of ethical theory, is socially constructed” (Hedgecoe, 2004, 126). In short the very practices that bioethics seeks to examine are social practices, and whether something is considered ethical is strongly tied to the norms, values and beliefs of the culture within which the practice is examined (Haimes, 2002, 98).

This problem is exacerbated by the apparent lack of connection between philosophical conclusions and what actually happens in practice (Hoffmaster, 1994, 1157). The applied ethics model that is dominant in bioethics assumes that “social reality cleaves down neat philosophical lines, with theoretical categories matching those in social reality” (Hedgecoe, 2004, 130). Hoffmaster raises similar concerns, arguing that there is “a gap that exists between the general concepts and categories of moral norms and the particularities of actual moral situations. The applied ethics model assumes that moral problems come neatly labelled and categorised, and that their preassigned categories match those in the norms” (Hoffmaster, 1994, 1157). To further this point, Hedgecoe gives the example of models of the patient–doctor relationship, arguing that philosophical theories are too divorced from the actual social reality, and as such

²⁰ This is a complaint that I will show is already present in Giddens’ (1979) concerns with philosophical theories of action, as well as Bauman’s (2002) critiques of universal moral theories.

bioethics done using *only* the applied ethics model “does not have the right tools to resolve substantive moral problems, external to these categories themselves” (Hedgecoe, 2004, 130).

The applied ethics model also assumes that the ways in which people make decisions can be mapped on to the various philosophical moral theories it uses. However, as Haimés and Whong-Barr’s work has shown, patients make context specific choices that do not necessarily involve complicated ethical calculations within a prescribed framework (as reported in Haimés and Williams, 2007, 463; see also Haimés and Whong-Barr, 2003, 2004a and 2004b). The data from their research suggests that contrary to the applied ethics model, “all parties are constructing themselves as more complex, responsive, ‘ethical beings’ who bring a range of ethical and social considerations to decision making” (Haimés and Williams, 2007, 463). In other words, participants from their research were not quoting complex moral principles and beliefs, or even some overarching ethical system that they ascribed to; instead they identified with the ambition of “being ethical”, while also constructing “being ethical” within a particular context with accountable reasons. Based on this, Haimés and Williams identified within that data “the social embeddedness of ethical understandings and moral reasoning whilst noting the strongly ethical nature of the discourse used to express ideas [in this case] about [the donation of tissue to a genetic database]” (Haimés and Williams, 2007, 463).

It seems that the universality of the applied ethics model may be too complex and abstract, if not completely irrelevant, for individuals in the real world to identify with. These applied ethics models may in fact be an inappropriate starting point of any analysis of “ethical issues”. Instead, the starting point should be what is seen to constitute an “ethical issue” within the social context being analysed. Further, patients’ inability to express themselves beyond “it just seemed right” need not indicate a lack of ethical knowledge that might otherwise help them make sense of the theories, but instead the level of embeddedness of certain moral intuitions, and the way these moral intuitions are used by different individuals in different contexts.²¹

²¹ In fact, moral theory may actually complicate matters by implying that individuals should only make choices that are in line with a specific moral theory, but may be instinctively the wrong choices for them to make in a particular context, despite it being “correct” according to the applied ethics model.

While the moral philosopher “cannot conceive of an ‘unprincipled’ morality” (Bauman, 2002, 31), sociological study has shown that the universal moral theories in traditional bioethics seem in practice to be epistemologically and ontologically limited, inappropriate or even wrong, thus prompting the social science critique of traditional bioethics. Philosophy can identify ways that decisions are made, and develop value systems, for example, but individuals in practice do not necessarily subscribe to these systems. When making a decision people are likely to have a complex set of reasons why they made it, none of which include “I made this decision because I’m a moral particularist”.²² While some people’s decisions (what could be understood as lay moral reasoning) may occasionally fit into the framework of, for example, consequentialism, the sociological critique of traditional bioethics argues that this does not mean that individuals ascribe to specific moral theories in their daily lives. The realm of the self-identifying consequentialist, deontologist or moral particularist (for example) belongs to that of philosophy where these are terms that carry technical weight within the discipline. Much like how a parent putting a plaster on their child would not call themselves a doctor because they are performing a medical action, an individual making a moral decision based on the consequences of their actions (for example), does not call themselves a consequentialist simply because their choice happened to fall under the purview of that particular moral theory *this time*. Furthermore given that individuals do not identify with these terms, is it analytically useful to understand their actions within such theoretical moral frameworks? In short, it appears that individuals do not make consistent choices in line with moral theories because, for the individual, the decisions are *context specific*, not *value system specific*.

These critiques, and their examples, make it clear that ethics *is* and should be considered a key area of study in the social sciences. As Haimés argues, ethics is “embedded within those aspects of the social world that tend to be taken as given, or as unproblematic, features of the world, by the normative statements of ethicists in general” (Haimés, 2002, 98). These aspects of the social world described by Haimés are not, using Hedgecoe’s words, unimportant “epiphenomena”. To ignore the social world is to ignore a significant part of ethical study. As I argue in the following section of this chapter, the social sciences, and in particular sociology, contribute theories, epistemological frameworks and methodological skills and techniques that interrogate

²² Moral particularism (most notably defended by Jonathan Dancy in his 2004 book *Ethics Without Principles*) argues that there are no overarching principles that can be used in every case to make a moral judgement, instead only “rules of thumb” to help guide choice.

and engage with what Bauman describes as our “messy” human reality (Bauman, 2002, 32; Haimés, 2002, 106). The theories and methodologies that stand behind ethnography, participant observations, in-depth interviews etc., allow social scientists to access this “messiness” through the lived realities of individuals in society, allowing for discovery of how it is that “people think and act ethically in their everyday lives” (Haimés, 2002, 106). These observations can then be fed back into the bioethical theories that philosophers argue should govern the “oughts” in our lives; namely the norms about behaviour and practice in medicine that bioethics seeks to critique, define and defend.

3.2 Sociology, Ethics and Agency

In many ways this so-called “new” interest from sociology²³ in bioethics is neither surprising nor even all that new (Haimés, 2002; Haimés and Williams, 2007); sociology has always taken an interest in ethics, though not always explicitly under the title of ‘ethical inquiry’ (Haimés, 2002, 94). As Haimés argues, the domain of social life labelled “ethics” is routinely shaping and being shaped by major social forces, is historically and culturally located, works in conjunction with ‘key social institutions’ and helps to define social groups such as gender, sexuality and profession (Haimés, 2002, 98). “Ethics”, in short, is social. To understand how sociology contributes to bioethical inquiry, it is important first to understand the strong tradition of ethical inquiry in sociology, in particular the sociology *of* ethics. These are important arguments to make as much of the current literature surrounding the use of sociology in the field of bioethics focuses on the problematic claims that somehow sociology and ethics have been kept separate in the past (and should continue to be kept separate), and that this separation has contributed to sociology being ‘left out’ of the disciplines that make up the interdisciplinary field of bioethics.²⁴ Recent attempts to bring sociology into bioethical inquiry, by using empirical methodology borrowed from sociology, treats the *whole* of sociology as a mere methodological tool. Instead, I argue that sociology should be considered one of the disciplines that contribute to the study of

²³ Throughout this thesis I will predominantly use the term “sociology”, however I will occasionally use “social sciences” and “sociology” interchangeably when referring to their role in bioethical inquiry. This is not uncommon, and I will be doing it in line with those reasons set out by Haimés in her 2002 article, page 91.

²⁴ A counter-argument may be that sociology may not be interested in contributing to bioethics and for this reason has allowed itself to be “left out”. Regardless “ethics” is part of the social world that requires analysis and by extension bioethics requires this same analysis. As such I would argue that sociology is interested in the phenomena studied in bioethics.

ethics and ethical theory²⁵ (Haimes, 2002). This is a subtle, but very important distinction as it clarifies that sociology and social science methods are not simply the handmaidens (to borrow from Haimes, 2002) of philosophical ethical study, but instead that sociology brings a set of critical analyses to the kinds of questions that ethics traditionally asks, and contributes to the methods that ethics traditionally uses.

3.2.1 *Sociological Work on Ethics, Morality and Agency*

The focus of this research project is on patients' decision-making and bioethical conceptions of autonomy. In examining sociological work I found that the bioethical term "autonomy" and the sociological term "agency" have much in common. In this section I examine sociological research in ethics through the lens of agency, looking at both Weber and Bauman's understandings of agency, morality, and ethics to illustrate the ways that sociology examines "ethics", before focusing on Giddens' accounts of agency.

In his study of ethics, Weber argued that it should focus on how individuals and society interact with each other, as "how one ought to be and how one ought to act can influence a broader cultural trend towards the emergence of certain types of society and away from other possible lines of development" (Haimes 2002, 94). Further, Weber argued that life itself is 'charged' with moral meaning (Weber 1958; Bauman, 2002, 5). If so, then this gives moral value to every aspect of modern life (including medicine and science). This in turn opens up every aspect of modern life to moral and ethical scrutiny, thus obligating individuals to determine what in life has moral value. By arguing that life was 'charged' with moral meaning, Weber confirmed that there was a very real need to study and observe morality in everyday life.

Bauman defines 'moral' as "the aspect of human thought, feeling and action that pertains to the distinction between 'right' and 'wrong'" (Bauman, 2002, 4). In defining moral through the "human", and more specifically through human action, Bauman is setting up a distinctly sociological conception of morality that is seen through the lens

²⁵ The reader will notice that there is a lot of movement between 'ethics' and 'bioethics'. I am not conflating these two terms, instead I am moving between what I consider to be an overall field of ethics and a sub-area of that field: bioethics. In other words, it is crucial to understand how sociology and ethics come together in order to understand how the sub-area of sociology and bioethics come together.

of human life and human interaction. Notions of right and wrong can only come from human agency, and then become set within human/social institutions. However, Bauman's definition is deliberately incomplete as it does not tell people what 'right' and 'wrong' are or how to distinguish between right and wrong actions. Bauman argues that this has changed over time as those actions that were 'weighed' right and wrong were initially set out on a *divine* scale (Bauman, 2002, 4), and as part of a social institution, i.e. religion. Bauman argues (though I disagree) that this is no longer the case, and that in the postmodern era people no longer know where to acquire moral knowledge and skills, and so knowing which actions are 'right' is unachievable. For Bauman, being postmodern means that there is a moral uncertainty that exists, such that people are likely to accidentally act immorally even when the original action was done without malice.²⁶ He argues that ethical rules about how certain actions to certain people constitute morally good behaviour is influenced by social institutions (Bauman, 2002, 18) and by extension people are morally ambivalent (Bauman, 2002, 10).²⁷

– *The post-religious moral world* –

Without the religious basis of morality, moral philosophy has filled that gap with universal moral frameworks supposedly accessible to all individuals. These universal frameworks for morality are still based on the premise that people must be prevented from using their freedom to do 'wrong' things (Bauman, 2002, 7). In other words, there is still an overarching set of 'right actions' thought to be generalizable, as with the "old" religious morality. However, the universal approach to moral theory is still problematic as it does not consider the individual or the social with the same weight as it does generalizability or consistency. Universal moral theories fail to recognise that individuals are an active part of the 'universe of social activity' that surrounds them, and when faced with difficult and intimate problems, they will alter that universe in one way or another (Giddens, 1991, 12).²⁸

²⁶ Though, it is important not to conflate knowing or having confidence in what to do and knowing what to do, but then actually being wrong. Both are possible, especially in the postmodern world described by Bauman.

²⁷ Another way of considering this argument is to not see people as morally ambivalent because the moral theories are changing, but instead recognise that there are various combinations of moral theories that inform moral choices, and thus are still relevant.

²⁸ I believe this supports Bauman's point that individuals do not make moral choices based on universalizable theories, but instead on a number of different and ever changing criteria and influences specific to the context and their own personal values.

Instead, while the focus of moral assessment is often on chosen actions, Bauman argues that these actions should be viewed in a context-specific light where “actions may be right in one sense, wrong in another” such that actions, and specifically right actions are no longer universally derived (Bauman, 2002, 5). A fool-proof, universal ethical theory offers little help to the individual, as “an ethics that is universal and ‘objectively founded’ is a practical impossibility; perhaps also an oxymoron” (Bauman, 2002, 10).

– *The flaws of moral universality* –

The push towards universality in ethical/moral theories is premised in part on the claim (based originally in philosophy) that universality affords individuals some sort of authority over more contextual theories, rules and choices, and that this authority is a ‘good’ thing (Bauman, 2002, 39). Universal theories are often considered ‘better’ and thus more ‘moral’.²⁹ However, from a sociological perspective, people interact with each other through social encounters and these encounters are not universalizable, just as individuals in the encounter are not universalizable. The “context” cannot be removed and so to ignore it or gloss over it, as universal moral/ethical theories do, is to ignore individuals and their relationships. Ignoring the context is a fatal error: the social relationships that we have with each other (what Bauman calls the “I versus other” relationship) are what make social encounters moral encounters (Bauman, 2002, 47).

Social encounters are moral encounters because ‘the moral person and the object of that person’s moral concern cannot be measured by the same yardstick—and this realisation is precisely what makes the moral person moral’ (Bauman, 2002, 51). This idea is best understood with an example (taken from Bauman, 2002, 51): Take the following as a moral statement “I am ready to die for others”. While this may require me to die for others, it does not require others to die for me. It is my decision and the importance of the statement is measured by *my* moral yardstick, not theirs, therefore they are not bound by my moral yardstick as they have their own and will measure the above statement against their own yardstick. This means that the moral command cannot be universalizable, as this would be unfair to those who have ‘larger’ moral yardsticks than others. Bauman argues that this makes moral choice individual and context specific, but also inherently social without being universal (Bauman, 2002, 54). Whether or not someone will die for another is their own choice, no one else’s and is directly linked to

²⁹ While it is necessary to be fair to moral philosophers here and point out that when they are arguing for “universal moral theory” they are most likely aiming for universality as an ideal (while recognising that in practice it will not be possible) however, even striving for this ideal is problematic.

how they themselves relate to society and the actions they deem are appropriate within society.

While the idea of different moral yardsticks may seem an overly complicated and theoretical concept, it is in fact grounded in the sound and rather logical idea that humanity is neither generic nor universal, and so moral responsibility is individual and thus must be carried individually (Bauman, 2002, 54). This is a distinction that helps to illustrate many of the concerns expressed later regarding bioethical accounts of autonomy. Bauman argues that this makes morality and moral choice non-rational and incalculable (Bauman, 2002, 60). I disagree. Instead I argue that moral choice is individual and context specific: to consider it (and society) to be untouched and uninfluenced by the concepts of universality that have come before (simply because we are in a postmodern era) would be to ignore a crucial piece of the moral action/agency puzzle. From a sociological point of view, there are socio-culturally embedded beliefs in “seemingly universal ethical issues” that require a recognition of the effects of universality on the individual (Haimés and Williams, 2007, 459). While moral responsibility may be individual, we are still social people, who live in social settings in which we invoke the idea of codifiable rules, many of which regulate our actions towards each other. It is exactly for this reason that ethical issues have been, and are still, studied through a sociological lens in order to identify what influences moral choice/agency and how these influences affect individuals and society.

While more broadly concerned than Bauman with issues of individualism, liberalism and modernity, Foucault also saw the contemporary world as a venue for individuals to shape themselves into ‘moral agents’ (Haimés, 2002, 95) and shied away from universal moral theories. He shared similar ideas about the importance of context as well, arguing that “[t]he world we know is not this ultimately simple configuration where events are reduced to accentuate their essential traits, their final meaning, or their initial and final value. On the contrary, it is a profusion of entangled events” (Foucault, 1984, 89, as cited by McNay, 1992, 13). It is this “profusion of entangled events” (not unlike Bauman’s “messiness”) that influences our actions, but remains neglected by universal moral theories. Campbell argues that for Foucault “moral principles are ethically insufficient” and that Foucauldian ethics “requires a process of reflection not only about the relationship of self with self, but also of the relationship one has with others” (Campbell, 2010, 27–28). Reflexivity in ethics (and in agency) is something that is also

picked up in Giddens' work on agency and I would now like to turn to look at his sociological work on agency and ethics.

3.2.2 *Giddens and Agency*

A discussion about sociology and ethics would be incomplete if it did not include some consideration of agency, as the shaping of moral agents occurs through the interaction between the agent and the society in which they live. Sociologists have tried to capture how decisions are made the same way that bioethics has tried to prescribe the 'right' way that people should make decisions.

Giddens defines agency as a "stream of actual or contemplated causal interventions of corporeal beings in the ongoing process of events-in-the-world" (Giddens, 1979, 56). I would like to use a simplified version of this definition: agency is our ability to make our own choices and act on our own will. Agency and action are often used as interchangeable terms in the literature, and I do so here as well. In line with Giddens, I also understand agency to be influenced by, and to interact with, society and other actors. It is also subject to, and creates, normative judgements. These characteristics lend a moral quality to agency, linking ethics and agency in the social sciences.

Giddens' understanding of agency is a distinctly sociological way of thinking about decisions and actions. He argues that personal and social spheres influence each other. When dealing with difficult and intimate problems "individuals help actively to reconstruct the universe of social activity around them" (Giddens, 1991, 12). I would like to unpack Giddens' theory of agency as it is closely related to the underlying epistemology of this thesis and informs the methodology of the research as well.

Giddens differentiates his theory of agency by arguing that the philosophy of action focuses on the nature of reasons and intentions in human activity (Giddens, 1979, 50). Similar to Bauman, Giddens is unhappy with philosophical theories of action as they lack two crucial considerations that, for him, fundamentally link agency and social structure (Giddens, 1979, 54):

- 1) incorporating “temporality into the understanding of human agency”
- 2) incorporating “power as integral to the constitution of social practices”

Time and power are two social elements that are often not accounted for in bioethical theories of autonomy and decision-making (see chapters 5 and 6). Unlike traditional, bioethical theories of autonomy (outlined in section 3.3) Giddens argues that all social practices are situated within time, space and structure, and that power is inherent to all three (Giddens, 1979, 54).

If all social practices are situated within time, space and structure, then action and agency are as well. Giddens argues that “[a]ction or agency [...] thus does not refer to a series of discrete acts combined together, but to a continuous flow of conduct” (Giddens, 1979, 55). Agency involves intervening with the world and “it is a necessary feature of action that, at any point in time, the agent ‘could have acted otherwise’: either positively in terms of attempted intervention in the process of ‘events in the world’, or negatively in terms of forbearance” (Giddens, 1979, 56).³⁰ Further, if action and agency are continuous then this implies a reflexive monitoring of action on the part of the actor, in particular the intentionality of the action (Giddens, 1979, 56). However this intentionality does not mean that agency implies constantly knowing or giving a purpose to the action, instead “such intentionality is a routine feature of human conduct, and does not imply that actors have definite goals consciously held in mind during the course of their activities” (Giddens, 1979, 56). This is an important distinction, as bioethical concepts of decision-making often decree that decisions are only valid if they are consciously reflexive and goal-oriented for the individual making them. If we take Giddens’ view, this is not to say that people make decisions like animals (without reflection, or without goals) all the time. Instead, Giddens argues that what sets us apart is the “accountability of human action”, where accountability refers to how “the accounts that actors are able to offer of their conduct draw upon the same stocks of knowledge as are drawn upon in the very production and reproduction of their action” (Giddens, 1979, 57). Giddens’ views on agency are appealing as they are situated within the same shared history as the epistemological and methodological frameworks of this research project (interpretivism), which is premised on the view that people can and do tell us about their own lives. *However*, we are not always aware of *how* we make

³⁰ I would like to add to this by arguing that Giddens’ “could have acted otherwise” can be understood as a nod to the importance of respecting autonomy, but in a much more sociological way.

decisions and this Giddens calls “practical consciousness” (Giddens, 1979, 57). It is this practical consciousness that is often left out of bioethical accounts of autonomy. Practical consciousness is the “tacit knowledge that is skillfully applied in the enactment of courses of conduct, but which the actor is not able to formulate discursively” (Giddens, 1979, 57). Practical consciousness is a vital part of agency, which, when combined with the reflexive monitoring of action that Giddens argues we all do, brings together a more complete understanding of how people both act and (post-hoc) rationalise their actions.

However, this understanding of action does leave some areas that must be addressed. Giddens argues this as well, adding to his theory of reflexive monitoring by including both the behaviour of the actor *and* the setting of the interaction. He argues that the setting of the interaction is crucial to understanding agency as sometimes actors give reasons for their actions that are not the real reasons for the action. This occurs due to stocks of knowledge that the actors have for social conduct in different encounters with other actors that invariably are connected in some way with the setting of the interaction, and to the mutual knowledge that the actors have when they encounter each other (Giddens, 1979, 58).³¹ These interactions, or “social encounters” as Giddens also calls them, are a fundamental part of agency and justification of action. As Giddens puts it: “The giving of reasons in day-to-day activity, which is closely associated with the moral accountability of action, is inevitably caught up in and expressive of, the demands and the conflicts entailed within social encounters” (Giddens, 1979, 58). I interpret this as meaning the reasons people give for doing things are influenced by what is considered appropriate in social encounters, as well as the conscious and unconscious influences from the setting and the actors of the interaction.

Giddens’ account of agency is appealing for two reasons. First, it is developing in a distinctly non-bioethical way, and so brings a contrast to previous views; and second, Giddens discusses agency *and* morality, which is much closer to the concepts of autonomy that will be discussed in later sections of this chapter, thus giving a point of comparison, but also points of commonality. These points are important to consider as both agency and autonomy are theories about action. Neither exists in the other’s discipline the way it is understood in its own, however they are in many ways comparable and compatible. Finding these points are important as autonomy seems to

³¹ For this research project a good example would be meeting a doctor in a hospital.

imply normativity in bioethics; there is a wrong way to allow someone to make a choice and there is a right way. There is a wrong time to let someone make their own decisions and there is a right time to do so. Perhaps most simply it is wrong to constrict someone's autonomy and right to promote and protect autonomy. The entire concept of autonomy has come to be centred on a normative understanding of decision-making and agency. If I am to use a sociological approach to help illuminate and perhaps even contribute to the concerns raised about bioethical concepts of autonomy, it is necessary to have some points of similarity between sociological concepts of agency and bioethical concepts of autonomy. For this reason it is necessary to discover if agency can be normative.

3.2.3 Agency and Ethics: Can Actions be Normative in Sociology?

For Giddens agency has a normative quality in so much as it relates to structures and systems (Giddens, 1979, 59–62). A structure is a pattern of social relationships and these relationships are organised as systems, which necessitate various rules and regulations that are played out in interactions within these systems (Giddens, 1979, 62). Institutions, found within systems and structures, are “widespread among the members of a community or society” and to study these is to study the “mode in which actors draw upon structural elements—rules and regulations—in their social relations” (Giddens, 1979, 80). These rules and regulations are what lend the normative quality to Giddens' agency. While actors are free to choose and have available to them this notion of “could have acted otherwise”, they cannot act *any* way they choose without moral judgement. Giddens uses the example of “going for a walk” to illustrate this point (Giddens, 1979, 83). “Going for a walk” involves norms (conscious or unconscious) since going for a walk can *mean* different things. One can go for a stroll down the pavement on a nice day, *or* one can walk down the middle of a busy street, disrupting traffic and endangering their life and those of the drivers. While both options of “going for a walk” are possible, only one option (the stroll on the pavement) is considered morally appropriate (Giddens, 1979, 83). As I argued earlier, agents are reflexive about their actions, and therefore acts are attributed with normative value. By extension the decision to perform the act has normative value as well. This link between agency and moral normativity is the common point of interest between sociology and bioethics, as autonomy and morality are strongly linked as well. While sociological accounts of

agency often focus on how the actor/agent makes and carries out a decision, bioethical accounts of autonomy are concerned with the normative value of how the decision is carried out. Giddens account of agency also considers the normative value of how decisions are made within the context of the social world, making it a good sociological theory to consider alongside bioethical autonomy.

3.2.4 Power and Agency

One final aspect of agency that is very rarely addressed in the bioethical literature, but is often addressed in the sociological literature, is that of power. The connection between power and agency also figures more prominently in later chapters of this thesis. I continue with Giddens' definition of power, as his approach to understanding the connection between power and agency closely informs the epistemological and methodological underpinnings of this thesis.³²

Giddens writes that: "Action involves intervention in events in the world, thus producing definite outcomes, with intended action being one category of an agent's doings or his refraining. Power as transformative capacity can then be taken to refer to an agent's capabilities of reaching such outcomes" (Giddens, 1979, 88). This is a specifically Hobbesian/Weberian view that sees power as "the capacity or likelihood of actors to achieve desired or intended outcomes" (Giddens, 1979, 88). Power does not have to be viewed only in a negative light, and Giddens makes the interesting and valid point that many discussions about power revolve around the idea that power is: Person A being influenced (or even forced) by person B to do something not in A's interests (Giddens, 1979, 90). This is a naïve way of viewing power because, as Giddens points out, person A can be neutrally or even positively influenced by person B as well.³³ How power is understood is contextual to the individual person.

Perhaps the best way to understand power dynamics between actors in social encounters is to reconsider Giddens' concept of agency seen earlier, only this time including power

³² There are a number of scholars who have written on power (notably Foucault, Marx and Weber in sociology); however I will not be engaging with their accounts of power in this thesis.

³³ Many concepts of autonomy in bioethics seem to centre on this same negative idea of power where A is the patient and B is everyone else, such that somehow the only valid relationship to power is A being influenced by A to do something in the interest of A, which seems naïve and unrealistic given that we are social beings and may very well want to be influenced by B if we hold B in high regard.

in the definition. As Giddens puts it: “Power in social theory [...] is centrally involved with human agency; a person or party who wields power could ‘have acted otherwise’, and the person or party over whom power is wielded [...] would have acted otherwise if power had not been exercised” (Giddens, 1979, 91). This frames agency within the power dynamics that are inherent in social encounters and within social institutions, thus highlighting the importance of the effect of conscious/unconscious instances of power dynamics on agency.

But is there a normative quality to this power dynamic in agency? Is the exertion of power over agency right or wrong, or a little of both? This is a more difficult question to answer. Taking Giddens’ approach to power and examining it further finds that the exercise of power can be intentional or unintentional: “An agent can exercise power without intending to do so, or even wanting to do so: [...] the notion of power has no logical ties to motivation” (Giddens, 1979, 92). Giddens argues that any understanding of power as being solely intentional is simply vestiges of political concepts of power where “decisions are clearly articulated in relation to ends that actors pursue” (Giddens, 1979, 93). Intentional actions and power, he argues, have a particular form: “a range of notions such as ‘compliance’, bargaining’, etc. apply only within such a [political] context” (Giddens, 1979, 93). This suggests that for Giddens power is not always normative: if power can be unintentional, can we hold the person wielding the power morally culpable? However if power is normative, can having power over someone or their actions be positive, or pushing it further, be normatively ‘right’? Giddens seems to suggest that yes, it is possible if power is viewed relationally. If power is relational, then it makes the power dynamics between two actors a two-way street, where “power relations are relations of autonomy and dependence, but even the most autonomous agent is in some degree dependent, and the most dependent actor or party in a relationship retains some autonomy” (Giddens, 1979, 93).

Perhaps the best way to understand this is through an example pertinent to my research. Considered in the context of the healthcare system this relational power may go some way to understanding the power dynamics that exist between doctors and patients, where both parties have differing levels of power, but each still has some power. For example, with regards to information, doctors rely on the patient to provide them with information that they cannot access, the patient history, while the patient relies on the doctor to use that information, in conjunction with their medical training, to devise a

treatment plan. Both require a certain level of autonomy to fulfil their end of the bargain, tipping the balance such that levels of autonomy seem to peak and valley, depending on who needs what information: relatively full autonomy is the peak, while the valley is the loss of power required to get the information to inform the decision in the first place. Neither can make a decision about treatment without relying in part on the other to provide them with the correct information needed to inform the decision. This example illustrates how power viewed relationally provides a more complete understanding of the relationship between patients, doctors and their actions. Relational power also shows how 'having power' can be normative, as it suggests that there are instances when 'having power' is necessary, and thus the 'right' way for agents to interact.

Power and agency come together in a very strong way for Giddens. Even though autonomy and agency are not exact parallels, his conception of the relationship between decision-making and power is drastically different from the way that traditional, philosophical bioethics conceives of autonomy and decision-making, making obvious possible gaps between theory and practice.

3.3 Autonomy and the Philosophical Tradition

Just as sociologists are concerned with agency and decision-making, so is moral philosophy. The study of *patient* autonomy in medicine has belonged almost solely to the realm of applied philosophical bioethics, again reflecting the field's deep roots in moral philosophy. In addition, the bioethical study of autonomy has focused almost exclusively on overt decision-making. In this section I will briefly outline the philosophical conceptions of autonomy, focusing on two significant theories: traditional and relational autonomy.

3.3.1 Traditional Autonomy

Autonomy is a core concept in bioethics (Beauchamp and Childress, 2009, viii; Jonsen, 1998, 334; Fox, 1996, 6; Callahan, 1999, 277). Respect for autonomy is respect for every person's right to make decisions for themselves based on their own values and

beliefs. The importance of patient autonomy in bioethics can be traced back to traditional accounts of autonomy in philosophy (especially political philosophy) that are notable for their reliance on the “individual” and their distinct lack of the social in their conception (Mappes and Degrazia, 2006; Beauchamp and Childress, 2009; Jonsen, 1998, 337). The traditional bioethical view of autonomy is drawn from this philosophical background and is heavily influenced by two major philosophers: Immanuel Kant and J.S. Mill (Mappes and Degrazia, 2006, 45–46; Jonsen, 1998, 334; Beauchamp and Childress, 2009, 103; see also Beauchamp and Childress, 2009, chapter 9). I briefly examine both here.

Kant’s understanding of autonomy is rooted in the claim that individuals must be respected as self-determining subjects, capable of self-governance (Kant, 1964, 108). In particular respect for his third formulation of the categorical imperative, not to treat people as a means but always as an end, has had significant impact on bioethical theories of autonomy (Jonsen, 1998, 335). When they were developing the core principles of bioethics, ethicists and philosophers interpreted this respect to be equivalent to respect for personal autonomy, and support for an individual’s autonomous decision-making. Within the realm of medicine, this concept of autonomy has been reframed to focus on a particular type of individual, “the patient”. This Kantian legacy has informed the traditional view of patient autonomy by stressing the importance of autonomy relying on the patient being an individual,³⁴ rational person. This is particularly due to how Kant describes the ways to achieving autonomy with “self” actions such as, “self-control”, “self-direction”, “self-governance”, and “self-rule”, thus framing autonomy as a condition that is not only important to being an individual, but also a condition that is *required* to be individual in order to maintain the respect that it is given (Mappes and Degrazia, 2006, 46).

J.S. Mill also described persons with individuality as being autonomous “in a very strong sense, reflectively choosing their own plans of life, making their own decisions without coercion or manipulation by others, and exercising firmness and self-control in acting on their decisions” (Mappes and Degrazia, 2006, 46). For Mill there is a powerful connection between a person’s ability to introspectively make a choice and their autonomous status. The individuality of autonomous agents is also the primary concern for Mill (Beauchamp and Childress, 2009, 103). Mill argues that those individuals who

³⁴ Meaning without influence from others.

allow outsiders to choose or influence their life plans have “no need of any other faculty than the ape-like one of imitation” (Mill, 1962, 187). Owing to their different moral theories, Mill and Kant ultimately value autonomy for different reasons and believe that what it means to act autonomously is different as well; however they share the belief that *respect* for autonomy is of the utmost importance for persons and integral to being able to call oneself autonomous (Beauchamp and Childress, 2009, 104). Bioethical constructions of autonomy have been built on these key concepts of individuality, personal introspection, reflexivity and respect for choices made.

Traditional bioethical concepts of autonomy have been largely based on Beauchamp and Childress’ concept of respect for autonomy, which fuses “the Kantian concept of respect for persons with [J.S.] Mill’s quite different notion of liberty; that is, persons’ choice of action should not be obstructed unless those actions infringe upon the liberty of others” (Jonsen, 1998, 335). Because Beauchamp and Childress are concerned with the role of choice in healthcare, their principle of autonomy focuses more specifically on “autonomous *choice*” (emphasis added, Beauchamp and Childress, 2009, 100) whereby autonomous choice occurs when the individual is free from constraint, exercising self-governance, and has sufficient understanding of the information presented to the individual (Beauchamp and Childress, 2009, chapter 4).

In particular, the patient’s ability to understand is considered crucial when making an autonomous decision, and is specially safeguarded in the medical realm such that understanding and patient consent are seen as hand-in-hand with making an autonomous decision; and respecting the decision made is seen as both a negative and positive obligation (Beauchamp and Childress, 2009, 104). Sufficient understanding is interpreted as an understanding not only of what is at stake when one makes a choice and follows through with an action, but also of the implications and possible consequences of the action, and the available alternatives (Mappes and Degrazia, 2006, 42). Beauchamp and Childress illustrate the importance of sufficient understanding with an example from the medical field: “If a misperception prevents a person from adequately understanding the risk of a death and this risk is material to the person’s decisions, then the person’s choice of a procedure does not reflect a substantial understanding and does not qualify as an autonomous authorization [...] A single false belief can invalidate a patient’s or subject’s consent.” (Beauchamp and Childress, 2009, 130). In the medical realm the “informed” part of informed consent often stands in as a

proxy for sufficient understanding, as informed consent is the exercising of a patient's autonomy to agree or disagree with the treatment offered to them, based on the information that is provided and their understanding of that information.³⁵

One difficulty with the focus on sufficient understanding and informed consent is that there is no agreed standard against which to measure the sufficiency of a certain type or amount of information that will assist understanding (Beauchamp and Childress, 2009, 122). How much information an individual patient needs varies on a case by case basis and an individual has the right, as an extension of exercising their autonomy, to demand as much or as little information as they deem necessary to 'sufficiently understand' the situation.³⁶ Consent and understanding go hand-in-hand: insufficient understanding can delay or even cause invalid consent if the patient does not understand the information about their treatment and condition to a sufficient level for themselves.

Given these concerns, the criteria for the ideal autonomous individual become close to impossible to satisfy as they require the patient to be "capable of acting on the basis of effective deliberation, guided by reason, and neither driven by emotion or compulsion nor manipulated or coerced by others" (Mappes and Degrazia, 2006, 46). The traditional account of autonomy in bioethics assumes that questions of health can be considered without much emotion and through careful and considered conversation with medical professionals. The traditional account of autonomy also assumes that the relationship between medical professionals and patients is equal and that they can communicate and understand each other without difficulty. This assumption presumes patients and doctors are considered equals with similar backgrounds, levels of intelligence and who both have an understanding and familiarity with medical language and techniques. In practice the above situation is often not the case.

Due to the moral importance placed on autonomy, any infringement of autonomy by another agent must be rigorously morally justified. By extension all those who lack the

³⁵ This is also crucial. It is their understanding, not anyone else's. If the individual identifies something as not worth it according to their beliefs, then that is an autonomous decision, regardless of what that means for their health. For example, a cancer patient who decides to stop lifesaving treatment because they feel that it is not worth the cost to their quality of life is making an autonomous decision about how they want to live their life, in spite of the fact that it may well be a shorter life.

³⁶ Though it is often a paradox of autonomy that patients have to understand a lot about the situation before they can identify what they do and do not want to know. Despite this possible concern, the amount of knowledge that a patient requires to understand the situation in question is based on a threshold set by the patient themselves.

ability to exercise autonomy should be protected, as they are unable to use their autonomy to protect themselves from choices not congruent with their values. Traditional theories of autonomy have set up tall orders for achieving, respecting and protecting autonomy such that in the last few decades the traditional approach has been increasingly criticised.

3.3.2 Concerns with Traditional Autonomy: Are Philosophical Theories Enough?

Concerns about the traditional understandings of autonomy echo the concerns articulated by the social science critique of bioethics. Despite the emphasis placed on autonomy and respect for autonomy (in particular in North American bioethics), autonomy remains difficult to identify. Medical encounters, like most social encounters, are rarely the perfect environments for decision-making as seems to be required by traditional theories of autonomy. Nor are people islands unto themselves, as traditional understandings of autonomy seem to demand. The traditional conception of autonomy actively excludes the “other”, thus actively excluding any social influences on the agent as permissible when making a decision. Traditional autonomy ignores the social and social phenomena as being non-generalizable, and therefore unimportant, treating individuals as if at their core they are the same and untouched by the social world around them.

Traditional concepts of autonomy are a good example of the gap that exists between theory and practice in bioethics (Hedgecoe, 2004, 127). Hedgecoe cites Corrigan’s work on informed consent as an example that explored the depth of this gap. Hedgecoe argues that through Corrigan’s work it can be observed that “the conventional understanding of consent fails to recognize the social embeddedness of such a process [...] however noble the goal of patient autonomy, this is sometimes experienced by patients as abandonment. Informed consent is premised on an equitable doctor/patient relationship that [...] cannot always be realised” (Hedgecoe, 2004, 127). Individuals exist with other individuals; to ignore this is to ignore a crucial aspect of who we are as persons. No matter how solitary, people, patients and HCPs (when considering the medical environment) interact with each other on a regular basis. The ideal medical encounter required by the traditional conception of autonomy is unrealistic and rarely presents itself.

Anspach's 1993 work in intensive care nurseries exemplifies similar concerns with the traditional concepts of autonomy. Anspach investigated whether these traditional concepts are respected in practice, and if not, which concepts of autonomy are really used. Anspach found that "although professionals in both intensive-care nurseries [that Anspach] studied acknowledged the importance of involving the parents in the decision-making process, an assent model, rather than an informed consent paradigm, was most frequently used" (Anspach, 1993, 92). Healthcare professionals in Anspach's study admitted that while information was presented to parents, that information was tailored such that it limited the available options and steered parents towards agreeing with the decisions that the staff had already made (Anspach, 1993, 93–96).

Anspach's work highlights another concern from the social sciences: how useful are theories of autonomy that are based on conceptual analysis? Hedgecoe argues that traditional concepts of autonomy compete with each other, and that without the social sciences it is difficult to differentiate the different meanings of autonomy, as philosophical methodologies for parsing out these differences still cannot "resolve substantive issues about this term [...] [Philosophical conceptual analysis] cannot establish which one of the different competing concepts of autonomy occurs in the clinic. Analysing concepts cannot go on to settle a dispute over which is the 'right' kind of autonomy" (Hedgecoe, 2004, 128). Instead he claims that the social sciences can help resolve these disputes by "comparison with how autonomy occurs in clinical settings, how patients view their autonomy (and that of doctors and other staff) and how difficult decisions are reached" (Hedgecoe, 2004, 128).

It seems that a more inclusive account of autonomy, which considers the effects of the social, while also keeping in mind the practical applications of autonomy (e.g. informed consent), is needed. Recently 'relational autonomy' has been developed as a different way of considering autonomy that may help answer some concerns about the lack of the social in traditional accounts of autonomy. I would like to introduce it now as a possible theory of autonomy that may be useful scaffolding for building a more 'social' theory of autonomy.

3.3.3 *Relational Autonomy: Can it help?*

Relational autonomy is an umbrella term for a range of connected perspectives on autonomy (Mackenzie and Stoljar, 2000, 4). These perspectives are “premised on the shared conviction [...] that persons are socially embedded and that agents’ identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity” (Mackenzie and Stoljar, 2000, 4). Relational autonomy theory picks up on the sociological interpretations of individuality and human interaction that we saw earlier (in particular, though I believe not deliberately, Giddens’ concept of reflexivity; Giddens, 1991, 12, 35) by developing a theory of autonomy that deals with the full range of influential human relations, personal and public. As such it may be contrasted with the individualistic, proceduralist account often seen in traditional theories of autonomy (Sherwin, 1998, 19). Relational theorists argue that the basis for autonomy is not just individualistic and rationalistic. Instead, the “self” that autonomy is supposed to be governing is actually derived in part from relations with others and social institutions, and so theoretical understandings of autonomy should take this into account.

Relational accounts of autonomy question whether individual accounts are compatible with the social embeddedness of persons (Mackenzie and Stoljar, 2000, 4) and criticise the autonomous ideal that is based on the notion that “human beings are capable of leading self-sufficient, isolated, independent lives” as being unrealistic (Mackenzie and Stoljar, 2000, 6). It is from this misguided individualistic ideal that the “prescriptive conclusion” that humans should strive for self-sufficiency and hermit-like individuality has been derived (Mackenzie and Stoljar, 2000, 6). Over time, autonomy and individualism have become fused together as theoretically necessary for each other, while the importance of society and relationships has been marginalised.

Relational theorists argue that eventually an individual “encounter[s] a series of difficulties in attempting to reconcile autonomous agency with socialization, especially oppressive socialization. In particular, since structural procedural theories analyse autonomy as a feature of an agent’s occurrent mental states, they cannot do justice to the historical processes of socialization leading up to those states” (Mackenzie and Stoljar, 2000, 13). Similar to prevailing sociological thought, relational autonomy theorists argue that because the traditional, procedural account of autonomy is content-neutral, it

cannot offer an explanation for the *socialisation of agents* and is thus missing an important aspect of how autonomy is constructed. Relational autonomy can account for this socialisation, and thus includes this crucial piece of the puzzle. The traditional paradigm of autonomy sees the individual as being separate from and existing independently of society; a misplaced world view considering that humans are ultimately social creatures (Bauman, 2002, 30; Giddens, 1991, 12). The traditional criteria for determining autonomy reflect this individual focus, thus actively excluding individuals who rely on those around them in some way when making a decision. Relational autonomy moves away from this account by widening the scope of autonomous individuals, and the factors they use to make decisions, to include the social sphere that surrounds them, and socialisation over time.

As relational autonomy takes into account the importance of society, the social, and interpersonal relationships in decision-making, it is compatible with the sociological underpinnings of this study. For these reasons I have adopted a relational approach to the considerations and analysis of autonomous decision-making throughout the rest of this thesis. The sociological research in this thesis builds on this theory, supported by empirical evidence, to show how aspects of social influences like power dynamics, patient expertise and ‘time’ can become more obvious and permanent features of bioethical theories of autonomy.³⁷

3.4 Can Sociology and Bioethics Come Together? The Philosophical Critique of Sociology

As much as sociology has something to say about traditional, philosophical bioethics, philosophy has something to say about sociology’s role in bioethics. The critiques against the increased presence of sociology in bioethics have been articulated as three major concerns outlined by Daniel Callahan, who argues that these three concerns must be overcome for the social sciences to be useful to ethics (and by extension bioethics) (Callahan, 1999, 281):

³⁷ The discussion chapter of this thesis explains how these theories can be incorporated in to the concept of patient autonomy.

- 1) There must be “ethically relevant knowledge” generated from the social sciences
- 2) We need ethical theories that “efficaciously” use the social sciences
- 3) The social sciences must surmount the is–ought fallacy. (Something Callahan believes is impossible, but I will return to this point later).

It is important when considering these concerns to remember that Callahan is not a strong supporter of the use of the social sciences in bioethics, seeing information generated by social science research as ethically “interesting” but not ethically “relevant” (Callahan, 1999, 282). Callahan cannot envisage how to derive an ethical theory from social science research such that moral judgements can be made (Callahan, 1999, 282).

Callahan’s first concern can be overcome, as the social sciences generate “ethically relevant knowledge” already. To find examples of this “ethically relevant knowledge” one has to look no further than Hoffmaster’s 2001 book *Bioethics in Social Context*. Here Hoffmaster gives four examples of social science research in bioethics that have generated useful knowledge about ethics and morality in the medical setting (Hoffmaster, 2001, 3–8). For example, Kaufman’s 1997 study of medical responsibility in geriatric medicine found that there is “no clear demarcation between the moral and clinical” so that ethical rules and principles could not be separated out from the clinical context (Hoffmaster, 2001, 3). Anspach’s study of a neonatal intensive care unit is another example, as she found that consensus on moral principles does not remove controversy on how to treat the new-born patients when doctors and nurses disagree on treatment (Anspach, 1987; Hoffmaster, 2001, 5). Anspach argues that this is due to the effect that the hospital (as a social institution) has on the importance of the doctor and nurse roles, as well as the emphasis that each profession puts on “technological” cues and “interactive” cues due to their differing modes of knowledge (Anspach, 1987, 229; Hoffmaster, 2001, 6). These various influences mean that “from beginning to end, the moral disagreement between the doctors and the nurses is framed and settled by factors well beyond the confines of traditional bioethics” (Hoffmaster, 2001, 6). From examples like these it would seem that the social sciences have much to offer in the way of “ethically relevant knowledge”.

Callahan’s third concern, that of the is–ought fallacy, must also be addressed. It is perhaps not fair to lay the blame for the continuing controversy over the is–ought

fallacy in bioethics at Callahan's door. The is-ought fallacy dispute extends well beyond bioethics, but within the field the continued emphasis on it may be due to the distinct importance that Beauchamp and Childress put on separating the descriptive from the normative in *Principles of Biomedical Ethics* (Hedgecoe, 2004, 130; Beauchamp and Childress, 2009). Much of the controversy around using the social sciences for anything more than contributing "interesting" information is due to the distinction that philosophers (and sociologists) put between is and ought, fact and value, and descriptive versus normative ethics. The argument from the philosophers is that it is not possible to derive an 'ought'/value/normative from an observed 'is'/fact/descriptive. Looking at what *is* (i.e. the social) does not tell us what we *ought* to do (i.e. the ethics).³⁸ Hoffmaster and Hedgecoe both offer arguments against this philosophical critique, centred on the premise that the descriptive and the normative cannot be divided (Hedgecoe, 2004, 130; Hoffmaster, 2001, 2). Haimes and Williams argue that fact and value are of necessity two sides of the same coin, describing fact and value as a "couplet" rather than a dichotomy, as they are co-implicated (Haimes and Williams, 2007, 471). Hedgecoe argues that detailed social science research disputes philosophy's insistence on the fact/value distinction, showing that people (i.e. in everyday life—not philosophers) do not separate the descriptive and the normative when making moral decisions. Only philosophers routinely make testable statements about morality and ethics that are not necessarily based on practice, and yet these statements are often accepted as fact and used to build theory (Hedgecoe, 2004, 130–131).

De Vries and Gordjin suggest that there is a misunderstanding from the philosophers about the separation of is/ought, fact/value and normative/descriptive. They argue that empirical ethics does not commit the is/ought fallacy, as the focus of empirical work in bioethics is on the feasibility of, and compliance with, moral judgements and principles, not on deriving moral conclusions from non-moral premises alone (De Vries and Gordjin, 2009, 199). They also propose that using empirical research to help interrogate issues of bioethical concern is not the same as the philosophers' claim that empirical ethics rejects the fact/value distinction (De Vries and Gordjin, 2009, 200). Instead empirical bioethics assumes that facts and values are intertwined and cannot be separated (De Vries and Gordjin, 2009, 201).

³⁸ Though it is worth pointing out that Haimes and Williams (2007) question the authority of the self-ascribed role of bioethicists in stipulating what "ought" to be done.

The distinctions between fact and value, is-ought, and normative and descriptive are of legitimate epistemological interest, but they are less crucial for the evaluation and analysis of practical, situated actions. One agreed upon feature of moral experience that is crucial, Hoffmaster argues, is the context (personal, social and cultural), and the various backgrounds (institutional, economic, historical, political) that “structure moral problems and give meaning to moral concepts” (Hoffmaster, 2001, 2). Instead of moving our understanding of morality out of the lived experience (i.e. separating fact and value, is and ought) social scientists want to engage with that experience, as morality is ‘situated’, that is, “it cannot be severed from the seamless heterogeneity of that experience, and understanding morality as it is lived shows how intimately it is intertwined with culturally grounded knowledge, power, institutions, and practices” (Hoffmaster, 2001, 7). Social science research helps put bioethics into context, and that context includes the relationship between fact and value, and the ‘is’ and ‘ought’.

3.5 Towards a More Sociological Bioethics

With this in mind, can the social sciences (specifically sociology) contribute to bioethics in such a way that the social science critique of bioethics is addressed, while at the same time attending to the three concerns raised by Callahan about the involvement of the social sciences in bioethics?³⁹ This is not a new question, and has been addressed in several conceptions of bioethics in the last few decades. I would like to examine some of the different ways that the social sciences and bioethics have been brought together, focusing on feminist bioethics, the sociology of bioethics, empirical ethics, critical bioethics and symbiotic bioethics. There are several styles of ‘doing’ bioethics that involve empirical work and it is often apparent (and sometimes made explicit by authors) that one style has influenced another, or even that the authors feel their new style builds on previous work. As far as possible I have tried to examine them here in a roughly chronological order, to help make transparent the influences and critiques that have arisen over time.

³⁹ I have not forgotten Callahan’s second concern about using the social sciences in bioethics, but will be addressing it later on in this chapter.

3.5.1 *Feminist Bioethics*

Feminist bioethics is perhaps one of the earliest examples of bringing the social sciences and bioethics together. Feminist bioethics examines and considers bioethical problems with reference to gender of course, but also power dynamics, cultural norms, relationships, race and class (to name a few) (Mackenzie and Stoljar, 2000, 4). Feminist bioethicists focus on the marginalised groups that Western bioethics tends to ignore. They also shy away from the more traditional account of bioethics which relies on abstract, philosophical principles, and ignores the “contexts that frame health care and the relational networks that inform patient decision-making” (Stanford Encyclopaedia of Philosophy, 2012; see also Sherwin, 1998, 19). Feminist bioethicists have argued that favouring abstract principles over what is happening in practice has made it easy to miss or disregard unequal burdens, and difficult to identify marginalised groups (Stanford Encyclopaedia of Philosophy, 2012). Scully argues that to escape making the same omissions that traditional bioethics has done “Feminist bioethicists can never avoid asking the question, how does this work in the lives of real women and men, and in the current political frameworks in which we exist?” (Scully, 2010, 136).

Several concepts based in feminist bioethics have considered the context in which bioethics operates more carefully. As early as the 1980s Gilligan’s care ethics (1982) and Noddings’ narrative case-specific interpretation of bioethics (1984) started to move away from a reliance on abstract principles. By the 1990s books like *Feminist Perspectives in Medical Ethics* (Holmes and Purdy, 1992) and *No Longer Patient: Feminist Ethics and Health Care* (Sherwin, 1992) were providing different ways of understanding the role and nature of bioethics. Susan Wolf highlighted how little notice is paid to social or economic conditions when considering bioethical wrongs (Wolf, 1996), emphasising the need for examination of the context in which bioethics takes place. In Mackenzie and Stoljar’s concept of relational autonomy (outlined in *Relational Autonomy: Perspectives on Autonomy, Agency, and the Social Self*, 2000) the context is an essential part of patient autonomy.

Feminist bioethics, however, is not solely concerned with examining and using the empirical to conduct bioethical inquiry, and for this reason I only briefly highlight feminist bioethics’ role in the move towards a more sociological bioethics. In the 1990s, developing alongside, and sometimes together with, feminist bioethics, was an

increasing awareness of an absence of the social in bioethics. The social science critique I discussed earlier was growing and the move towards what is now characterised as the “empirical turn” opened the door to different ways of “doing” bioethics.

3.5.2 Bringing Sociology and Bioethics Together: A Review of Contemporary Approaches

At the same time that feminist bioethics was on the rise, and in tandem with a growing interest in the sociology of bioethics, early forms of an empirical-style bioethics could be seen emerging. Some research, such as Anspach’s 1987 research on neonatal intensive care units and Thompson’s 1992 work on hospital ethics (both of which might now be called empirical bioethics) show the early involvement of the social sciences in bioethics even before the first social science critiques were made. In her influential 2002 paper Haimés acknowledges this involvement, asking for recognition of the role that the social sciences play in ethics, and arguing that there exists already “a substantial body of theoretical and empirical work in the field of ethics from sociology and the social sciences in general” (Haimés, 2002, 90). Haimés argues that the two disciplines of Ethics and sociology should be in dialogue with each other, avoiding what she calls a “sociological imperialism” or as Hedgecoe puts it “an aggressive take-over bid” of bioethics by sociology (Haimés, 2002, 91; Hedgecoe, 2004, 129). Haimés, borrowing a phrase from Nelson, suggests that empirical research in bioethics should not be restricted to “scooping up the facts” which are then used by traditional bioethics, since this relegates the social sciences to the role of “handmaiden”, ignoring the contributions that sociology has already made to the field of ethics (Haimés, 2002, 99). Instead when ‘doing’ bioethics it is important to recognise that “those facts are inherently tied to theories of knowing the world and to a repertoire of techniques and skills for accessing that world” (Haimés, 2002, 99). The social sciences can throw new light on questions already being asked about bioethical issues, as well as contribute new questions and stimulate further lines of knowledge by contributing epistemological frameworks and methodological skills to bioethical inquiry (Haimés, 2002, 100–106).

Haimés stands out in the early years of empirical bioethics by arguing for the use of both social science methods *and* theory to analyse moral challenges. In addition, she argues for a sociology *of* bioethics; focusing on conducting a “social science analysis of

the social processes, meanings and institutions that frame and produce ‘ethics’ and ethical problems” (Haimés, 2002, 110). Hedgecoe echoes this statement, defining the sociology of bioethics as “an analysis of the social construction of bioethical problems, and the role of social structures in shaping the way in which bioethics has developed over the past 30 years” (Hedgecoe, 2004, 121). While the sociology of bioethics is useful, especially as it contributes reflexivity to the discipline, it is not intended to, and in practice does not, completely address the concerns of philosophical bioethics, which struggles to see how empirical research can truly prescribe moral action.

In recent years “empirical ethics” has been put forward as a possible response to this critique. Empirical ethics draws on social science methodologies, especially qualitative methods, to contextualise philosophical moral theories (De Vries and Gordijn, 2009, 193). It challenges the “core foundations of ethics” by abandoning the premise that ethical principles “must first be established and then applied to practice” (Molewijk and Frith, 2009, ii). The focus of empirical ethics is the study of ethics, but it has been prominent in the field of bioethics, where the use of social science methodology has been characterised as the “empirical turn” in bioethics (Borry et al., 2005). The empirical turn is described as “indicative of a growing acceptance of contextuality and greater questioning of the epistemological uniqueness of moral knowledge” (Scully, 2008, 45). This empirical turn is perhaps not surprising as bioethics is a form of applied ethics, which one would anticipate to be more favourably disposed towards empiricism. Ives describes the process of empirical ethics as philosophers “getting their hands dirty” by leaving their “Platonic ivory towers, and acknowledging that ethics is about people, not just good arguments” (Ives, 2008, 3). Social science methodology and theory are useful tools that bioethicists can use to “dirty” their hands as Ives suggests.

Empirical ethics has been the subject of much debate, as there is not one agreed upon way to conduct empirical ethics research (Molewijk and Frith, 2009, ii; see also *Bioethics* special issues 2009, 23(4), and 2010, 24(5)). De Vries and Gordijn have suggested that the empirical ethics remit is rather large, encompassing descriptive and analytical work on morally relevant issues, identification of moral issues that have “escaped the attention of ethicists”, making ethics more sensitive to context, providing a description of facts “relevant to normative arguments”, and finally “showing the normative aspects” of science and technology (De Vries and Gordijn, 2009, 194-196). Leget *et al.* point out in their 2009 article that empirical ethics is still a young field that

goes by several different names reflecting the many different methodologies available (Leget *et al.*, 2009, 228). They argue that these names indicate the varied nature of empirical ethics research, which can be known as: the social sciences perspective of bioethics, empirical research in bioethics, empirical-ethical research, and ethics-related empirical research (Leget *et al.*, 2009, 228).

What remains clear is that “empirical bioethicists use qualitative, quantitative or mixed methods to gather data relative to judgements concerning moral matters in medicine and medical science” (Leget *et al.*, 2009, 228). However, much empirical ethics research has been focused on using social science methodology to understand existing ethical problems in “the real world”, and there is disagreement about how exactly these empirical findings should be married to ethical/moral theory, and now, bioethical theory (Ives and Draper, 2009, 249).

Hedgecoe’s concept of “Critical bioethics” is one approach to marrying empirical work to ethical theory that has been influential in the literature, as to an extent at least it addresses the argument from Haiman that the social sciences can contribute data *and* theory. The critical bioethics approach views the social sciences as contributing more to bioethics than just descriptive elements (Hedgecoe, 2004, 134), styling itself as a bottom-up approach where “critical bioethics is rooted in empirical research. The problems, dilemmas and controversies analysed come from looking at a particular setting (e.g. the clinic), talking to participants and taking note of what they say” (Hedgecoe, 2004, 135–136). Hedgecoe argues that in this bottom-up approach philosophers concerned with certain issues or technology should turn first to social science research on that issue/technology, not “standard bioethics debate” (Hedgecoe, 2004, 136). Hedgecoe uses Rayna Rapp’s work on prenatal testing for Down syndrome as an example of this in practice (Rapp, 2000). Traditional bioethics debate about prenatal testing focuses on the moral status of the embryo. Rapp’s empirical work found that mothers were not concerned by this moral status, but instead with the burden on family life and various responsibilities that would come with having a child with Down syndrome (Hedgecoe, 2004, 136). Based on this conclusion, Hedgecoe argues that bioethicists should refocus their attentions on the rights and duties involved with family life, rather than the moral status of the embryo in their “standard bioethics debates” (Hedgecoe, 2004, 136).

It may appear that in structuring critical bioethics in this way, Hedgecoe is limiting critical bioethics to signposting issues of concern for the more important philosophical bioethics. This is not the case, instead Hedgecoe argues that “In critical bioethics, the results of empirical research feed back to challenge, and even undermine, an analyst’s cherished theoretical framework” (Hedgecoe, 2004, 137). In other words, empirical research is not *just* for informing theories, it can challenge them as well: it tests those philosophical bioethical theories “in the light of empirical ethics, *and changes them as a result*” (emphasis added) (Hedgecoe, 2004, 137). However Hedgecoe seems to limit this to *testing* philosophical theories in order to undermine “elements of the universalist stance adopted by traditional philosophical bioethics” (Hedgecoe, 2004, 138). He suggests little about how social science empirical research can *change* philosophical bioethical theories; just that it can and should. Nor does Hedgecoe really take heed of Haimes’ call for the use of more social science theory in bioethics.

The empirical bioethics approach has gone through much iteration, and I will end my examination of how sociology and bioethics have come together in the literature by examining Frith’s symbiotic bioethics, which is one of the more recent approaches developed that explains how to ‘do’ bioethics with the social sciences. Frith’s symbiotic bioethics stands out for its emphasis on ethical theory. Her approach views practice as important because it helps “formulate and reformulate our ethical theories and to ensure that they are nuanced and appropriate for the problems they are supposed to address” (Frith, 2012, 199). In developing symbiotic bioethics Frith builds on the Integrated Empirical Ethics described in a 2004 paper by Molewijk *et al.*, “formulating a practical methodology for integrating theory and practice [...] one that uses ethical theory both to explore the data and to draw normative conclusions” (Frith, 2012, 199).

Symbiotic bioethics differs from earlier accounts of empirical bioethical work (Frith uses Hoffmaster as an example) by using *ethical* theory as a tool for analysis of the empirical data (Frith, 2012, 202). Frith wants to use ethical theories and principles to analyse the data, just the way sociologists do (Frith, 2012, 203). She argues that the relationship between theory and data is a symbiotic one, and “theory can be used to approach the data and it can also arise from the data itself” (Frith, 2012, 203). Theory can be modified or extended in this process, as well as derived, while simultaneously being used to analyse the data (Frith, 2012, 203). Frith uses the example of her theory of consensus to illustrate this point, highlighting how the theory was developed by

considering the existing theories and literature on consensus, while also examining how consensus is used in practice (Frith, 2012, 203).

While I am sympathetic to the idea that practice informs theory and theory informs practice, I struggle with symbiotic bioethics as a contemporary account of empirical bioethics. As an approach to bioethics it recognises the importance of the context (or what Frith calls the particular), but it does not seem to acknowledge the discipline that so often examines the particular, sociology, or the role that sociology already plays in bioethics. Symbiotic bioethics appears to be based on the premise that applied philosophical bioethics should be allowed to use the same methods as sociology when examining bioethical issues and developing bioethical theory (Frith, 2012, 202-203). However if sociology is so good at this type of analysis and theory building that Frith believes bioethics should replicate it, why not do the analysis through sociology to begin with? Why shift to another discipline? I would push the methodology of symbiotic bioethics further towards the social sciences and argue that it should use ethical *and* sociological theory as tools of analysis and theory building. Symbiotic bioethics lacks the recognition of the role of the social sciences in bioethics that Haimes, Hedgecoe and Hoffmaster have argued for, effectively re-consigning the social sciences back to the role of handmaiden.

In the last ten years there have been several articles with suggestions, criticisms and even complaints about how bioethics and the social sciences can come together. The changing landscape of bioethics has challenged academics in the field to re-examine what bioethics is, with Ashcroft going so far as to argue that “Bioethics as a field of academic inquiry is undergoing a slight midlife crisis” (2010, ii). In the last four years criticisms of traditional, theoretical bioethics have “given way to forms of ethics that are contextual and open to practical experience and to learning from experience through dialogue with others” (Abma *et al.*, 2010, 244). With this changing landscape in mind I would like now to turn to my own understanding of the relationship between sociology and bioethics.

3.6 Sociology as Constitutive of Bioethics

Much of the scholarly writing on how bioethics and the social sciences can work together has focused on how social scientific knowledge debunks existing bioethical theories. However little has been written on how the social sciences can change or improve those theories. This is because empirical ethics has so far been confined to illuminating, or identifying “deficiencies in existing ethical theory” (De Vries and Gordijn, 2009, 194). Critical bioethics functions in much the same way, focusing on testing existing theories for practicality and validity. Symbiotic bioethics contributes ethical theory, but neglects the important role of sociological theory in bioethics. Bioethics needs the reflexivity described in empirical ethics and critical bioethics to ‘check’ existing theories, but to that must be added social and ethical theory, which can contribute to bioethical theories alongside the sociological methodology used to produce the empirical data. For example, a bioethical theory of autonomy that does not account for the power differentials experienced between patient and doctor is incomplete and will be difficult to put into practice. However, instead of limiting the commentary on that theory to the impracticality of it, it is possible to use social theory on power differentials, in conjunction with the empirical data, to change bioethical theory such that it reflects the influence of the power differentials in the medical (and other) contexts.

In addition to recognising the role of sociology in bioethics, philosophy and sociology must talk to each other (as advised by Haimes, 2002) in order to address the second concern brought forward by Callahan: that bioethical theories must use the social sciences, and by extension sociology, efficaciously (Callahan, 1999, 281). One without the other is not enough for bioethics, but together philosophy with sociology can bridge the gap between theory and practice, while also building new, stronger bioethical theories.⁴⁰ The role of sociology is particularly important to consider as the social has always been present in bioethics, and so an orientation towards the social (in the form of sociology) should be viewed as a necessary, constitutive element of bioethics. Sociology is not just a discipline with which to examine bioethical issues. Sociology is *constitutive* of bioethics, as much as philosophy, law, and theology. In response to Callahan’s second concern, it is not that bioethics has to find a way to efficaciously *use*

⁴⁰ However we need to be less proprietary about which disciplines’ theories develop the “ought” statements that bioethics pronounces.

sociology, it is that it must be recognised that bioethics already does contain sociology as one of its constitutive parts (no matter how overlooked this part has been in the past). If sociology is constitutive of bioethics, then there can be no reason to doubt its use in bioethical inquiry.

Recognising sociology in this way also means that the “empirical turn” in bioethics is misleading shorthand used to describe sociology’s role in bioethics. The term suggests that sociology is only now being included in the field, when really bioethics examines the kinds of human experiences, choices, and practices that are inherently social activities. What has been missing is an awareness of all the disciplines within which bioethical inquiry takes place. While interest in the so-called “empirical turn” has brought to light how bioethics has been neglecting the social, the “empirical turn” still neglects the discipline behind it, sociology. Sociology has always been a constitutive force of bioethics, it is not *in* bioethics, but instead it is what helps “make” bioethics.

A sociological bioethics reveals “how ethics gets done on the ground, how fluid terms pick up specific meaning within institutional contexts [and] how the same action can be interpreted differently depending upon social location” (De Vries et al., 2007, 12). Just as it does with ethics, sociology has a large part to play in identifying and contextualising bioethical areas of concern that are culturally or socially bound, and that without sociological resources, philosophical bioethics would be unable to recognise as problematic. Sociology as a whole can be used to investigate these bioethical issues, while still considering the philosophical contributions to bioethical inquiry (as philosophy is also a member of the constitutive disciplines of bioethics). As Schenck points out, it is important to understand both the philosophical and the sociological sides of an issue before tackling it in its entirety: “Going into discussions of medical ethics attending only to ethical theories [...] would be like going into a discussion of the rules governing ball games without paying attention to the differences between football, basketball and baseball, focusing only on abstract discussion on the nature of ‘rules’ and ‘games’ and such” (Schenck, 1986, 50, also cited in Haimes, 2002, 109). The same could be said of tackling bioethical issues using only sociology and ignoring the philosophical “past” that bioethics brings with it. It is necessary to understand the theory and the practice, the philosophical *and* the sociological sides of a bioethical issue in order to make any lasting and valid pronouncement on the concern at hand.

One of the ways to bring the social sciences and philosophy closer together is by recognising sociology (its methods, methodology *and* theory) as one of the major disciplines that makes up bioethical inquiry, and using that discipline to examine areas of bioethics concern and to develop bioethical theory. Sociology has a place in the “troika” of disciplines (law, philosophy and theology) that make up bioethics (“troika” borrowed from Callahan, 1999, 278). It is not necessary to eliminate a member of the troika to accommodate sociology’s place, but instead necessary to recognise sociology as the often overlooked fourth member of a quartet. In this way sociology has an equal place alongside the other disciplines that are constitutive of bioethics. The social sciences are not something *outside* of bioethics, but instead an integral, constitutive force of bioethics. It is this redefined view of the field of bioethics that informs this PhD research and that makes up the backbone of the analytical framework that I will use.

3.7 The Analytical Framework

I would now like to relate the recognition of sociology as one of the constitutive disciplines of bioethics back to my own research on patient autonomy in the field of oncofertility. In this thesis I use sociological methodology and methods, as well as social theory on power dynamics, agency, and structuration to reflect on, critique and add to bioethical theories of autonomy, specifically drawing on relational autonomy and critiquing the traditional philosophical conception of autonomy. Using this combination of bioethical theory, alongside sociological methodology and theory, I explore the following research questions that examine bioethical autonomy and decision-making within the social context of medicine, focusing on the field of oncofertility:

- 1) How are patients’ experiences of decision-making in oncofertility influenced by their encounters with their healthcare professionals?
- 2) How are these experiences shaped by other biographical elements?
- 3) What is important to patients when they are making decisions?
- 4) What role do medical encounters play in women’s decisions about cancer treatment and fertility preservation?
- 5) Do female cancer patients feel differently about the potential effects of treatment on their fertility at different stages of their treatment?

- 6) With regards to oncofertility services, what are the needs of adult female cancer patients in the UK?

With reference to the data collected during fieldwork I respond to these questions in the substantive chapters, I use the tools I have identified from both bioethics *and* sociology (theories of autonomy, qualitative methodology, sociological analysis and existing social theory on agency, power and structure) to help draw conclusions about how and why these patients make decisions in the medical context. These conclusions can in turn be used to feedback to bioethical theories of autonomy such that they may more accurately reflect how patient autonomy is understood and used in practice.

Chapter 4

Methodology of the Research

In this chapter I outline the rationale for the methodology and research methods used, while also charting the connections between the theoretical framework of the research, the methodology and the methods. I begin by recapping the focus of the study and identifying what kinds of data I judged to be useful for answering the research questions. I then explain the methodology that best allowed access to this data, as well as the more practical details of how the specific methods were used. Finally I outline how the data were analysed, and end with reflections on the data collection/fieldwork and the data analysis.

4.1 Focus of the Study

This thesis is a qualitative, bioethical inquiry into patient decision-making,⁴¹ exploring patients' understandings and experiences of fertility preservation in relation to cancer treatment, within the context of bioethical interpretations of patient autonomy. The project focuses on how adult, premenopausal female cancer patients experience the interplay between cancer treatment and fertility preservation, and, alongside that, how female cancer patients make decisions about their future fertility in the medical context.

In order to access these experiences and understand them better, the central research question developed for this project was:

How do premenopausal female cancer patients, in the United Kingdom, experience and socially shape the relationship between cancer and fertility?

A further six contributing questions, detailed in section 3.7, were identified as essential to answering the central research question. These questions addressed the intersection between cancer and fertility, how patients and healthcare professionals interact with

⁴¹ Throughout the thesis I will use the term “decision-making” to refer to the decisions that interviewees identified themselves as having made, as well as those decisions that they recognized retrospectively. It is not meant to be understood as describing discrete actions, but rather as a term describing the processes of making a decision as understood by the interviewees.

each other, and how patients experience decision-making throughout the diagnosis, treatment and aftercare processes.

I decided that the patient's own accounts of these experiences would be the most valuable source of insights through which to address the research questions. With the focus on firsthand accounts, I designed a qualitative study, grounded in interpretivism, a conceptual approach that lends itself to methodologies that are effective in eliciting such accounts, using in-depth, one-to-one interviews. In the following sections I explain and justify the methodological approaches of this study, and outline the methods used to conduct the research.

4.2 Methodological Approach and Justification

Methodological claims carry within them assumptions about the nature of what is being researched (ontological assumptions) and assumptions about the nature of knowledge and claims to knowledge (epistemological assumptions) (Brewer, 2000, 28). These assumptions directly influence the data collection and analysis methods that will be used. Working with this understanding, this project required a methodology grounded in the premise that: adult female cancer patients are able to interpret and discuss their world around them (not just in the hospital, but in their whole lives), and are able to talk about how they see their world. This included how their experiences with cancer influenced their interpretation of their world and whether fertility is an important aspect of it (the ontological assumptions). It was important that the methodology not only prioritise the meanings given to these experiences by the interviewees, but it had to also value the inductive work of interpreting those experiences and endowing them with further meaning through analysis (the epistemological assumptions). For these reasons the methodological framing of this research project is underpinned by an interpretivist epistemology, which emphasises a naturalistic methodology that focuses on everyday life (Brewer, 2000, 33). The research questions emphasise people's everyday accounts; therefore the methodology must value these experiences as well. A grasp of the theoretical underpinnings of interpretivism (sometimes referred to as interpretivist methodology) is needed in order to understand why those methods are best suited for the data collection in this thesis. Below I outline the methodological theories used to

design the research and how the qualitative method known as grounded theory helped frame the analysis of the collected data.

4.2.1 *Interpretivism*

The interpretivist⁴² approach sees people's interpretations, perceptions, meanings and understandings of events as the primary sources of data in research (Mason, 2002, 56). Derived from phenomenological philosophy, interpretivists are interested in understanding the social world that people have produced, and continue to produce around themselves (Mason, 2002, 56). Interpretivist approaches to research allow the researcher to identify and access the everyday realities of individuals, indicating some parallels with the relational approach to understanding autonomy seen previously in the theoretical framework (see chapter 3). As Blaikie argues, "this everyday reality consists of the meanings and interpretations given by the social actors to their actions, other people's actions, social situations, and natural and humanly created objects" (Blaikie, 2000, 115). Further, as I have already argued in chapter 3, it is crucial to engage with everyday life in order to better understand morality and ethics in society; an interpretivist approach to research allows for this engagement through methods (such as interviews) that provide accounts of experiences that are part of this everyday life.

Ontologically, interpretivism is well suited to this research as interpretivism views people as meaning-endowing, actively capable of interpreting and constructing the world, as well as being able to talk about it (Brewer, 2000, 34). Interpretivism considers society to be constantly changing, being reinterpreted, discussed and influenced by the people in it, in interaction with each other (Brewer, 2000, 34).⁴³ Epistemologically, interpretivism sees knowledge as inductive: it is necessary to start with observations before then making empirical statements based on those observations (Brewer, 2000, 34). It is also crucial to consider how people construct meanings and the significance of those meanings to those people. For interpretivist research, one effective way to access these meanings is to study them in the context in which they would normally occur (Brewer, 2000, 34). This epistemological and ontological base of interpretivist

⁴² Sometimes also referred to as "interpretative", however I will use the term "interpretivist".

⁴³ It is worth noting that Giddens' understanding of agency (which is central to the theoretical framework of this research) also takes as its starting point an interpretivist understanding, arguing that "individuals help actively to reconstruct the universe of social activity around them" (Giddens, 1991, 12).

methodology necessitates that certain imperatives are considered when working interpretively: i.e. (i) the researcher tries as far as possible to access people's meanings, (ii) by asking people to explain their meanings in their own words, (iii) in a way that is sufficiently in-depth to get at the complexity of those meanings, (iv) as well as addressing the social context in which those meanings were formed (Brewer, 2000, 35).

Using methods associated with interpretivist methodology it is possible to fulfil these requirements, and as far as possible, access “the meanings people attribute to their experiences and social worlds” (Silverman, 2004, 126). From there it is possible to start to understand how people construct themselves and their lives in relation to these experiences (Silverman, 2004, 126). To reflect these imperatives, I designed the research around qualitative methods, specifically in-depth, semi-structured interviews, as they facilitate access into individuals' lived experiences.⁴⁴ Interpretivist research generally views knowledge as situated and contextual, and therefore qualitative methods such as in-depth interviews allow for a ‘thematic, topic-centred, biographical or narrative approach’ that is in line with interpretivist ontology (Mason, 2002, 62). Specifically, semi-structured interviewing involves an interactional exchange of dialogue that is relatively informal in style, as well as fluid and flexible, allowing for the personalisation and tailoring of the interview to the interviewee. It allows the interviewee to display how they interpret the world and attach meaning to it, which in turn can give the participants more control and agency throughout the interview process, as well as more freedom (Mason, 2002, 62). This is important as it means the interview is more likely to generate a “fairer and fuller representation of the interviewees' perspective” by allowing the interviewer to follow up on unexpected and unforeseeable clues and insights that arise (Mason, 2002, 66).

In addition, semi-structured interviews were chosen over unstructured interviews to help the interviewees feel more comfortable during the research process. Unstructured interviews require significant conversational skill on the part of the researcher (Brewer, 2000, 66), but also on the part of the interviewee as they are participating in what is essentially a “conversation with a purpose” (Burgess, 1984, 102). They are usually part of ethnographic observations and run the risk of being so conversational that they can

⁴⁴ Though it is important to note that as with all qualitative research, any analytical interpretation is the researcher's interpretation of the participant's interpretation of their lives, informed by theory and the empirical evidence.

leave the interviewee without guidance, making them unsure about which areas the research is focusing on (Silverman, 2006, 125). Given the sensitive and emotional nature of the research topic, semi-structured interviews were better suited as they allow for a navigational tool (in the form of an aide-memoire) to help guide the interviewee and interviewer.

4.2.2 *Grounded Theory*

Along with thematic analysis (discussed later on), I also used an approach influenced by grounded theory to analyse the data. Grounded theory developed out of Glaser and Strauss' work on death and dying in the American hospital setting (1965, 1967, 1968), as a reaction to the common practice at the time of using only positivist hypothesis-testing approaches in sociological research. At the time it was claimed that qualitative methods were not rigorous enough to produce replicable valid data and generalising theories, in comparison to large scale, hypothesis-testing quantitative methods. Glaser and Strauss responded to these claims with grounded theory, which offered "systematic strategies for qualitative research practice", that were both logical and theory generating, just like positivist epistemologies and methodologies (Charmaz, 2006, 5). Grounded theory is a rigorous method that combines both inductive and deductive techniques systematically to develop refined conceptual categories that have been routinely tested and retested in the data, to the point of theoretical saturation. Grounded theory differs from positivist approaches as it is not hypothesis testing but hypothesis generating.

When conducting grounded theory research a new research question is approached with "no preconceived ideas to prove or disprove" (Ghezeljeh and Emami, 2009, 15). Instead the important issues emerge from the participants' stories and experiences (Ghezeljeh and Emami, 2009, 15). Grounded theorists do not force their data to fit into preconceived ideas or theories, but instead try to "evaluate the fit between their initial research interests and their emerging data" (Charmaz, 2006, 17). This means following new leads and considering new theories as the research progresses. Grounded theory becomes a deductive process once the researcher starts re-exploring the initial data and refining it into core conceptual categories. What started as theory building, and thus inductive, becomes deductive as the researcher seeks data to test connections between

the existing concepts and developing theories, as well as data that challenge these theories.

While much of the data analysis in this thesis resembled grounded theory methodology and methods, the analysis did not adhere strictly to some aspects of grounded theory. Data analysis that is conducted under the umbrella of interpretivist methodology is often done using a grounded theory approach, however rarely in its “pure form” (Brewer, 2000, 108). As Brewer points out “there are very few genuine cases of grounded theory” (Brewer, 2000, 109). Grounded theory-inspired analysis is often found in interpretivist research (as is the case here) because it adheres to the data and has a number of steps that can be used to help organise and understand the data (Brewer, 2000, 109).

This research project diverged in two key ways from “pure” grounded theory. The first is that the research is (in part) a deductive study already, without having gone through the various levels of data collection, coding and re-examination that grounded theorists normally do. I am conducting a study of the bioethical concepts of autonomy, and as such it carries with it certain already-formed bioethical theories about what patient autonomy is and why it is important. Further, the study can be understood (again in part) to be testing the hypothesis that autonomy is important to patients. So while the study has been designed to generate new theories about how individuals exercise their autonomy (and how they make decisions), and to assist identification of how the medical system can support the exercising of patient autonomy, it is also examining bioethical theories of autonomy. Specifically I examine whether autonomy as a bioethical concept is important to patients, but also what else is important to patients when they make decisions.

The second way that this project deviates from traditional grounded theory has to do with the actual research process. In order to collect and analyse their data grounded theorists use five main (usually overlapping) steps in their methodology: data collection, coding, memo-writing, sampling for theory development, and constant comparison of the data. A completed grounded theory has a close fit with its data, has conceptual density, is durable over time, can be modified, and wields explanatory power (Charmaz, 2006, 6). The way this is reached is by achieving thematic saturation, whereby new data no longer adds to the conceptual density of the theory. Traditionally this is done by continually comparing old data and conceptual categories to new data that are coming in

from fieldwork until the new data no longer contribute novel aspects to the research. As a PhD research project is time-limited, it was not possible to guarantee that thematic saturation would be reached by the end of the fieldwork year. Further, given that the research focused on a smaller sub-group of the larger “cancer survivor” population in the UK, I was concerned about the research’s ability to provide thematic saturation. Thus, although influenced by the style of grounded theory, in particular through research design, data collection and analysis, this was not a true grounded theory study as it could not conform to the full standards of grounded theory.

4.3 Research Design

The research design for this project was chosen based on the epistemological and methodological background of this study, using qualitative methods as this was seen as the best way to answer the research questions effectively, but also in response to the fact that very few qualitative studies have been done in the field of oncofertility.⁴⁵ Here I outline how the research project was designed, and address the necessary changes that occurred when the actual recruitment of patients began.

4.3.1 Participant Sampling

The original project design included recruiting approximately twenty recent and/or current (but specifically not new) female breast cancer patients between the ages of 18–43, who had entered the General Hospital⁴⁶ as patients in the Northeast between 2007 and 2009. Patients would be identified by an oncology clinician at the General Hospital who would act as a “gatekeeper” by looking through patient records to ensure patients recruited to the study were within the recruitment guidelines. A gatekeeper was needed as non-NHS staff are not allowed access to patient records. Initially the project was conceived of as a prospective patient study (i.e. with newly diagnosed patients) for two key reasons. First, almost all previous studies have been retrospective, so a prospective study might bring new and fresh data to this area of study as patients would presumably have access to the most up-to-date treatment available. Second, fertility preservation

⁴⁵ See table 2.1 in chapter 2.

⁴⁶ All hospitals, clinics and NHS locations have been given the generic pseudonym “the General Hospital” and bear no relationship to any similar sounding medical facilities.

techniques have recently undergone rapid change, such that a retrospective study might not reflect the current fertility preservation possibilities available to patients. However after extensive thought and discussion, I concluded that these advantages did not outweigh the possible disadvantages to patients participating in the study. These disadvantages included imposing a research burden on the patient during a time of probable high emotion and confusion, and the possibility of accidentally informing patients that they may face fertility problems before their doctor had the opportunity to raise this issue. These were major ethical considerations. The study was therefore designed to be retrospective, looking only at recent/current patients who had already been diagnosed, and in some cases had already been treated. Imposing a time frame of 2007 to 2009 meant that two to four years would have passed since patients were diagnosed, providing a time buffer which avoided the possibility that patient participants were in the early stages of diagnosis while participating in the study, thus reducing the above concerns.

An age range of 18–43 years old was suggested by the “gatekeeper” clinician at the General Hospital, who felt that 18–43 years old accurately captured the fertile age range of most women. The women recruited could be older than 43, however they needed to have been diagnosed before that age. Breast cancer was initially chosen as the cancer type to focus on after considering the gaps in existing studies on oncofertility (see chapter 2).

4.3.2 Access and Recruitment of Participants

Initially access to participants in this project was to be through the General Hospital, with a clinician “gatekeeper” who would help identify patients in the clinic who fit the criteria and would send a mail-out to these prospective participants. The mail-out consisted of an introductory letter to the study, an information sheet, a consent form, a contact sheet they could use to request further information about the study, contact information and a freepost envelope.⁴⁷ Interested participants could self-identify by returning the freepost envelope with a request for more information and/or a consent form. Participants who signed the consent form, or indicated they wished to be contacted, were then to be contacted to set up an interview.

⁴⁷ See Appendices C, D, E and F for copies of recruitment materials.

After three months, emerging practical difficulties⁴⁸ meant that an alternative recruitment strategy was used. The original research design had an alternative stream for recruiting patients by contacting breast cancer support groups in the area. This alternative stream had been added to the project as a safety measure, in the event that recruiting through the NHS was unsuccessful. As this second recruitment strategy proved successful it became the primary form of participant recruitment.

Two significant changes to recruitment came out of this switch to the alternative stream: The first was related to the limited number of breast cancer-specific support groups in the Northeast. These groups are either run by the NHS and/or conducted at a number of Newcastle area hospitals. This presented a problem, since research with the NHS must first be checked by their extensive and lengthy ethical review system (see section 4.4). Ethical approval given to projects is site-specific; meaning that the research permission is given for specific NHS locations. For this study permission had been granted to do research at only one specific hospital. Each hospital with NHS-run breast cancer support group would require a separate site-specific amendment to the existing ethical approval, and given the time constraints of a PhD it was decided that these amendments would cause too great a delay to fieldwork.

Instead non-NHS support groups were approached, most of which are not breast cancer specific. In speaking with the organisers of these groups it became clear that not only were there not many breast cancer patients available who fit the criteria in the Northeast, but by limiting the recruitment to breast cancer patients the research would miss out on the opportunity to speak with women who were premenopausal, but had other forms of cancer. As a result the original criterion that the participants be breast cancer patients was expanded to include all premenopausal women who had any type of cancer (see table 4.1 below).

⁴⁸ See section 4.4.

Cancer Type	Number of Participants
Gynaecological	3
Breast	6
Other	2
Total Number of Patient Participants	11

Table 4.1: Breakdown of cancer diagnosis of patient participants

The second change expanded the original age range (suggested by the clinician gatekeeper) from 18–43 to 18–50. This change was due to a misunderstanding among women interested in participating who thought they had to be under the age of 43 to be interviewed. However, the criterion was that they had to have been diagnosed before 43. This was not considered a concern before as the clinician gatekeeper could easily identify the women who fit the criteria by looking at their medical histories and narrowing the possible participants down by age of diagnosis. As recruitment was no longer occurring through the hospital this was not possible. Changing the upper age limit to 50 helped make it clear who was eligible for the study (see table 4.2 below).

Age of Participant (Years)	Number of Participants
18–32	4
33–38	1
39–43	2
44–50	4
Total Number of Patient Participants	11

Table 4.2: Age of patient participants at the time of diagnosis

Once these changes had been made, the Macmillan Cancer website (www.macmillan.org.uk), and the Cancer Research UK website (www.cancerresearchuk.org) were accessed and their search functions used to find all eligible support groups in the Northeast. This was particularly easy on the Macmillan website where it is possible to narrow the search criteria down to a region and even a

type of cancer.⁴⁹ Once a list of eligible support groups had been generated, each group was contacted by phone and email if an email address had been given. All voicemails were followed up with a phone call one week later and a second voicemail was left. Non-responsive support groups were followed up two weeks after that. Many groups responded to say that they currently did not have any members that fit the criteria. Some groups no longer existed and some did not respond to repeated messages. I went in person to give presentations to interested groups and explain the study. This yielded one particularly enthusiastic support group with members who fit the criteria and were keen to talk. From these initial meetings a number of participants came forward. Further participants were found by “snowballing” from the support group members’ connections to other groups and interested women.

Interviews were conducted with as many interviewees from the Northeast support groups as were interested (6 in total), and when further contacts with the groups yielded no more participants the recruitment catchment area was widened to include all of the United Kingdom, reaching out to those support groups that could be easily accessed from Newcastle. An extensive list of eligible support groups in the UK was generated using the same criteria as before, relying again on the Macmillan and Cancer Research UK website support group search functions. In addition to phone calls and emails, these support groups were also sent a brochure about the study, an introductory letter, an information sheet, an example of a consent form, a business card and a freepost envelope.⁵⁰

A project website (www.oncofertilityinthenortheast.co.uk) was also set up with all the project details, and a dedicated mobile phone was bought so that participants could call, text or email their questions. Social networking sites were not specifically targeted, however some interviewees offered to post information about the research on their private Facebook support groups, which I accepted. I also attended a number of “drop-in” sessions at support groups to answer questions and meet potential participants face to face. This yielded further patient participants (five additional interviews), all of whom were interviewed over the phone as this was more convenient for them. Recruitment was ongoing throughout the data collection phase and went on for a year and a half in total.

⁴⁹ See: <http://www.macmillan.org.uk/HowWeCanHelp/CancerSupportGroups/CancerSupportGroups.aspx> (accessed April 20th, 2012).

⁵⁰ See Appendices C, D, E and F for posted materials.

While the approach to recruitment moved from being systematic to opportunistic, and relied somewhat on snowballing, it also provided access to a group of enthusiastic and interested interviewees. All participants who expressed interest in participating were interviewed. The method of recruiting did change the characteristics of the participants recruited as some of the women interviewed had been diagnosed before 2007, so their cancer stories were more retrospective. The recruitment approach no longer focused on one cancer type either. Instead the snowballing approach brought different kinds of cancer (and the related treatments) to the forefront that may not immediately have been obvious as affecting fertility. This change had advantages and disadvantages: it was advantageous because it made it clear that any type of cancer treatment can cause fertility difficulties for its patients, and concerns about fertility are not just limited to those patients who are treated with chemotherapy or radiotherapy (for example: cervical cancer and vulval cancer have different treatments that also affect fertility). However the approach was disadvantageous as the patient participant “sample” was no longer uniform in terms of the type of cancer being treated. Despite this the interviews and discussions made it clear that while different cancers are treated in different ways, they all seem to carry overlapping concerns about infertility for patients, giving greater validity to the findings and interpretations on oncofertility, cancer treatment and patient choice in this thesis.

4.3.3 *Healthcare Professional Recruitment*

Many of the American studies on oncofertility focused only on how HCPs’ understandings of fertility preservation and cancer influenced patient understanding (see chapter 2). For this reason an initial ambition of the project was to explore the points of view of British HCPs to see if and how they may be influencing patient decision-making. Though this ambition eventually proved unsuccessful, there were initial attempts to recruit HCPs to the study. A number of group meetings with nurses and doctors were set up at the General Hospital to introduce the study in person, and hand out brochures about the study to be left in the break rooms of the oncology wards. Each attendee also received an information package that included an introductory letter, an information sheet, a business card, a consent form and a freepost envelope. While many HCPs expressed interest, getting interviews of significant depth proved difficult as most wanted to be interviewed at the hospital before their shifts, which only left about 15 to

20 minutes for an interview. The time crunch that the HCPs experienced (especially nurses) was cited as the main deterrent to setting up an interview. As a result there were very few HCPs interviewed for the study (see table 4.3 below).

Participant Type	Number of Participants
Cancer Patient	11
Healthcare Professional:	
<i>Nurse</i>	1
<i>Oncologist</i>	1
Total Number of Participants	13

Table 4.3: Breakdown of patient and healthcare professional participants

4.3.4 Interviews

Recruitment took place throughout 2012 and into early 2013 with data collection (using in-depth, one-to-one interviews) occurring simultaneously. Interviews were set up at a time and date convenient to the participant and lasted for around an hour. In most instances I had already met the interviewee in person and discussed the research project with them before scheduling an interview. Some interviews were conducted face to face (8 interviews), while others were done over the telephone (5 interviews) if this was more convenient for the participant. All interviews were audio-recorded (with the interviewee's consent), fully transcribed, and anonymised. To help keep the interviews on track an aide-memoire was developed based on the key topics and research questions of the study. The semi-structured interview format also allowed for follow up on lines of enquiry specific to each participant's unique circumstances and experiences. Since participants often interpret questions differently, a number of questions on the same topic were asked to make sure as many aspects were explored as possible (Brewer, 2000, 65). For example, when asking the participants whether they were concerned about their fertility this question was often asked in two different ways during the interview:

- 1) Was fertility a concern or issue that came up during your diagnosis or treatment?
- 2) Had you thought about having children prior to diagnosis?

Both questions are asking about fertility, but by changing the emphasis, as well as the wording from the clinical “fertility” to the more commonly understood “having children” it was hoped that important and relevant responses would not be missed by potentially idiosyncratic interpretations of terms on the part of the interviewee.

In addition, these less structured interviews required some form of ice breaker questions so that the interviewee felt comfortable enough to answer the more personal questions that followed, so these were added to the interview aide-memoire (Brewer, 2000, 66). They included questions about the participants’ age, marital status and home city. These questions helped set the tone of the interview, as well as loosely set up the roles of interviewer and interviewee. As a result the beginning five minutes of each interview were more structured, each having the same set of easily answered questions for each interviewee that helped ease them into the discussion.⁵¹

With the interviewees from one particular Northeast cancer support group a certain amount of ‘reciprocity’ was required in order to undertake the interview. This reciprocity was less in the form of giving back to the community in the way Liamputtong (2007, 60) describes, but more in the form of shared stories, as this is the primary currency used by the members of the support group and is how information is ‘traded’ in the group. Many of the interactions that took place there occurred during the drop-in sessions where they told each other stories about their everyday lives with cancer. Through ethnographic observations of the support group it became evident that the group members regarded individuals who came to the group, but did not talk to others or share their stories, as odd and in some cases even selfish. Listening to these types of comments in the drop-in session made it clear that a certain amount of my own story would have to be told in order to be allowed to hear the group members’ stories. I began sharing my own stories about my life and my experiences with friends and family who had had cancer in an effort to take part in this reciprocity. I tried to keep all personal stories to a minimum and as much as possible I only shared my stories before or after all interviews so as not to influence (or interrupt) the conversation during the interview.

Striking the balance of how much to share is a common concern in qualitative research, where the interviewer is required to “offer support and sympathy while also withholding

⁵¹ See interview aide-memoires in Appendix B.

information that might influence a respondent's answers" (May, 2003, 214). Within the interview when it seemed like an interjection was needed I would draw on and make reference to what I had read in the literature about cancer instead of any personal stories I had about cancer. In this way I felt that I could move the discussion along without dominating the interview.⁵²

4.3.5 *Ethnographic Observations*

Once interviews were underway it became clear that it would be useful to include observations and ethnographic notes of one enthusiastic support group, especially the "drop-in" sessions that the group holds weekly where members meet for tea, coffee and biscuits. These sessions were initially attended to recruit more participants. However it quickly became apparent that in these drop-ins all aspects of cancer were discussed openly and without reserve, giving insight into how women with cancer feel more generally about being a female cancer patient, and how the women of this group viewed cancer and fertility. Ethnographic style notes were taken that captured these conversations and actions at the drop-ins. This was not a 'big E ethnography' of the support group;⁵³ instead it was an attempt to understand the community created by the organisation, in order to better interpret and analyse the interviews with its members. Keeping ethnographic notes of the group helped construct an analytic picture of their particular world that gave ethnographic richness to the data analysis, without changing the focus of the study to an ethnography. As the data analysis for this research is based in an interpretivist epistemology, which sociological ethnography and ethnographic methods draw on, the addition of ethnographic notes was in keeping with the theoretical and methodological frameworks for the project.

⁵² This is a difficult task as there are conflicting views on the influence of the interviewer on the interviewee. Some studies (see Lee, 1999, 99–101) suggest that "interviewer characteristics" have little impact on the interviewee's responses. However, Creswell (2007, 140–141) suggests that the opposite is true and that interviewers must be aware of their influence on interviewees, as the interview is a hierarchical interaction where the interviewer projects their own self (i.e. status, race, research agenda) into the interview. I have tried to remain reflexive and aware of my own influence on the interviewees in this study.

⁵³ By 'big E ethnography' I mean a full scale traditional, anthropological ethnography. Instead I took informal notes and had informal interviews and conversations with the members of the drop-ins, and staff, whenever I felt that it might be beneficial to my research.

4.3.6 *Withdrawal from the Field*

Since ethnographic style interactions with the group took place, it was necessary to develop a strategy for withdrawing from the 'field'. This was initially tricky as the group was quick to adopt me as their own, introducing me to new members as "our Alexis". By attending the drop-ins as a researcher, I had inadvertently established myself as a member of their community and could not suddenly stop showing up. In addition, after attending a number of the weekly drop-in meetings I had become emotionally involved with the support group. This tied me to the members more closely and as the weeks went on conversations with the members became more in-depth and more personal. In particular the female group members who were too old to officially participate in the research were no longer speaking in the abstract about having cancer, but were sharing personal stories like those in the one-to-one interviews. Becoming emotionally attached to participants of research is not uncommon, especially when research involves observations (May, 2003, 213). As a researcher, but also personally, I was worried that my absence would or could be viewed as a slight to the group, and as I felt attached to the group I did not want that to be the case.

Leaving the field can be tricky, especially when it is prompted by a project deadline, and has to be handled with a level of discretion on the part of the researcher, who is in the best place to judge how to leave (May, 2003, 214). Initial plans to withdraw from the field were to start by reducing my visits to the drop-in from weekly to bi-weekly, and then explain to the group that I would have to be absent for some time while the thesis was written. In the end this was not necessary as the group decided to renovate the house where they meet and the meetings were cancelled until all renovations were complete. As the timing of the renovations coincided with the time needed to withdraw from the field to do data analysis it was much easier to reduce my visits after renovations were complete. Before the house closed for renovations I announced that I would be gone for several months during and after the renovations in order to write-up the thesis. I maintained links with the group through email with the coordinator of the group.

4.4 Gaining Ethical Approval

Gaining ethical approval was a significant consideration in the research design. There were two major institutional approvals that had to be sought for this project: one through the NHS Research Ethics Committee (the REC) and one through the NHS Research and Development department (R and D). NHS REC approval is necessary to ensure the ethical treatment of any NHS patients participating in research, and also identify and resolve any ethical issues the committee feels may arise from the research.⁵⁴ NHS R and D approval is required for any research on NHS sites, and if NHS healthcare professionals are involved (either in research or recruitment). Both applications are governed through an online application process referred to interchangeably as either IRAS or NRES. The applications to the REC and R and D have very similar questions; however they are distinct and separate applications and ultimately end up in different departments. For this project the approval process for NHS R and D provided hurdles that, while not insurmountable, were formative to the project's overall structure, organisation and design. Here I outline how the R and D approval processes impacted on the research, as well as offer reflections on the overall process.

4.4.1 NHS Research and Development

As I initially intended to conduct interviews with patients and healthcare professionals, and the recruitment was to take place at an NHS site using NHS patient records, Research and Development (R and D) approval was required. This presented some challenges to the research design, since despite this research project involving no medical treatment or intervention, current criteria for R and D approval require a Principle Investigator (PI) to be an NHS clinician with Good Clinical Practice training. The PI must also assume the role of responsible clinician to the research participants in order to oversee patients' medical wellbeing. These requirements meant that the leadership role of my research could no longer be filled by myself or the thesis supervisors, but instead had to be filled by a member of NHS clinical staff. This required a substantial amendment to the project which caused some concern as the

⁵⁴ A full outline of the NHS REC process can be found at <http://www.hra.nhs.uk/research-community/the-review-process/nhs-research-ethics-committee-rec-review/> (accessed 19 June 2014).

prospect that a PI would also be a member of clinical staff at the NHS site where recruitment would take place, threatened the careful balance in the research design that ensured the confidentiality of the interviewees.

Recruitment was to take place through the PI's clinic, with patients and healthcare professionals identified by the PI as eligible to participate. Unfortunately the assigned PI was a very busy clinician, whose priority (understandably) was not this study, but their own clinical practice. As this project was not a priority to them, the PI failed to assist as agreed with the original recruitment strategy. As a result the original recruitment strategy was abandoned in favour of one that had no involvement or reliance on the NHS or the PI.⁵⁵

4.4.2 Reflections on the NHS Ethics Approval Process

It is difficult to write about submitting a social science research project to NHS ethics review without sounding as if one is “whingeing about the unfairness of the world” (to borrow a phrase used by Dingwall to describe the process: Dingwall, 2008, 7). In the following comments personal frustrations are set aside in order to reflect on the effect that the NHS ethics review has on social science research, and in particular, to reflect on how regulations for biomedical research are often a poor fit (or even irrelevant) to social science research, and yet are still applied to it. I discuss this process here not just because it affected my thesis, but because its affects have wider implications for other researchers facing similar blocks. I am not arguing against regulation (or even against regulation by the REC), but outlining the unsuitability of aspects of the biomedical oversight model to social science research.⁵⁶ This unsuitability stems from the use of a model that is based on the belief that “pre-emptive ethical regulation in biomedical science” is necessary due to the “nature of the interventions” which have a “potential for harm that cannot necessarily be identified when subjects are recruited or easily reversed should problems develop during the course of the intervention” (Dingwall, 2008, 2–3).

⁵⁵ See recruitment strategies as outlined in section 4.3.2.

⁵⁶ There are several different arguments for how the social sciences should be regulated, however I will leave these arguments to one side, focusing only on the concerns I felt were raised by my experience with research regulation. I have focused on some of Dingwall's arguments about why biomedical regulation is not suitable to social science research; however I do not follow his argument to his conclusion that no regulation is needed at all. See Hedgecoe (2008), Schrag (2011) and Jennings (2012) for other recent exploration of the role of ethics committees in the social sciences.

However social science research cannot be compared to biomedical research as it does not carry the same risks of harm to the participant (Dingwall, 2008, 3). This is to do with two important aspects of the nature of social science research. First, social science research uses methods and methodology readily recognised by participants as familiar. For example, conducting an interview with someone is an easily recognised and understood practice, and potential participants are able to competently assess the risks to themselves if they participate (Dingwall, 2008, 3). Second, social science research is formatted differently from biomedical research, as the social science researcher is only a “guest in [the participants] lives and, like any guest, are likely to be asked to leave if their behaviour is inappropriate” (Dingwall, 2008, 3). An interviewee can stop or leave the interview at any time without any adverse effects on their health or wellbeing. How great a risk they take is in their hands, not in those of the researcher. This is not the case with biomedical research, where leaving a clinical drug trial early (for example) can have real and lasting health concerns for the participant if left unmonitored.

Social science research under the auspices of the NHS appears to suffer from a degree of “regulatory creep” whereby “systems with narrowly defined missions have gradually expanded their jurisdiction” (Dingwall, 2008, 4). Perhaps the best example of the effect of regulatory creep is the use of the word “intervention”. In the REC application, the word “intervention” is used to describe any and all interaction between the research participant and the researcher. What counts as an intervention when no medical treatment is involved is left open: while a participant interview could be broadly construed as an “intervention”, the REC also consider participant information packages, information brochures left in public places and participant requested follow-up reports as “interventions”. While it makes sense that medical research, in particular clinical trials, should list all interventions in order to track any and all burden on the patient’s participation, this is much more difficult to anticipate and plan for with interview-based research. For example, while I could specify how many letters I would send and how many brochures I would leave, it was impossible to know that some of the interviewees would want multiple email or telephone exchanges before having an interview, each of which could be considered an unauthorised intervention on the patient. This uncertainty can (and should) be stated by the researcher, but the application (at the time that it was filled in for this project) required an actual number be given that would be adhered to.

In addition, the “intervention” style language clings to the interviewee in the forms, continuing to brand them as a medical patient when they may no longer consider themselves to be a patient, or in the case of the few healthcare workers interviewed, never were to begin with. By painting all participants with the same ‘patient’ brush, the REC form makes crucial decisions about identity that should arguably be left to the participant to decide. It could be further argued that this process prolongs the time that a person is considered a patient and thus under the auspices of the NHS. In particular the idea that any participant who was *ever* a patient is always considered a patient thereafter is one that ultimately necessitated a major change to this research design by requiring a PI clinician to be “responsible” for these “patients” wellbeing.

Finally there are several practical difficulties that the NHS requirements (based on the biomedical model) create. For example, this project had been originally designed to ensure that patients and doctors would have no knowledge of each other’s participation, however if the project had been conducted under the auspices of the NHS this would have been difficult to achieve due to the addition of the responsible clinician from the same clinic where recruitment would take place.⁵⁷ Qualitative research is also inherently more flexible than the NHS ethics forms allow. Often one style of interviewing (for example) may prove to be less useful, necessitating a change in methods within the overarching methodology to a form of data collection that better accesses the issues being researched. While this change is possible by applying for amendments to the research project, each step of the NHS ethics approval process is slow and time-consuming. In addition, removing PI status from a social scientist means that the individual with the ultimate control of, and responsibility for, the research project may have no knowledge of the methods or methodology of the research being conducted. It seems an odd system when the reverse (a social scientist in charge of clinical research) would be considered unprofessional, irresponsible and unethical.

While I disagree with opinions that social science research does not need to be regulated,⁵⁸ the requirements necessary to meet REC and R and D approval restrict

⁵⁷ Granted this would not be the case if several clinicians were involved with the research, but this was not the original intention, nor was there funding to do this for my research.

⁵⁸ I am sympathetic to the points made by social scientists such as Hedgecoe (who observed and interviewed members of three RECs in the UK to discover how qualitative research was viewed) who argue that the REC are not biased against qualitative research (Hedgecoe, 2008). However, the actual committees themselves are not the concern, but the requirements to get to the committee meeting, as well as the further requirements from the NHS R and D to allow research to begin.

social science research negatively, as the applications and terminology based on the biomedical model are not transferable to the social science model of research. Different requirements and oversight should be given to social science research in the medical context to better reflect the different nature of the field and style of research. Further research may be necessary to discover more about how social science research with the NHS can be better governed through the NHS ethics approval processes.

4.5 *Ethical Considerations for the Study*

The central ethical considerations for this study, which were addressed from the outset and included in the final application for approval, were divided between ethical considerations for the participants and ethical considerations as a researcher. I will outline these considerations below:

4.5.1 *Ethical Considerations for the Participants*

There were four major ethical considerations for participants that were worked into the design of the project: (a) ensuring informed consent from the participants (b) consideration for the emotional well-being of the participants, (c) issues of participant confidentiality, and (d) possible “gatekeeper” issues connected with recruitment of the clinical staff.

– Ensuring informed consent from the participants –

Informed consent was ensured in a number of ways: Interviewees were given the consent form before the interview date, so they had time to look it over and ask questions. In some cases the interviewees signed it and sent it back to me. Regardless, before interviews took place the interviewee and I went over the form and again addressed any questions or concerns. The form was signed by both of us, and we both had a copy of the form. Only after the form had been signed did the interview take place.

– *The emotional wellbeing of the participants* –

Cancer diagnosis, treatment and follow-up are a particularly sensitive time for patients and there was a concern from the NHS REC that participants could be upset by discussing that sensitive time during the interview. To avoid this, participants were given the space and time needed to discuss their story, and were also reminded that they could stop at any time they wished and leave the interview or project. In addition, participants who would have been recruited through the NHS site would have been offered access to a counsellor and/or psychologist provided by the responsible clinician should they have wished to use this service.

Another concern for the participants' emotional well-being was the possibility of revealing to patients that they may experience fertility problems due to cancer treatment *before* they had discussed it with their doctor. To avoid this possibility participants recruited to the study through the NHS were going to be limited to those patients who had attended the General Hospital clinic between 2007 and 2009. Limiting recruitment to this time period ensured that patients had already received their diagnosis and were either in treatment or had been treated. In practice, since no patients were recruited through the NHS this precaution was not applicable as all the interviewees recruited from support groups had already undergone treatment. When recruiting through the support groups, a presentation was made to the group members outlining the project's focus on oncofertility. As a result all participants were already aware of the link between cancer and fertility when they indicated that they wanted to participate in the research. In addition women interested in taking part were urged to only do so after they had undergone treatment. All the women who took part had already undergone treatment and were either in remission or cancer-free survivors.

– *Participant confidentiality* –

There were initial concerns that the small community of cancer patients and healthcare workers would make it possible for participants recruited through the hospital to be identified through their interviews. However, as no patient participants were recruited through the hospital, it would be difficult for the participants to be identified in this way. Any risk was further minimised by ensuring that all personal information remained confidential as transcripts were anonymised and identifying details edited. All the hospitals and clinics mentioned by interviewees have been renamed "The General Hospital" to help further anonymise the interviews. The project also followed the

Caldicott principles regarding the confidentiality of patient data and all information was anonymised on receipt. Only I had routine access to the personal data and by the nature of the supervision my supervisors had access to the anonymised research data included in the thesis. Any data held on computers was password protected. No identifying information was or will be used in published or presented work.

– *Confidentiality and gatekeepers* –

In the original design I had intended to interview HCPs as well as patients. The same measures of confidentiality implemented for patients were used for the few HCPs who participated. Clinicians and some administrative staff at the General Hospital acted as “gatekeepers” and identified possible groups of staff to contact about participation. These gatekeepers were not informed which of the members of NHS staff were contacted. As with the patient participants all data were anonymised and identifying details removed and securely stored. Ultimately it was decided to focus only on patients, however the interview of one healthcare professional is included in this thesis, and all measures of confidentiality outlined above were followed for storing their personal data and including their interview data in the research.

4.5.2 *Ethical Considerations as a Researcher*

As the researcher my own actions had to be given ethical consideration as well, especially since an informal ethnography was conducted of one of the main cancer support groups where recruitment took place. The ethnographic observations were conducted to help understand the structure of the support group and have not been discussed in the data chapters of the thesis. However, ethical consideration had to be given to the information gathered through non-interview conversations. Those conversations were treated with the same level of confidentiality as the interviews. I explained to the group that notes of relevant conversations held in the drop-in group sessions would be taken, and I made it transparent whenever I took notes. The ethnographic notes were anonymised and pseudonyms given to anyone named in the notes to ensure confidentiality.

4.6 Data Analysis

4.6.1 *Transcription*

I transcribed all the interviews within the week that they were held. I checked the transcriptions against the audio recording several times for accuracy and clarity. My transcribing of the interviews also acted as a review of the interview material and the interview questions, allowing me to check that they made sense to the participants. It also offered the opportunity to pick up on some of the emerging, preliminary themes that would later be developed during the thematic analysis of the data.

4.6.2 *Thematic Analysis*

Data analysis for this research was done primarily using a thematic approach. Data analysis did not follow data collection in a sequential fashion, but instead started alongside interviewing, as emerging themes and issues used in the interviews became apparent. Consistent with interpretivist framing, the primary data for this research were the interview recordings and transcripts; due to the small sample size it was not necessary to use data analysis computer programmes such as NVivo for data management.

Analysis followed the same pattern for each interview. I read through the interview and listened to it in its entirety several times. Any possible themes based on salient or recurrent issues within the data were noted down (Attride-Stirling, 2001, 390–391). A list was kept of all emerging themes. Once all the interviews had been examined, I then organised them into a list of emerging themes to identify any overlapping or recurring themes from the list. This helped to identify those themes that were most likely major themes and those that were actually sub-themes. Once the list had been divided into themes and related sub-themes I re-examined the interviews to see how all the themes and sub-themes related to the data as a whole. This aspect of analysis was time consuming as it involved organising the data into distinct themes, discovering those sub-themes that belonged under major theme headings, as well as distinguishing between those themes that were common across all the interviews and data, those themes that were common only to the interviews done in the same region, and those themes derived from just one interview. The process of returning to the data with a

refined list of themes was performed several times until I identified three major themes and 11 subthemes (see chapter 5 for a detailed account of these themes).

4.7 Reflections on the Research Process

There were several points of contrast between myself (as a researcher and person) and the women interviewed that necessitated reflection on my involvement and influence on the research. Throughout the research I was aware that being a woman, from Canada, for the most part younger than the participants, unmarried and without children set me apart from the interviewees. While there was not much to be done to change that, I nevertheless strove to remain aware of these differences and the effect they may have on the research. Having outsider status is incredibly useful as it allows the researcher to ask the naive questions, and cross boundaries that insiders cannot, providing a unique perspective (May, 2003, 212). However being an outsider also requires reflexivity on the part of the researcher, as they cannot wholly separate the influence and effect that they have on the researched, and the other way around (i.e. interviews are co-constructed and co-produced). Rather than trying to avoid these influences, they can best be managed by making them explicit whenever possible. As Spencer argues, “A strong reflexivity [...] recognizes that the ethnographer and his or her language are inevitably a part of the phenomenon that is being investigated” (as quoted by Mason, 2002, 194). The researcher has a responsibility to “recognize complexity and difference, rather than hide them beneath a veil of homogeneity and generalizations” (Spencer, as quoted by Mason, 2002, 194). With this in mind I have tried to make any differences between myself and the interviewees explicit.

Despite acknowledging our numerous points of commonality and contrast, there was one point of contrast that required effort on my part to bridge the gap between interviewer and interviewee: I do not have, nor have I ever had cancer. While I could sympathise with their experience and, in most cases due to the ethnographic observations, I developed a lay knowledge of what different treatments and drugs entailed, I could not truly understand what it was like to have cancer. This sometimes made it difficult to reciprocate conversation in the interviews as I had no personal cache of cancer stories to contribute and I worried that some of my responses to the more difficult stories would come off as trite. I also found that the women who had cancer

spoke to each other in a shorthand of medical jargon that made perfect sense to them and made absolutely no sense to me. I sometimes missed the significance of the use of a word because I did not have their shared experience of being a cancer patient. For example, breast cancer patients are often treated with a drug called tamoxifen and they would often drop the term into conversation without explaining what it was. The women referred to tamoxifen in an almost off-hand way that suggested they assumed that I knew what it was and what its side-effects were. In the case of one participant, Robyn, she even personified it:

Robyn: But my tamoxifen and I have come to an agreement and I just wish it would let me lose weight now and then we'd be very happy.

As I had never used or known anyone who had used it before I was unaware of what was implied when they used the word tamoxifen the first few times in interviews. This made the consequences of my lack of first-hand experience with cancer acutely apparent.

To help fill the gap, I dealt with my lack of first-hand experience two ways: First, I endeavoured to look up and define all the terms and treatments used by the interviewees so that I knew what they were referring to. Learning the terminology was relatively easy as the Cancer Research UK and NHS web pages on cancer and cancer treatment are very comprehensive and include information on drug names and effects. This allowed me to understand and in some cases use the terms that the interviewees (and drop-in members) were using, giving a little more fluidity to our conversations. It also allowed me to understand, for example, that saying the word "tamoxifen" with a resigned sigh or a bit of laughter often signalled a number of frustrations that the interviewee was not explicitly voicing. However these frustrations were immediately understood by the other women, the biggest one being the weight gain that is often associated with taking the drug. In other words, it was not the "facts" about tamoxifen that mattered, but rather the interviewees' shared stock of knowledge that had to be understood. Learning their terminology demonstrated my commitment as a researcher to understanding the interviewees' circumstances and experiences, and using the same terms helped maintain a flow to the interviews (Mason, 2002, 74).

In addition to learning the terminology common to cancer treatment I also used the knowledge that I gained from writing the literature review to share “experiences” that I had read about. This helped me be more reciprocal about the cancer experience in interviews as it gave me something to add to the conversation. I always made it clear that it was something I had read in the literature and not personal experience, but it did help in instances where the interviewee wanted to have a reciprocal conversation about having cancer and I could contribute more than “I see” and “that must be hard”. Instead, for example, I could say things like “I have read that tamoxifen can be a difficult drug to take. I understand your frustration with its side-effects”. This type of reciprocity was very important as “the success of any qualitative approach requires creating bonds across the researcher–respondent divide” (May, 2003, 215). Part of creating this bond was participating not just in an interview, but in a meaningful conversation with the interviewees.

Ultimately there was no way I could bridge the gap between those who have had cancer and myself, however I feel that it is precisely my naïveté (as I have never had cancer) that allowed me to collect and analyse the data effectively throughout my research (Kvale and Brinkman, 2009, 30). As the stranger in the group I could ask the naïve questions that revealed the otherwise taken-for-granted knowledge held by the interviewees. Being reflexive, as well as self-critical about my own presuppositions and my influence on the research, also meant that I was open to “new and unexpected phenomena”, thus allowing me to ask truly in-depth questions about the interviewees’ experiences (Kvale and Brinkman, 2009, 31).

4.8 Summary

This chapter serves to clarify how and why this research was conducted as it was. While the process is laid out here in a rather linear fashion, this was not always the reality of the “doing” of the research. In this chapter I have tried to capture the changes in the fieldwork that necessitated alterations to the methodology and methods. While none of these changes were detrimental to the research design, and in fact enhanced the overall research itself, they did make the fieldwork a lengthy and sometimes arduous process. This left less time to recruit as many interviewees as originally targeted. In carefully outlining the thought behind the research design, along with the details of the research

methodology and methods, I hope that the reader is able to better understand the data collected and its subsequent analysis in further chapters. In the next three chapters I discuss the data from the interviews, focusing on three larger themes: Time, Information and Understanding, and Being Guided.

Chapter 5

Time

In the following three chapters I present my analysis of key elements of the data collected from the interviews. However, before discussing key points in the analysis of the thematic categories identified, I provide a brief overview of the range of issues identified in the data. Over the course of the fieldwork I interviewed 13 individuals, 11 of whom were cancer patients, and two professionals working in oncology. Through the recruitment process I came to know each interviewee well, learning about their history as well as their present lives. To provide some of this information, I have written short biographies of all 13 interviewees, which are available in Appendix A. I recommend that these biographies be read before starting on the substantive chapters so that the reader is able to better understand the biographical context within which each interviewee was telling their story.

5.1 The Range of Issues

Examining the data I identified a range of relevant issues. Many of these issues centred on the relationship that the interviewees had with their healthcare professionals (HCPs). Difficulty in gaining access to information about their disease was also a chief concern for the interviewees. The initial assumption that having a child post-cancer would be the biggest concern for the interviewees was not the case. This was surprising as unlike previous studies in the literature,⁵⁹ which showed that American patients were most concerned with not being able to have a child post-cancer, the interviewees of this study were more interested in fertility preservation as a means of avoiding early menopause. As I show in these three chapters, interviewees had a strong desire for knowledge about fertility preservation. Many expressed the wish that they had known about fertility preservation, but again this was not primarily so that they could have children post-cancer. Instead fertility preservation mattered to interviewees because they saw having information about fertility preservation as a means to accessing further choices for their lives post-cancer.

⁵⁹ See chapter 2.

Seen in this way the term “fertility” can be seen to mean “choice” for the interviewees, and “fertility preservation” is actually “choice preservation”. Interviewees wanted to know about fertility preservation and oncofertility because they wanted to be informed about all the choices available to them, and preserve as many future options as possible. Access to this information about fertility preservation was seen by interviewees as dependent on their relationships with their HCPs. How they perceived this relationship, and how they felt the HCP perceived the relationship, is dominant in their interviews. Interviewees viewed their HCPs as the primary source of valued information about fertility preservation, which perhaps explains the power dynamics/differentials observed throughout the interview data, something I will examine more closely in chapter 6. The importance that interviewees gave to information, “choice preservation” and relationships is in part what makes the decisions that they took, and why they took them, so interesting from both a sociological and bioethical point of view. In brief, fertility preservation matters because it gives patients additional choice, and choice informs decision-making, which in turn is one aspect of patient autonomy in practice.

5.2 Themes and Subthemes

When interviewees discussed decision-making, fertility, and cancer they linked them with the following areas: their relationship with their HCPs, their ability or inability to understand the information they were given about their disease, how they felt about having cancer, their need for further support during cancer diagnosis and treatment, and the different ways that they made decisions. I then labelled these as the following themes: “Time”, “Power Dynamics”, “Decision-Making”, “Information and Understanding”, “Emotional Wellbeing”, “Control”, “Communication”, “Patients as Experts”, “Being Guided”.

Several of these themes could be grouped together as subthemes of the others, as interviewees often discussed them together in this way. For example, the themes of “Emotional Wellbeing”, “Control”, “Communication” and “Patients as Experts” became sub-themes of the wider theme of “Information and Understanding”. Additional subthemes were also added to help capture the multifaceted view interviewees had of their experiences. As a result three major themes emerged that subsumed the others, organised in the following way:

- 1) Time
 - a. Manipulating Time
 - b. Future Planning
 - c. Predictive Fuzziness
 - d. Needing Time
 - e. Healthcare Professionals and Time

- 2) Information and Understanding
 - a. Communication
 - b. Information, Understanding and Decision-Making
 - c. Emotional Wellbeing
 - d. The Patient–HCP Relationship

- 3) Being Guided
 - a. Being Guided and Trust
 - b. Being Guided and the Medical Protocol
 - c. Being Guided: A Coping Mechanism
 - d. Being Railroaded

In organising the data into major thematic categories two themes are not represented as stand-alone themes: “Power Dynamics” and “Decision-Making”. These two themes are present in all the other themes in such a way that to tease them out so that they stand alone would be too artificial, making them seem flat when they are in fact dynamic and pervasive in the data. Instead power dynamics and decision-making have been used as lenses through which to view the three major themes. In particular the influence of power dynamics has been addressed in the themes of “Information and Understanding” and “Being Guided” as these two themes are informed by interviewees’ understanding of their relationships with their HCPs. Experiences of decision-making run through all three analytic chapters, as interviewees make reference to the decisions that they have made with regards to all three major themes.

Finally, while the data have been categorised into neat themes, all three themes and 11 subthemes interconnect and overlap with each other. It is difficult to make the themes and subthemes fit neatly into their categories due to this overlap. Where possible I have tried to make these connections apparent and explicit so as to show how and why one

issue may be connected to a number of thematic categories. In the rest of this chapter I focus on the substantive issue of time.

5.3 Time

All of the interviewees discussed how they experienced time and timing while they were patients, marking out “time” as a possible point of interest and concern for them.⁶⁰ From the interviewees’ point of view, time stood out as one area of the oncofertility patient’s experience that they felt caused difficulty not only for patients, but also for the HCPs. Time seemed to permeate all aspects of the patient experience, from waiting to be diagnosed, to worrying about survival (i.e. thinking ahead to a time they may or may not have), to feeling like they did not have enough time to understand, and finally, wondering how to plan their future given all this uncertainty. Examining how the interviewees experienced time and timing has also pointed to its crucial role in agency and autonomy, as time was identified by interviewees as being a vital part of how they made decisions. I have organised the experiences and concerns of the interviewees into five subthemes pertaining to time: “Manipulating Time”, “Future Planning”, “Predictive Fuzziness”, “Needing Time”, and “Healthcare Professionals and Time”.

5.3.1 *Manipulating Time*

In relaying their experiences, interviewees appeared to do something that I describe as manipulating time to justify and to cope with the decisions that they felt needed to be made. This manipulation came in a number of different forms: for example some interviewees placed important decisions in a far-off future, not to be dealt with in the present. Others appear to have reorganised the chronology of events in their retelling so that the story suited the choices that they made. The manipulation of time was often unintentional, occurring in the retelling of their experiences. Two interviewees, Stephanie and Heather, stood out as having done this frequently in their interviews. While I focus on their interviews here, as it is in these interviews that I found this “manipulation” to be the most evident, many of the other interviewees described similar

⁶⁰ Throughout these analytic chapters I will use the terms “participant” and “interviewee” interchangeably to refer to the women who took part in the research. I will use “patient” as a more general term to refer to all patients in the medical context.

instances of manipulating time.

Time was important to Stephanie as she was diagnosed with brain cancer while on the paediatric ward at her hospital; however the majority of her treatment occurred between the ages of 19–24, when she was an adult. Stephanie often described time with reference to her age and being, as she described it, young:

Stephanie: At the time I wasn't really bothered, you know. I'm only young and I'm not really bothered at the time. We'll come to that when it comes to that.

Stephanie was made aware of fertility preservation, however she decided not to do anything to preserve her fertility (though she did state that she would be “gutted” if she could not have children in the future). Her justification for not preserving her fertility is that at the time she felt she was too young to think about having children, and that she will deal with it “when it comes to that”. Her use of the phrase “when it comes to that” is indicative of one style of time manipulation where interviewees put important decisions into a distant time that has yet to come, and so do not need to be dealt with at present. Stephanie is waiting until “it comes to that” and described putting off those decisions:

Stephanie: I don't think until the time that I am wanting to have children will it really bother us that much. [...] Obviously it will at the time if I do find out that I cannot. But I guess I don't have to think about it at the minute, I'm too young.

By putting her difficult decisions about having children into an unidentified future time, Stephanie manipulated time to justify her decision not to make efforts to preserve her fertility during her treatment, because the decision to have children is one that she “wasn't really bothered” with at the time of her diagnosis. She did express a desire to have children, but her concerns about whether she can seem to also exist in this undetermined future time when she is “wanting to have children”. She appeared to be placing that decision in a future time when she will be more able to cope with the prospect of having children. As long as Stephanie does not “come to that”, by which she means that she is ready to have children, then she does not have to consider the

consequences of her decision not to preserve her fertility. Nor does she need to consider what decisions she will have to make about having children in the future. Until that time has occurred, and only Stephanie will know when that is, she justifies her past choices about foregoing fertility preservation by being “too young”.

Stephanie also placed the emotions that she has about having children into a future time so as to not deal with them in the present. For Stephanie “not until the time that I am wanting children” will her decision to not preserve fertility really “bother” her. For her it is “obvious” that she will be bothered “at the time” if she finds out she is infertile. Stephanie did express a desire to have children, however, despite this desire Stephanie distanced herself from having to make difficult decisions about fertility in the future. In doing this she also distanced herself from her emotions about the decisions that she has already made about fertility preservation. She manipulated the timing of her decisions to make space for the decisions she will have to make, but also used this manipulation as a coping (or even a protecting) mechanism against the difficult decisions that she has already had to face.

Other interviewees manipulated time in a similar fashion to Stephanie, placing difficult decisions, as well as difficult emotions, into a future undetermined time when they felt they would be more able to make them. This is also a phenomenon that has been observed in other difficult medical situations. Scully *et al.* (2007) found similar time manipulation in their study of patients undergoing genetic testing. They describe the patients manipulating the relationship between decision time and chronological time (Scully *et al.*, 2007, 214) by “an active manipulation of their subjective experiences of time passing, by fractioning the anticipated future into an immediate step and further steps that could be thought about later.” (Scully, 2007, 211).

By adopting a cross-that-bridge-when-I-get-there approach patients are shifting their temporal field such that it “separates difficult moral decisions that in practice are interlinked” (Scully, 2007, 214). This type of “fractioning”, as described by Scully, is similar to the way that interviewees in my study assigned their decisions to a future unknown time. The nature of fertility helps to facilitate this cross-that-bridge coping mechanism adopted by patients, as the loss of fertility is difficult to predict, and most individuals can only be diagnosed as infertile once they have started trying for a pregnancy (i.e. they are ready to cross the bridge).

Another interviewee who manipulated time was Heather. She used it to justify her decisions as she was making them. As Heather was pregnant at the time of her diagnosis she had to make a decision about termination and in her interview she described how she manipulated time in making her decision to have her baby before going ahead with her cancer treatment:

Heather: I thought well, having the baby is only bagging the time that I would have normally spent if I had had the normal smear test 18 months down the line. Add the 9 month pregnancy, add the 3 month. And I think at the time that's what I was thinking. I would never have gone. I could have ignored that. I could have rang them up, said "Look on your system; I'm not due another 18 months". "Right, fine." they could have said to me, and given the time I would have had me baby. And that's really daft, but that's how I was thinking.

Heather manipulated time so as to consciously exclude the urgency of her cancer treatment. Heather only found out about her cervical cancer because she insisted on having her smear done at the 6 month mark, and not at the 18 month mark as her GP wanted. In her mind the pregnancy would have happened if she had not insisted on having a smear done early, so she decided to carry on as if she had never had the smear. The time elapsed was equal, however choosing to ignore her early smear and pretend that she would have one in 9 months' time, as originally scheduled, resulted in having the time to bring her baby to term, then deal with the cancer. Again Heather manipulated the relationship between decision time and chronological time, but in her case she did this retrospectively, "bagging" the time she should have had and using it towards bringing her pregnancy to term.

Most of the interviewees manipulated time in an effort to make space for themselves to make difficult decisions. This manipulation of time occurred in part because interviewees felt that they needed more time to make the decisions that they had to make, so they were making that space available to themselves. Needing time to make a decision is one of the five subthemes identified, and I discuss it in its own right later in the chapter.

5.3.2 Future Planning

Planning for the future was another way in which time featured in the interviews. Interviewees placed importance on their ability to plan for the future, and linked this planning with the decisions that they would have to make in the future, or to preserve a particular future. Interviewees expressed frustration that planning for the future was often difficult due to the tentative survival percentages given by their doctors, as well as the difficulty in predicting whether they would retain their fertility post-treatment. The emotions expressed by interviewees about their ability/inability to plan their futures, and the impact that planning (or the inability to plan) had on their decision-making, indicates its value in helping them make treatment decisions.

For example Robyn in particular felt that planning for her future with her children helped her to make decisions to move forward with her treatment:

Robyn: And I wasn't going to not be there for my kids. I was determined that I was going to be there. We had my daughter's prom coming up at that particular time, that was just a few days after and I knew that in two years' time it would be my son's prom, and I needed to be there for that as well [...] And every time I thought about the future, thought about the kids it was quite difficult because that was the only time I felt any vulnerability. And it wasn't for me, it was for them, because I couldn't not be here for them.

Robyn had both negative and positive associations with planning for the future that impacted on her decision-making in different ways. On the one hand, Robyn needed to plan for the future as she felt that she must be there for her children, and so this made her determined to survive her cancer. In this case, planning for the future, specifically her future with her children, influenced the choices she made about treatment and survival. On the other hand, Robyn could not know for sure that she would survive her cancer, and so while she used planning for the future to help her make decisions to move forward with her treatment, she also found that this made her vulnerable and that imagining the future was quite difficult as it required engaging with this vulnerability. Robyn is a good example of how complex the connection is between planning for the future and decision-making. Planning for the future was an integral part of moving

forward for many of the interviewees, who, like Robyn, focused on how attaining a future goal (in Robyn's case being around for her kids) affected and influenced their present action.

Anne also felt that knowing what the future held was integral to planning for the future and making decisions, but in this case she was thinking about future treatment, and the side-effects of treatment. Anne described how damaging she felt not knowing about the future implications of treatments could be for making decisions in the present:

Anne: I know like one of our support members [...] has had radiation damage [to her reproductive system], it's a long time since diagnosis, but still has issues and none of this is kind of explained when they go for it. It's the end goal that you're not going to have cancer but some things that you're left with you know are quite hard to deal with.

Kathleen felt similarly, stating about her doctor's choice to treat her with a radical vulvectomy: "My future was never discussed".

While there is always a level of ontological uncertainty⁶¹ regarding the side effects of many treatments, Anne felt that not having these "issues" explained leaves the patient in a vulnerable position as they are not aware of what the consequences of their decisions will be, what she referred to as the "things that you're left with", making planning for the future difficult. Kathleen felt she had even less of an opportunity to discuss her future than Anne, as her HCPs never discussed with her what life would be like after her radical vulvectomy; simply that it needed to be done to save her life. Many interviewees wanted further discussion with their HCPs about their future (survival, side-effects etc.) then they had received as standard practice.

As discussed in the introduction to this chapter, interviewees were also concerned with looking to the future as a way of planning to keep their options open, thus securing the possibility of future decisions after cancer diagnosis. Angela expressed this best when asked why she would have liked to have known about fertility preservation:

⁶¹ By ontological uncertainty I am referring to the uncertainties that exist because uncertainty is a fundamental part of being in the world and it is impossible to know everything. For more on ontological uncertainty see Matthias (2010, 201).

Angela: If someone could've said we're going to take something and keep it to one side [...] Definitely, yeah. [...] I would have said yes, keep the bit and then I can make my decisions later.

Planning for the future is similar to the manipulation of time that some interviewees performed, in that patients are making decisions in the present that ensure options to choose from in the future. This is part of what makes oncofertility patients so unique, as they make decisions in the present about fertility preservation that will ultimately preserve choice for them in their future. As Angela explained, fertility preservation would have allowed her to “make my decisions later”. Had she known about it, fertility preservation would have helped her to plan for her future, by preserving choices in a future time (her “later”) when she was ready to make decisions.

Monica also viewed fertility preservation as a way of preserving choice in the future. Monica knew she might want to have children, but at 24 she was not ready to make that decision. In addition, Monica did not want to preserve embryos (the only option as egg freezing was not yet a widely available treatment) with the man she was dating at the time she was first diagnosed with breast cancer. Despite being pushed to freeze embryos, she pushed back for a better solution (the drug Zoladex) that did not force her to make decisions she was not ready for:

Monica: And my oncologist at the time Dr XXXX said that it might be worth giving it a go because I was only 24 and I hadn't really given much thought to having children at that point. But I couldn't say that I definitely didn't want them [...] But at that time the guy that I was going out with, I definitely didn't want to have children with. So when they were saying that we could have had embryos frozen and all that there was just no way that I wanted to do that [...] And they said about freezing eggs and things but the percentage of success rate that they were giving me at the time, I just didn't think it was worth putting myself through it. So I just thought well this here Zoladex is not going to have any side effects apart from the menopausal ones and its only short term so I just decided to go with that.

Fertility preservation was seen by interviewees as choice preservation for the future in more ways than one. It allowed patients to plan for the future without having to commit to a child, just to the (future) option of a child. As Monica put it “I couldn’t say that I definitely didn’t want [children]”, and because of this uncertainty in the present, she did not want to close off the possibility of having a child in the future. The focus of interviewees was less on the ability to *have* children after cancer, but instead on the ability to *choose to have* children after cancer if that was what they decided: a subtle but important distinction that would not force patients to make decisions that they were not ready to make. In addition having children is an uncertainty that all prospective parents must face, as it may not be successful regardless of being a cancer survivor. However, for oncofertility patients this uncertainty co-exists within the identified uncertainties of survival and the return of fertility after cancer, making decisions in the present about their future fertility all the more important to them.

– *Uncertainty and planning for the future* –

To cope with uncertainty individuals will try to reduce the uncertainty of the uncertain thing (Mattias, 2010, 201), which may account for the value interviewees placed on information about fertility preservation and cancer when planning for the future. For example, Monica felt quite strongly that patients should be made aware of all future fertility preservation possibilities so that they can make what she called an “informed decision” about which future they want (emphasis added in quote):

Monica: I think so that people can make an informed decision.

Rather than, if they’re not made aware of [fertility preservation] and then six months down the line is too late to do anything about it, it’s something that should definitely be an option to everybody to at least go and listen. [...] I think as a woman, or a man, I suppose, having children is just part of life I suppose and **should be made available to everybody.**

Oncofertility patients are also making decisions about their cancer treatment when considering their future life. They have to look to the future within the context of their cancer diagnosis *and* their fertility needs, which are not always in sync.⁶² Interviewees

⁶² By this I mean that fertility preservation is incompatible with certain cancers: for example, if the cancer is so advanced and aggressive that chemotherapy cannot wait the 6–8 weeks for egg retrieval, or if the

felt that being able to plan for the future was connected to how much information patients receive (and understand) about their diagnosis and treatment. Alongside the importance of planning for the future, interviewees expressed a need to have as much information as possible about their possible futures. Treatment outcomes were a particular focus, with interviewees wanting to know more about the different outcomes of cancer treatment on fertility, before making decisions about the future. For example Anne felt that all the different treatments for cervical cancer should be discussed as they offer different options in the future:⁶³

Anne: But I think they will now, with younger people try the trachelectomies a lot more. Because that's, like, gives people a bit of an option.

When making decisions, interviewees described information about their futures as just as important to them as understanding the present concerns of their cancer treatments. Many interviewees focused on their future during their treatment, and the way that they felt they could attain their future was by tailoring their current actions and choices so that these choices led to the future they wanted. Interviewees felt that not understanding or knowing all the information about the various available futures (in terms of fertility preservation, treatment outcomes and treatment side-effects) made it difficult to know which future to aim for and thus how to tailor their actions in the present. This is a point supported by Barbara Adam who argues that individuals “create their futures as a continuing affair in the present [...] the future is no longer merely predicted, it is actively constructed” (Adam, 1990, 98). Part of why “colonizing the future” as Hagerstrand (1985) put it, is so important to patients is that extending into the future is a way to control and even eliminate the uncertainty felt in the present (Adam, 1990, 139). For oncofertility patients fertility preservation is a way of ensuring one's imaginary future existence by such colonisation, thus securing both future fertility and future choice about fertility.

treatment requires the surgical removal of the uterus, ovaries or cervix, or if the cancer is oestrogen receptor positive (in which case the process of retrieving eggs would actually stimulate the growth of the cancer).

⁶³ Anne is referring to the difference between a hysterectomy (which offers a woman no chance of carrying their own child) and a trachelectomy, which preserves those parts of the reproductive system necessary to carry a baby to term.

5.3.3 Predictive Fuzziness

One aspect of planning for the future that may be specific to the medical context is something that Scully *et al.* (2007) call “predictive fuzziness”. Predictive fuzziness is a term from the 2007 study on genetic testing (Scully *et al.*, 2007). In that study the term was used to describe how genetic testing often cannot tell a patient everything about their disease (for example course and severity) just that the patient has it (Scully *et al.*, 2007, 209). Predictive fuzziness can cause uncertainty about the patient’s future.⁶⁴ The predictive fuzziness of genetic testing patients parallels that of oncofertility patients, who experience this fuzziness in two different ways: as fertility patients and oncology patients. Oncologists cannot accurately predict the level of damage to the reproductive system by cancer treatments, or if the reproductive system will recover once the patient is through treatment, leaving patients uncertain about their future fertility. In addition, oncofertility patients also have predictive fuzziness surrounding their survival, as it is difficult to predict the success of survivorship for many cancers. Many of the interviewees felt that this uncertainty contributed to difficulties in planning for the future. As the future that they were facing was uncertain, interviewees felt it was difficult to pinpoint which options are actually available to them at the time. Predictive fuzziness makes decision-making difficult as the possible futures to choose from are not clear to the patient.

Interviewees experienced predictive fuzziness in several ways. For Mary, the predictive fuzziness about her prognosis was frustrating because she did not know how long she would live, and her doctors were unable to give her an exact timeline, which made it difficult to make decisions about removing her ovaries:

Mary: And that’s what I kind of went away and tried to find out about. I don’t blame the doctors because people that I’ve spoken to, everyone wants to know something different and the people are given lots of facts and figures and say [...] I don’t want to know that I’ve got an 80% chance of living for ten years. But from my point of view that would have been exactly what I wanted to know and I couldn’t make them tell me, you know I sort of got “Well 50/50. With your ovaries

⁶⁴ Patients experience uncertainty about a number of different things in their lives, predictive fuzziness is specific to medical uncertainty.

gone you've got good things going on". You know they were very bad at sort of responding to the hard facts.

Here the predictive fuzziness that Mary experienced was due to the conflicting messages that she received from her doctor. On the one hand she had a 50% chance of surviving her cancer, but on the other hand she had "good things going on" if she removed her ovaries. The phrasing of "good things going on" is Mary's own interpretation of her discussion with her doctor, however the opaqueness of the statement shows how she interpreted the vague statement about her survival, which made it difficult to decide if removing her ovaries was worth (to her) this ambiguous "good things going on" promoted by her doctor.

Predictive fuzziness was frequently experienced by the interviewees as a lack of information about their futures. Uncertainty is often related to "the sufficiency, reliability and validity of information" (Babrow and Kline, 2000, 1810). Uncertainty about diagnosis means uncertainty about survival, making decisions about the future difficult. Patients value predictive information about their disease when planning, preparing and making decisions about the future. Predictive fuzziness is a form of epistemological uncertainty, which is uncertainty about specific information and the applicability of that information (Matthias, 2010, 201). Oncofertility patients experience this epistemological uncertainty alongside the existing ontological uncertainty that everyone experiences as part of living in the world and the impossibility of knowing everything (Matthias, 2010, 201). Interviewees expressed a frustration with epistemological uncertainty as they felt that they did not have the right information (for them as patients) about survival and treatment, making it difficult, if not impossible for them to make decisions, and by extension exercise their autonomy.

Kathleen's experience is as a good example of how information and understanding are linked to predictive fuzziness, as she was so unsure if her unborn baby would survive the surgery to treat her cancer that she was unable to plan or prepare for the birth. Predictive fuzziness affected Kathleen's agency, and therefore her decision-making. Her example is perhaps an extreme, however her reaction to uncertainty points out how paralysing predictive fuzziness can be:

Kathleen: And it was then that I realised that I wasn't really doing any bonding with the baby at all. [...] I just felt that I couldn't even go out and buy clothes for this baby, and prepare for him coming. Me first baby I had everything [...] It was like a bird making a nest ready for the eggs to hatch [...] I just couldn't. I wouldn't let anybody buy anything or bring anything into the house, I just seriously, probably frightened in case something was drastically going to go wrong. That baby was born and I didn't even have any new vests. That's how unprepared. Not unprepared, just didn't want to know until I knew this baby was alright. And even when I knew the baby was alright, I couldn't bond, properly.

As Kathleen was the first case of vulval cancer at her hospital, her doctors were unable to give her any indication of her own survival, or that of her baby's. Kathleen's uncertainty stemmed from her doctors' predictive fuzziness on survival, which made it impossible for her to make decisions, or to act to prepare for her unborn child. As she put it she "just couldn't". Kathleen's uncertainty about the baby's survival made it impossible to act of her own volition, even when she knew that she should be preparing and "making a nest" for her second child. Without the sure knowledge that "this baby was alright" Kathleen was unable to make any decisions about her baby.

Predictive fuzziness may be difficult to escape as "uncertainty is central to the illness experience" (Babrow and Kline, 2000, 1812). For oncofertility patients an aspect of the illness experience is survival of the cancer itself, which is very difficult to predict. Amy, for example, needed to know her prognosis in order to make decisions about supporting herself during and after treatment:

Amy: [...] the immediate concern for me was how I would manage financially. But [...] I had no idea what the prognosis was [...] whether it had spread anywhere. I mean you kind of don't know whether you're expected to survive or not. You're sort of thinking, "Well what do I do about my finances?" [laughs]

Amy felt unable to make decisions, as her doctors were not able to give her an accurate prognosis early on. She did not know what to think or how to harness her concerns as

she was unsure if she would survive her illness. Anne and Brenda expressed similar concerns. For example, Anne was worried about how to plan for next Christmas when she did not know if she'd survive to it:

Anne: I remember putting the tree up and thinking you know, “how’s this going to work? [...] Does it just go away when you have the surgery? [...] what will happen in twelve months’ time when it’s Christmas again? [...] How will me health go from there to there?”
[...] Because it is a worry.

Anne phrased her concerns about the uncertainty of her survival in a series of questions that show the influential effect of predictive fuzziness on making decisions about the future. Her concerns were not just about the more immediate future, so the next Christmas, but what was going to happen to her health and how was her treatment “going to work” to make sure that she did survive. Anne asked these questions to try and prepare for different possibilities, but like Amy, without answers it was difficult for her to know where to concentrate her efforts or where the decisions needed to be made. Brenda had a more matter of fact way of explaining predictive fuzziness, stating:

Brenda: [...] they can’t ever tell any cancer patient, you know, 100%.
They’ve always got to say it’s a 99%.

What is striking about all the interviewees is that the 1%, to use Brenda’s phrasing, often loomed larger in the interviewees’ minds than the 99%, especially if the 1% meant dying. Most interviewees wanted both certainty and clarity about their survival, something that their doctors were unable to give them.

Only one interviewee took a different approach to the predictive fuzziness of her diagnosis and that was Heather. She used the predictive fuzziness to her advantage to make and justify the decision about taking her baby to term before being treated for her cervical cancer. As her doctors could not be sure that her biopsy results were not influenced by her pregnancy hormones, she decided to use that uncertainty as a positive reason to keep her baby:

Heather: And he was explaining things and he was lovely and he was saying “you know these biopsies could come back and they could be less and they could be not as bad as what the smear test has shown, you know they’re not as conclusive as the biopsies. And the other thing to remember is that when you are pregnant, your hormones, we’re not really getting an exact measurement of what is going on inside there, I want you to keep that in mind”. And I always kept that in mind. And when I did get the [biopsy] results back, and they did say the worst is the worst and it’s what we feared, I always kept that in the back of me head. I’m pregnant, and the hormones [...] It can change after 3 months. So I had a lot of things that I think just pacified, or I tried to pacify myself.

Heather used this predictive fuzziness to her advantage. Instead of seeing herself with cancer of an unknown severity, Heather took this to mean that she might not have cancer, or that it might not be severe, instead of the other way around. She was waiting to be proved wrong in her assessment that “it can change after 3 months” due to her hormones and pregnancy.

Heather was in fact an exception in other ways among the interviewees, in that throughout her diagnosis and treatment she preferred to have the minimum information possible about her situation. She felt that she was unable to cope with knowing all the details and it seemed that she was using this self-imposed lack of information as a protective measure. This is perhaps why the predictive fuzziness she encountered did not frustrate her, but instead helped her to justify her actions, and as she said “pacify myself”. Limiting the information available is one of the ways the people often cope with uncertainty, as it reduces the amount of new information that feeds the uncertainty (Dennis *et al.*, 2008, 417; Babrow and Kline, 2000, 1811). Heather took a slightly different approach to coping with her uncertainty: by limiting the information that she had, but also by embracing the unknown severity of her cancer, she widened the possible outcomes to include more positive and desirable ones, helping her to cope with having cancer (Babrow and Kline, 2000, 1811).

Apart from Heather, all the interviewees found predictive fuzziness difficult to deal with, as they disliked the uncertainty that it brought to an already difficult situation. In

general this uncertainty impeded the interviewees' abilities to plan for the future by making that future unknown, thus making it difficult for them to colonise their futures through their decisions in the present. Planning for the future is the enacting of patients decisions, based on the information they are given, while predictive fuzziness is experienced as a lack of this information on the part of the patient; a theme that is woven through all of the analysis (and will be dealt with more specifically in its own dedicated chapter).

5.3.4 Needing Time

All the interviewees expressed a "need" for time. This need for time related to four specific areas: time to allow information to sink in and be understood; enough time with their HCPs to allow that to happen; time to reflect on and use the information given; and time for discussion with HCPs. Here I address all four ways interviewees described needing time.

– Needing the time to understand –

Interviewees expressed a need for the time to understand the information about their diagnosis and their treatment. Both of these seemed lacking in their experience. Without the time to understand what they are being told, interviewees felt that the information they are given could be overwhelming and difficult to use to make decisions. Some interviewees regretted the actions that they took as they did not have the necessary reflection time. For example Kathleen says:

Kathleen: And that was the point when I really thought you know, "I would have loved to have had more children" [...] and that's when I thought about the sterilisation [...] I REALLY didn't have time to think about nothing.

By not having the time to think about her diagnosis and treatment, Kathleen was unable to reflect on the fact that she did in fact want more children before she agreed to the sterilisation. It was only after the surgery and sterilisation had been done that she realised that she had wanted more children, but was no longer able to have any. She felt that more reflection time may have avoided this situation.

Interviewees indicated that the lack of reflection time was due in part to when information is given to patients. Interviewees found discussions about the diagnosis and subsequent treatment plans overwhelming, owing to how quickly cancer diagnosis and treatment occur, but also owing to the volume of information given to them in that short period of time. There are a number of examples in the data of interviewees expressing a desire to be given more time to digest the information, reflect, and sort out what they understood and what they needed clarification on. I have included some of these quotes below (emphasis added):

Mary: [...] somebody perhaps who was wanting to have more children [...] there is an awful lot of information at first and to have something as major as that, to you, thrown in at that stage, **I think you'd need a bit more time to think about it.**

It is Mary's choice of words that shows how overwhelming the volume of information can be. To her it was "thrown" at the patient, perhaps implying that there was little time to react; a patient must simply do their best to catch whatever information they can get. Having children is a "major" decision and any decisions related to that should be considered carefully, which to Mary meant having "more time to think about" the decision.

Heather expressed a similar opinion, pointing out that time is necessary for patients to understand the information given, but also having that time to understand, in her words, empowers the patient to feel more comfortable with the decisions that they have to make.

Heather: Even if it can be explained to you. [...] To go away and deal with that emotion first. I mean what's a day, or two or a week. You know? [...] At least then you're empowering the patient with the information. You've given them that. That's my opinion. I think it would work better that way. Go away and think about it, however in my opinion the doctor *can* say this surgery needs to be done because it's going to save your life. [...] But here's this little bit of time for you to go away and think about that. Because this is what's going to happen afterwards, *No* children. You're going to go into full blown

menopause. [...] Take some time, go for a walk, come back in a few days [...] if it's done like that then the patient, certainly in my—when I've worked with clients, I think it gives them a little bit of space to absorb what's happening and that feeling of being in control because they've got all the information and they're coming back with it. I think that would work better. Instead of “You've got this. We're going to do this. Your appointment will come through the post.”

While this quote expresses a number of different concerns about the levels of information accessible to patients, it also shows how critical time is for any and all of these things to occur in a way that makes the patient feel like they can make a decision. In particular, time plays an important part for patients when they are trying to understand the information given to them (what Heather called absorbing the information). Heather felt that “coming back” to the HCPs with an understanding of the information, after having reflected on what that information means can empower patients, thus giving them a sense of control against the uncertainty of the disease. Having time can also be a way to cope with uncertainty, as uncertainty can be related to how individuals integrate new information into existing beliefs, values and life plans (Babrow and Kline, 2000, 1810), which patients cannot do if they do not have the time available. Having this time allows patients to come back with an opinion that informs a decision about what they would like to do next; a process that is very similar to what bioethicists might call making an autonomous decision.

Angela also stressed the importance of having time to understand and reflect on the information given to cancer patients. Angela felt that time was needed to help get over the shock of diagnosis, so that the patient can face the information that has been given to them with a clear head:

Angela: Yeah, so you've got time to soak it in. Rather than you're sitting there having a conversation with the consultant who then hands you your schedule for chemotherapy [...] and you sort of get going the next day or so. So there wasn't much time there to do some thinking between seeing the chemotherapy man and it starting. So yeah, I think it's got to be earlier on. I know it's a big shock and I know you're thinking about your boob and the rest of it all and whatever cancer that

you're getting but yeah, I think it has to be earlier on to give you time to think about it. Because your head does have to get over the first bit of cancer first and then you've got to say to yourself "Well there's other things to be thought about" and if as you say, saving fertility. So yeah, I'd like at least a week or so to think about it!

Angela's explanation of how diagnosis and the discussion of treatment plans often occur in the same appointment demonstrates the speed at which patients are expected to make decisions. For Angela this was going too quickly, she felt that these decisions were being made before the shock of having cancer had been dealt with. The only way to deal with this shock is to allow "time to think about it". When I asked Angela to elaborate why time was important she explained that time was so important to her that it made her emotional:

Angela: I know sometimes you have to rush off and start treatment but a week here or there or a few days can just make the difference. Definitely. Yeah. Time to go home and sit down and think about it, have a night's kip. Or not sleeping maybe! [laughs] Worrying about it. But yes, you do need time, definitely, I can honestly say that [...] Oh yeah, I mean time, I can't even put words to it my love, you need to make your own mind, your own head has to—I'm going to cry now sorry [...] I needed time to think it through and have my mind to it. I was a bit upset about losing the boob, so yeah I needed to get that in my head. To me I was being disfigured to lose the boob, I rather liked my boobs beforehand [laughs] I'd even flashed them on the Isle of Man once! [laughs] [...] So I was rather proud of my boobs so to lose one was rather a heart wrench!

The above quote shows how emotionally invested patients are in having time. Angela found the quick turnaround needed on the decision to have a mastectomy very difficult to cope with, not only because she was getting over the shock of the diagnosis, but because she attached an enormous amount of value to her breasts, and had even at one point considered dying from cancer *with* her breasts rather than have them removed. For Angela time is crucial for patients to think through what has been said, but also to be able to "make your own mind" by reflecting on what they have been told. For her

having time and making the decisions that she did about her treatment are linked together. She later explained that it was her consultant taking the time to explain the possible treatment scenarios and answering Angela's questions that made Angela decide to go ahead with the mastectomy. Angela felt so strongly about the need for time that she even gave recommendations for how information should be given to patients:⁶⁵

Angela: But yeah I think that's the rule, someone talk to you, give you all the information verbally with a sort of backing up leaflet to take home and read at your leisure when the initial shock of everything is over with and you can sit down and read about it in the peace and quiet of your own home. So yeah, that's the sequence I would have wanted stuff to be in, yeah.

–How interviewees experienced the time spent with their healthcare professionals –

Interviewees expressed two different ways in which they needed time with their HCPs: they wanted enough time with the HCP to feel they had understood the information being given, and they wanted the HCP to spend time listening to patients' questions and concerns. In particular interviewees felt that the latter should be included as part of the former for a better patient–doctor encounter.

Some interviewees, such as Amy, felt that the time spent with their clinician or consultant was helpful in achieving the informed understanding that they needed to make a decision:

Amy: I don't think there was ever going to be a good time because the treatment was urgent. I don't think they could have really given me much more time for it to sink in. And they did give me a sort of information leaflet and gave me lots of information. And one oncologist was just brilliant [...] you could go to her and talk to her about anything and she really was fantastic. I know that I could have

⁶⁵ It is possible that some HCPs already offer this type of information provision, especially as this research focused only on the patient's perspective. There is extensive literature on patient information provision that I will not engage with here as I am examining the specific experiences of the interviewees. Further it should be noted that the NHS has recommended guidelines for patient information provision: see <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information> (accessed 24 March 2014), however these guidelines are only suggestions, not requirements, which clinicians can choose to follow or ignore.

[...] if at some point between my seeing her and my treatment actually starting if I had thought, “Oh actually I’m not sure about this” I know that I could have gone to her and said I need to talk to you about it and had a discussion. But because of the urgency of it I don’t think that there was ever going to be a good time [...] normally people would have the surgery first, and they would have a lot more time to think about these things I guess. But for me that just wasn’t an option.

Despite her aggressive cancer, which required urgent treatment, Amy felt her oncologist was readily available to give her time as Amy could “talk to her about anything” at any point that she needed. Amy is also a good example of how patients *and* HCPs do not always get to dictate how much time is spent together, as the urgency of the cancer and the need for immediate treatment are often driving the pace of action. Despite this, Amy’s HCP did make her time available to Amy, which Amy valued as she felt that if she needed the time to clarify or understand anything (what Amy characterises as being “not sure” about treatment) that time was there for her to have. And knowing that time with her HCP was available, without actually using that time, was enough for Amy to feel she was being considered by her HCP, which made her feel more comfortable with the urgency of her treatment.

However, when reflecting on their experience, the majority of interviewees felt they were cut off from their HCPs, and that the time spent with them was rushed. Many interviewees felt that shortcuts were taken on the provision of information to save time, and that this only led to further misunderstanding. This connection between time and understanding has not gone unnoticed in the literature, for example, Morgan points out that discussions with patients do not necessarily require longer consultations, however, if they do, then taking the time to discuss may save time in the future by eliminating future misunderstandings (Morgan, 2008, 63). Mary was particularly vocal about this, saying:

Mary: I mean my experience was that I felt I had very good treatment but I didn’t feel like the doctors were very good at discussing much at all really. They did seem to be in a hurry, and not always very clear [...]

Mary did not feel that her HCPs withheld anything from her, just that the rushed nature of the delivery of the information meant that she felt what they were telling her was unclear. The lack of clarity led to her belief that her doctors were not “very good at discussing much at all really”.

Anne felt that she not only lacked sufficient time spent with her doctors, but also that when she did have time with them it was not enough for her to listen to them and for the doctors to listen to her concerns. She felt they were focused on their job, describing the clinical encounter as “it’s all business”, and felt that HCPs leave little room for the patient to strike up a conversation.

While Anne spoke at length about this frustration she was not the only interviewee to voice concerns over the short space of time patients get with HCPs. It was not just more time that the interviewees wanted with HCPs, but time where their concerns were treated with respect and interest. In general interviewees wanted better relationships with their clinicians, which they felt could be built in part through HCPs respecting patient concerns by spending time discussing them with patients.⁶⁶ Anne in particular felt that the lack of time with her clinician contributed to the poor relationship she had with him:

Anne: Because they see it every day, and I think that one of the problems is that because they see it every day they don’t think, whereas I was thinking that they should treat each person as if it’s the first [...] and I’ve recently complained about one of my doctors [...] I was telling him about something that had happened following on from my recent surgery and he was just kind of going like “yeah, yeah, yeah”. But it was quarter past five at night and the clinic was running an hour and a half late but that’s not my fault [...] Yeah, I feel like if you go to an appointment and you’ve sat patiently for say an hour and a half and you go in you want your little 7 minutes or whatever it is. You only get like a very brief, so you’ve got to kind of think what you’re going to say, you’ve kind of got to plan what’s going to be said in that room before you go in. Because if you don’t you’re out and you

⁶⁶ Interviewees also expressed the opinion that a better relationship between HCP and patient might help dissolve some of the tensions that they experienced around information provision and addressing patient concerns: a concern that will be addressed in detail in further chapters.

won't have that chance to ask and you know previously I've always gone in and said "no issues, great". But this time I was having some issues and I thought right I'm going to say something and when you're treated like that you think right, why have I bothered?

This example from Anne shows how influential the time spent with the HCP can be, especially if the patient wants to use that time to get information or communicate information to them. The type of behaviour Anne described above shuts down communication between patient and HCP in the future. In addition, the time spent with HCPs is limited (seven minutes as Anne says) which forces the patient to plan what they will say, but leaves little room for the unexpected or follow-up questions that may arise in the consultation.

Interviewees also felt that *when* a patient is told information by the HCP is as crucial as *what* they are told. Both Amy and Anne described the chaos of the moment of diagnosis and how it affects the patient's ability to understand what is happening during their brief consultation with the doctor:

Amy: It was weird, it was just kind of, it is almost like your ears are ringing and your head's throbbing and there's so much that stands out.

Anne mentions a similar feeling of shock:

Anne: I think [the lack of understanding is] about the timing of when things are done because sometimes when they say you're going to have a surgery or treatment you're overwhelmed [...] Because a lot of people go back and they'll wait till say a couple of years after [diagnosis] because it's took them that long to get over the shock of the diagnosis.

Interviewees felt that they were often too upset and overwhelmed at the diagnosis to fully understand the information given to them by the HCP. This may mean that further time spent with HCPs may be necessary to help overcome the shock of diagnosis and be able to fully understand what they are being told. Without time to revisit what they have been told, patients may not have absorbed all the information about their disease, and

HCPs may not be aware that patients are missing any information.

– *Time with the breast care nurses* –

One group stood out from the rest of the interviewees for having an overall positive experience with their HCPs: interviewees who had had breast cancer. They said they were more satisfied owing to the face-to-face time they received with their breast care nurse. However, these interviewees felt that the nurses were picking up the slack left by the rushed clinicians. As Mary described below, in some cases the nurses act as a sort of interpreter between patient and clinician, facilitating patient understanding of the information that the clinician has hurriedly given out. I have chosen to quote from Mary as she was equally dissatisfied with the time spent with her doctor as she was satisfied with the time spent with her nurse, though both (presumably) gave her the same information about her diagnosis and treatment, but in different ways:

Mary: But the breast care nurses they were brilliant at all that kind of thing [...] in my experience it worked really well because there is this person that you can phone or speak to whenever you want to and they've always got time for you [...] you get the time with the doctors just when you've got an appointment, and then you go away and you think, "oh, I wish I had asked that". But you can't just pick up the phone and ask the doctor again, whereas you can pick up the phone and ask the breast care nurse and certainly within my experience there were a few times where I was having difficulty understanding the doctors [...] and sometimes the breast care nurse was actually in the consultation with me, and then afterwards she would say, "oh, OK, let's go have a cup of coffee" and would explain some things that I hadn't managed to grasp.

When I asked Mary about who would be the best person to discuss time-sensitive oncofertility treatment she immediately nominated the breast care nurse because of the nurse's accessibility to patients:

Mary: Yes, in my opinion the breast care nurse would be the person, certainly to raise it in the first place. And what the options are and I think partly because it's something that you want to think about very

slowly and with the doctors there never seems to be that reflection time [...] And particularly it's not just that [breast care nurses] have a little more time at the time, but because you can have a chat with them, go away, and then ring them up again. Do you see what I mean? You can talk to them little and often, rather than just these very set consultation periods where you get them.

Mary's concerns about getting enough time with the doctor and nurse are related to the previous concerns about reflection time identified by interviewees. Mary wanted to be able to think slowly about the decisions she had to make and the doctor is too rushed to provide that reflection time. Unlike the interviewees with other types of cancer, Mary was able to get that time she needed because she had a breast care nurse to turn to. In the above quote Mary also identified a key issue that many interviewees brought up: that they need constant access *across* time to information throughout the course of their treatment, little and often as she put it. It is not just at the point of diagnosis, or when a decision has to be made that time should be spent on going over the information patients want. Interviewees with breast cancer felt that the constant access they had to breast care nurses helped facilitate their understanding of what was happening and the information they were given, as they could go over and ask questions whenever they needed, for as long as they needed.

5.3.5 Healthcare Professionals' Experiences with Time

With the emphasis that theories of autonomy have on the patient it can be easy to forget that the patient is only one half of the interaction between doctor and patient. Doctors are also experiencing time in ways that influence how they spend that time with patients (Morgan, 2008, 63). During the interviews I had the opportunity to speak with two HCPs, one of whom was an oncology surgeon, James. James pointed out that clinicians experience a crunch on their own time, due to increased clinical responsibilities, that he felt limits how much time they can spend with patients. Clinicians have responded to this time crunch in different ways that have knock-on effects for the patient's understanding of their disease, which in turn can influence how patients make decisions. Clinicians either cram as much as possible into a single consultation, or provide only the bare minimum, relying on the nurses to fill in the gaps. Unfortunately, as James explains

in the quote below, this leaves little to no time for the patient to understand the information and choices that are being presented to them, but equally, the clinician feels there is no time to return to the patient and go through the information again:

James: Each newly diagnosed person with cancer is discussed at the weekly multi-disciplinary team meeting, for every cancer for every hospital there is a multi-disciplinary team that comprises of the physician, the nurses, the pathologist, the radiologist, the oncologist and so on. And from that discussion one of that team will then be meeting with the patient to discuss their treatment options. So, yes they will be given choices to a certain extent, but this is the problem, understanding those choices takes time! [...] And that time often isn't there and it tends to be understood that [the patient and doctor] talked about it and they suggested that [the patient] should have this and it's OK. But having said its OK [the patients] often say, "oh I wonder what could I have had and why did they choose that?"

In addition to not having enough time to discuss options and information about their diagnosis, James felt that clinicians experience an additional time crunch to give patients information as quickly as possible. He argued this can be seen in the organisation of rapid access for breast cancer diagnosis, where the mammogram, biopsy etc. are all done on the same day and often diagnosis happens at the end of that day. Patients who need more time than this allotted day are at a loss as to how to slow the process down to a time scale they can manage, understand and digest, and (James believes) can be seen as "difficult" by time-stressed clinicians. Being labelled in this way further impedes the patient's ability to understand and use the information given to them to make important decisions about their cancer treatment (emphasis added):

James: Now for some women, many women that was absolutely brilliant, they weren't kept on tenterhooks waiting. For some women it was far too fast. But then again that philosophy was then followed up with "AND we'll do your operation next Monday". [...] So there is not the angst, the anxiety of waiting [...] But for a lot of women that was far too fast. Far too fast.

Alexis: I'm wondering what would happen if you're the patient who says, "I need to go home and make this decision on my own"?

James: "You are being difficult, aren't you?"

While some of this time crunch is relieved by the presence of specialist nurses, this only really works for those cancers where the specialist nurse role is established, in particular in breast cancer. The specialist nurses were originally brought in to take the burden off the clinicians, however the success of this arrangement relies heavily on clinicians continuing to perform certain duties and roles that are not only time sensitive but also time consuming.

The Little Red Book is an example of the continued importance of the role of the clinician. This was created for cancer patients so that they had a patient-held record of their disease and treatment plans. It was meant to be carried on them at all times. If they needed to see another doctor, or went into A and E, they could take the Little Red Book out, give it to the attending clinician and the clinician could read through it and be accurately up to speed with the status of the patient. It was also a way of empowering patients to always have with them some information on the progression and treatment of their disease, and allowed them to revisit that information after their appointments were over. The Little Red Book was a physical representation of patient autonomy in practice. The main flaw was that clinicians had to take the time to fill it in, something that was met with resistance (emphasis added):

James: It transpired that when the people who had the patient held record went along to their outpatient clinic and saw the consultant [...] they would say "oh doctor I've got this, could you please just put in the results" and so on, because you would put in the results and scan as well. "Oh, don't be stupid, I'm far too busy [...] **I haven't got time for that.**" [...] They gave up taking it with them because of the attitude of the medical professional. [...] But the initial start of that story, it failed because of the resistance of the medical professionals.

Alexis: Do you think that it was just a timing thing?

James: Time. I mean it was time. It was time, of course it was.

James is the only oncology clinician that I spoke to, therefore it would be inappropriate to draw concrete conclusions from his experience alone. However, his experience offers some insight into how HCPs experience time in the medical context and how that may influence how patients experience time in that same context. Further research into how HCPs experience time, and whether they feel time influences their practice is needed.

5.4 Summary

Time was an influential factor in how interviewees made decisions throughout their diagnosis, treatment and aftercare. The data show that patients have an active relationship with time, allowing them to manipulate time, use it to gain control, slow down something they do not understand or simply put off or remove decisions to a future time when they feel ready to tackle them. Interviewees also felt that time could influence them negatively as they felt they would benefit from more time spent with their HCPs in the clinical encounter, as well as more time to make decisions.

In line with this, some scholars argue that time permeates all aspects of human life. As Adam argues “we have a relationship to our past, present and future [...] Collectively these aspects of time affect the way we see ourselves, our families, our society and our fellow human beings. They influence the timing of our interactions, the way we relate to others, and how we interpret daily and extraordinary events” (Adam, 1995, 23). The patients interviewed reflected all of these aspects outlined by Adam, going into detail about how to use time as a tool to facilitate their autonomous interactions and decisions in the medical realm.

Specifically the interviewees wanted more time to understand the information they were given, and time to then reflect on that information and make decisions based on that information. When interviewees felt uncomfortable making decisions in the short amount of time given they attempted to manipulate time to gain the moral space necessary to make their decisions autonomously (Scully *et al.*, 2007, 214). Interviewees felt that patients need the time to plan for the future in order to make decisions in the present. This is part of their temporal understanding of the long term framework within

which they make decisions. However, in order to make these decisions, patients want and need information about their futures. This information is not always easily available due to the predictive fuzziness that cancer diagnosis imposes on the patient. Interviewees also felt that time spent with their doctors should to be increased such that it reflects their needs and concerns.

It can also be argued that interviewees used time to assert their autonomy. They made it clear that having more time would help them to make decisions with which they were more comfortable. I interpret this as supporting and respecting patient autonomy.⁶⁷ Most interviewees felt that a better relationship with their doctors would facilitate this, as the doctor would spend more time explaining the information given, more time listening to the patient, and allow more time for the patient to make decisions, thus creating more moral space for the patient to exercise autonomous decision-making. As I discuss in the following chapter the structure of the relationship between the patient and doctor plays a significant role in whether patient autonomy and agency are fostered or compromised.

⁶⁷ This is closely related to the concept of self-trust, a crucial aspect of relational autonomy which I address in the following chapter.

Chapter 6

Information and Understanding

“Sufficient information” and “sufficient understanding” are two criteria that are often pre-conditions for autonomy in bioethics. This is due in part to the importance that is placed on informed consent in medicine, which assumes that the patient has been informed of their clinical status, and that signing the consent form means that the patient understands the information that has been given to them.⁶⁸ However, the signing of the consent form is one moment in time during the diagnosis, treatment and aftercare, and, as the literature shows and is reflected here, patients require continual access to information, as well as help understanding that information. Informed understanding was a primary concern for all the interviewees. While they conceded that there was information available through pamphlets, websites, nurses and consultations with their clinicians, many interviewees felt that their access to that information was not easily facilitated, and that information was often given without any help by HCPs⁶⁹ to process and understand it.

For these reasons interviewees closely linked information and understanding. It is not enough to have the information; to be autonomous patients also have to understand that information (Beauchamp and Childress, 2009, 130). Interviewees expressed similar beliefs. For the interviewees, if they did not understand the information that had been given to them, it was the same as not having that information in the first place.

In this chapter I focus on the importance of linking information and understanding, what I call informed understanding, outlining the concerns that interviewees had with the lack of both in the HCP–patient encounter, and the effect this has on their ability to make decisions. I further focus on how communication between HCPs and patients can serve to help or hinder the process of informed understanding and decision-making, and how the patient–HCP relationship plays a crucial role in achieving informed understanding.

⁶⁸ See chapter 3 for further discussion on the relationship between autonomy, information, understanding and informed consent.

⁶⁹ In this chapter I will switch between a discussion about HCPs in general (nurses, clinicians, and surgeons) to a discussion about doctors (clinicians and surgeons). I will make this switch explicit when it occurs.

Many of the observations I make in this chapter about information provision, and the HCP–patient relationship, are not new. Both areas are commented on, in different contexts, in the literature review. Nonetheless, it is important to be able to demonstrate how they arise and are expressed in particular settings; this chapter does that. In doing so, I highlight how these issues continue to be areas of concern. I also highlight these findings so they can be used in later chapters when discussing the concept of autonomy.

It was difficult to decide which subthemes fell under the theme of Information and Understanding. In many ways the data presented here are about the HCP–patient relationship, because that relationship is greatly influenced by information provision and patient understanding. However, the phenomena that influence information and understanding are not just related to the HCP–patient relationship. Most of the data in this chapter have to do with the HCP relationship, but not all of it. All the data presented are concerned with information and understanding, so for this reason they have been grouped under this theme. As noted in chapter 5, while the themes are presented as neat categories, they overlap significantly, sometimes making it difficult to separate out seemingly unrelated themes that are actually closely connected. This is definitely the case for this chapter.

6.1 Communication

Interviewees considered communication a vital aspect of the patient–HCP encounter. This may be because communication between patient and HCP facilitates the exchange and understanding of important medical information (Zikmund-Fisher *et al.*, 2012, 199; see also Siminoff *et al.*, 2006; Street *et al.*, 2007; Martinez *et al.*, 2007; Moreau *et al.*, 2012). Interviewees reported experiencing problems with communication in three ways: communication between HCPs and patients is not always reciprocal, communication is often hindered by assumptions made by the HCPs, and in the case of breast cancer patients, communication with clinicians is considered poor, leaving them to turn to their breast care nurse to interpret what the clinician has said. I examine each experience in turn.

6.1.1 *Reciprocal Communication*

Many of the interviewees felt that while their HCP gave them information about their medical status, the HCP did not communicate it effectively. Information was often presented to patients as a list of items, instead of being brought up as part of a reciprocal dialogue. The doctor–patient interaction has been previously described as being not a two-way dialogue, but a one-way patient interview oriented towards making treatment decisions (Todd and Fisher, 1992, 128–167), and this is often still the case. Interviewees felt that this one-way communication did not invite further discussion, and often kept them from asking clarifying questions or voicing their opinions. It often left interviewees wondering if they would or could make any decisions on the matters being discussed by their HCPs, in particular leaving them to worry about treatment plans they were unsure of or did not want. Angela, for example, felt that the way information was presented to her about her fertility post-treatment left little opportunity for decision-making or voicing dissent:

Angela: [...] their conversation about, “oh you’re going to stop [ovulating] because of the chemo”, was very brief, it was a few minute sentence at that really [...] maybe they should have said, “Do you wish to hang on to fertility?” [...] It was never discussed. [...] the question was never brought up about my future fertility, it was just that the chemo is *going* to stop your periods and shut down your ovaries. That seemed to be the be all and end all of it. There wasn’t any alternative choices [...] This is *going* to happen to you, like you’re *going* to be sick with the chemo, you are *going* to lose your hair sort of thing. It was a fact that was coming rather than a choice [...]

Angela’s use of the phrase “you’re *going* to” is an example of one-way communication from the HCP where information is presented as a list. It is an imperative way of providing information that made Angela feel there were no alternative choices available; it was simply a “fact that was coming”. Mary felt similarly, pointing out that how HCPs communicate really dissuades patients from being too assertive:

Mary: So I think it surprised me in a way talking to people how often they say, “oh I’d really like to raise that” [...] so I think it’s important

that the doctors raise everything, to give the patient the opportunity to discuss the things that perhaps they feel are a bit off limits [...] I think it's just the sort of long standing attitude of the doctor-patient relationship, that people feel [...] that the doctor is very important and there are only certain things that they can talk to them about.

Mary's experience shows how difficult patients find it to discuss those things they feel are more pertinent to them, which Mary characterised as being "a bit off limits", since for her there are restrictions on the communication between HCP and patient.

In addition, interviewees also expressed a need for a better quality of communication, emphasising that doctors cannot take a one-size-fits-all approach to explaining individual health situations, especially since terms and techniques in the medical field are not universally understood. Interviewees felt that they were often thrown a lot of jargon all at once from a doctor who assumed the patient understood, and a lack of reciprocal communication made it difficult to clarify points of confusion. This can be damaging to a patient, who then has to make decisions based on a poor understanding or even a misunderstanding of that information, an opinion shared in the literature on doctor-patient communication (see Siminoff *et al.*, 2006; Martinez *et al.*, 2007; Zikmund-Fisher *et al.*, 2012). Heather used the example of a hysterectomy to show how confusing this can be for patients who do not know what a hysterectomy is and need a more straightforward explanation (emphasis added):

Heather: Well I think before any treatment it's got to be discussed. If it's like what I had and say I got down to theatre and a whole hysterectomy needs to be performed, before any of that's done I think it would be *wonderful* if that could be discussed like "Look, listen, when we get you down in to theatre, if we need to do a full hysterectomy it will be done. **A hysterectomy means no children**" [...] But everybody is unique and everybody is different. I guess there will be some people that are going to sit in that office and they're going to hear hysterectomy and they're going to know straight away "wham, bam, no kids" and they're going to deal with it all there and then. We're all different [...] everybody deals with it differently.

Heather characterised her ideal communication as a “discussion”, indicating a desire for reciprocal communication that clarifies for the doctor how the patient understands the terms and techniques being used. Like Mary, Heather argued that the burden of starting that discussion rests on the HCP’s shoulders, and information provision should be part of an on-going discussion. Amy felt similarly, as her HCP “assumed” they both had the same understanding of medical vocabulary, which she felt made it “difficult” to talk to him about her surgery choices:

Amy: [...] you’ve got so much going on in your head the last thing you need is people perhaps throwing a lot of technical terms, or medical terms at you that you don’t understand. Or sort of expecting, I found at one point that my surgeon was quite difficult to talk to because he sort of assumed that I knew what he was talking about, so I found it really difficult to talk to him.

Interviewees felt that a better quality of communication would be a substantial help to patients making decisions, as it would allow for reciprocal, face-to-face discussions between patients and doctors. Interviewees also felt a pamphlet or a website cannot offer the same kind of clarity and reassurance that a person provides. For example Robyn felt that decisions about fertility preservation are too important, and patients need a “real life person” to talk to about their options:

Robyn: I would think real life people actually. I think that talking to real life people is much better than—I certainly wouldn’t advocate going [...] through any of the websites, because I think you can make it sound and do whatever you want to make it sound and do. And I think it’s too important a decision to rely just on that [...] I actually think more talking to people than anything else. Because I think you get so much more.

Without this proper level of communication important details can be lost, leaving the patient feeling frightened and confused, as Anne explained:

Anne: I didn’t really know what to expect, a bit of a frightening thing when you go in to colposcopy [...] you go in and there is this big flat

screen TV and then they sort of put you on the bed and say, “well what we’re going to do is we’re going to put this stain on”. So they proceeded to put the stain on and the tissue turns sort of pink to white, and again me not knowing what that means. But I could see that there was a lot of white—that was my initial thought was that there was a lot of something.

Miscommunication and one-way communication contribute to poor environments for the support and facilitation of patient decision-making (Zikmund-Fisher, 2012, 203), and by extension patient autonomy. Without proper communication it is difficult to achieve the informed understanding that theories of autonomy require for autonomous decision-making. As Anne said, she could see that there was “a lot of something”, but with no communication as to what that meant she did not know if she should be preparing herself for a good or bad thing, and what decisions to make moving forward. Communication is vital to patient decision-making, and reciprocal communication (where both patient and HCP are participating in the conversation) is how patients get a further and deeper understanding of the information they need.

6.1.2 *Communication and Healthcare Professionals’ Assumptions*

The difficulty that interviewees had in achieving reciprocal communication was due in part, they felt, to the assumptions that their HCPs made about them as patients. Interviewees thought their HCPs made several assumptions about their age as related to fertility, and whether they had completed their families, when communicating about fertility and cancer. Some HCPs assumed that patients would no longer want to have children as they were older, or that patients wanted to have children because they were younger. For example, Angela did not think she was too old to have children, and was actively trying to hold on to her fertility. Despite Angela’s strong feelings about remaining fertile, she felt her HCP assumed that she had completed her family given her age, and would not want to preserve her fertility. Because of this assumption she felt he limited the information that he gave Angela about her chemotherapy treatment options:

Angela: But on the subject of fertility, it was the chemotherapy bit that was sort of an issue. Nothing was said at first, because I’d sort of, I’d

hung on to my ovaries deliberately because I wanted to maintain them [...] I thought it was good [...] keep the bone density up [...] And though I had sort've completed my family at that point, I just felt that I wanted to hold on to my ovaries as much as possible. So when they came to the chemo and he said, "Well the chemo is going to stop your ovaries working and if you're near to your menopause, your natural menopause, that's it, you won't have any more periods and that will be it". There was no more further mention of it, nobody said "do you want to hang on to your fertility" or anything like that, nothing was actually mentioned. And I was like, "oh, alright then". It's got to happen, it's got to happen sort of thing.

Due to this mistaken assumption there was "no further mention" of fertility/fertility preservation options, when in fact Angela was very interested in knowing about these options due to her prior interest in keeping her ovaries despite her family history of ovarian cancer. A similar situation happened to Robyn, who was an older mother and had decided that she did not want any more children, and again she felt her HCP assumed that she would not want to hold on to her fertility:

Robyn: And he said that tamoxifen would be the best course because I was pre-menopausal, but there wasn't really any kind of discussion about whether [...] I wanted more children, but then again he knew I had older children. So it was probably assumed that with my age and everything that I wouldn't want children any way, I was at that time 47 [...] It was probably assumed that because I had children I wouldn't want anymore, and because of my age that I wouldn't want anymore. So whether it was something that maybe should have been discussed in a little more detail, I'm guessing that it probably should have been. Yeah, I'm guessing that it probably should have been, to be fair.

Robyn felt that all aspects of her treatment, including the effect on her fertility should have been discussed regardless of the beliefs of the HCP. While many interviewees did not want more children, interviewees were concerned about their fertility, and felt that assumptions made by their HCPs meant that they did not always have all the information and/or a full understanding of their treatment side-effects. This is

problematic given that one of the roles of the doctor is to communicate “information on all relevant options and their benefits and risks to enable the patient to make an informed treatment decision” (Morgan, 2008, 64). All of the interviewees said they would have liked to have heard about fertility preservation regardless of their age and family size. The assumptions of the HCPs interfered with the interviewees’ decision-making by limiting the options that were made available to them. As many interviewees also had difficulty communicating reciprocally with their HCPs, they had little opportunity to make it clear that they needed more information or wanted to be made aware of all options available for treatment and fertility preservation.

Interviewees in this study are not alone in feeling that their HCPs were making incorrect assumptions. In the United States a number of studies have examined the criteria that HCPs use to decide if they should tell a patient about fertility preservation. None of these criteria are related to the patient’s own fertility needs. Instead studies found that HCPs are less likely to tell a patient about fertility preservation if they are older, single, in an unstable financial situation, identify as homosexual or are HIV positive (Cope, 2002; Nisker *et al.*, 2006; Goodwin *et al.*, 2007; Quinn and Vadaparampil, 2009).⁷⁰

6.1.3 Breast Care Nurses as Interpreters

While many of the interviewees had difficulty communicating with their doctors, those interviewees who had breast cancer found that this was made easier by the breast care nurse.⁷¹ Interviewees with breast cancer felt that the breast care nurse was much better at communicating than their doctors. In general they felt that the breast care nurses were essential in interpreting to patients what doctors were telling them. Interviewees with gynaecological cancer reported not having specialty care nurses of the same kind as breast care nurses. As a result some of the interviewees with gynaecological cancer who knew about breast care nurses reported feeling marginalised or left out, while other non-breast cancer interviewees felt a specialty nurse in the style of the breast care nurse would have helped with confusion after clinical appointments. The levels of communication, understanding and trust that existed between the breast cancer patients

⁷⁰ See chapter 2 for a full discussion of this phenomenon.

⁷¹ Breast care nurses are nurses that are specially assigned to care for breast cancer patients only. They spend a number of face to face contact hours with patients, in particular helping patients cope with the side-effects of chemotherapy and mastectomies.

and their nurses were in stark contrast to the confusion and frustration that the non-breast cancer patients felt.

The breast care nurses were identified as being constantly accessible (unlike their clinician counterparts), easy to understand and were felt to be supportive of the patient. Breast cancer patients felt that their breast care nurse was on their side, and so the patients trust their communications with them. Angela felt quite strongly about this:

Angela: [...] they become your friend and your sort of little soldiers in all of the battles that sort of happen around the time of diagnosis [...] the doctor saying this, that and then the breast care nurse is always there and she comes and sits in with the consultation, she's always there [...] she's your little hand to hold all the way through [...]

Angela's use of the phrase "she's always there" indicates the value that she placed on accessibility, as well as the idea that the breast care nurse is there "all the way through", unlike the clinicians who may only be in the patient's life for a brief period of treatment.

All of the breast cancer patients interviewed felt that any discussions about fertility preservation and fertility loss should be covered by the breast care nurse as they have the time for the discussion necessary that ensure that the patient is comfortable, and understands everything being told to them. As Angela put it:

Angela: And all through the chemotherapy I would go and visit her and [...] she's the lady I think, or the member of the team that I'd want to have long chats with and discuss things. Because the doctors are there for: "We're going to cure your cancer". Whereas she was more for: "Well what are we going to do about your wig for your hair loss" and that sort of thing [...] She was the one who listened and chatted and gave all that, that made you feel—she would give you facts and figures and information if I asked, but she was there to listen. If fertility was a thing I was discussing, then yeah, she would have been the one I would have chatted about to it. Chat to her about it.

Communication between patients and breast care nurses was experienced as easier and more accessible. Often interviewees used phrases like “long chats”, “stayed in touch” and “friendly catch-up” to describe their interactions with the breast care nurses. In contrast most interviewees described their communication with doctors as “appointments” or “meetings”. In almost all the cases of interviewees with breast cancer the bulk of the information that they deemed useful for making decisions came from the breast nurse, and they valued their relationship with the breast nurse for the information and understanding that she or he could provide. To paraphrase Angela, the breast care nurses were always there.

While it is difficult to compare the breast care nurses to the nurses that the non-breast cancer participants had, what is clear is that the model of cancer specific nurses like the breast care nurse is one that patients value. Interviewees felt that the breast care nurses were better communicators, better at fostering relationships, better at emotional/psychological care, and perhaps most importantly they offered all of these services in a way that interviewees identified as accessible. In general the interviewees with breast care nurses seemed happier with their experience as patients, and identified the breast care nurse as one of the primary reasons for that. Taken as a whole, the presence of the breast care nurse went a long way to facilitating decision-making and therefore supporting autonomy.

6.2 Information, Understanding, and Patient Decision-Making

Perhaps as a result of unsatisfactory communication with their HCPs, interviewees had several concerns about informed understanding with reference to decision-making. Interviewees felt that they often made choices about the options that they *thought* were available, when in fact there were other, more desirable options that they were not aware of. For example Mary would have preferred to have her ovaries removed via surgery as she felt she understood surgery better, but surgery was not presented as an option. As a result Mary felt uncomfortable with the treatment decision she made:

Mary: I think what wasn't mentioned at the time that came out later was that actually I could have had that surgery at the same time as I

had my mastectomy, because I still hadn't had the cancer surgery. And you know if there was anything that I could go back and change about it that's probably what I'd do [...] it was the radiotherapy to ovaries that I felt slightly uncomfortable about [...] my view is I would have understood [surgery] a bit more, you know, rather than radiotherapy is just a bit, to a non-medical person it's just a bit weird. I mean you go and have these x-rays and then something happens as a result.

Mary's use of the phrase "and then something happens as a result" shows how little she felt she understood about the radiotherapy. Because she did not understand the radiotherapy she felt "uncomfortable" with her decision to use radiotherapy for her ovarian ablation, showing how she linked understanding to comfortable (to use her words) decision-making. Mary was not the only participant to voice this type of discomfort. Heather also felt similarly, that her lack of understanding meant that the information given to her did little to help her make decisions. Heather's example shows how the urgency of cancer treatment shapes how information can be received and understood in a rushed way, which as a result can leave the patient very confused:

Heather: You know if you're going to go for leg amputation, that surgeon who is going to be performing that is going to say to you, "You know listen, you can get a [prosthetic] leg [...] You can start walking in the future, you're not just bound to a wheelchair or hopping about you know". It's explained better, that you know there are other options out there. And why should it not in my case? Nothing was discussed with me [...] Because you know when you've got the word cancer thrown at you, it's panic. It's panic. Just do what you have to do to get better and put everything else aside. You don't think about anything else. So these things have to be put to us and explained to us I think.

For Heather the focus is on explanation, which for her leads to understanding. She would have liked her options explained to her, but as "nothing was discussed" she felt that she lost out on considering those options. In addition Heather identified feelings of

panic as contributing to a patient's difficulty understanding information.⁷²

Kathleen felt similarly to Heather, but while Heather attributed some of the difficulties she had in understanding her situation to the panic of being diagnosed, Kathleen felt that the shock of her diagnosis made her feel like she was in “a bit of a dream and don't really take on board the severity of what they've said”. However despite this feeling, her clinicians pushed her to make a decision about terminating her pregnancy. Kathleen was so confused by her diagnosis that she routinely refers to herself as being “ignorant” when describing her limited understanding of her cancer. She and her husband agreed to terminate as they felt they had to make a decision, despite being uncomfortable with their limited understanding of the overall medical situation. Ultimately the termination did not occur, however the original decision to terminate brought up feelings of regret and guilt for making the wrong decision:

Kathleen: So I went to see the consultant, had agreed [to the termination], but in the meantime I went to see the surgeon, the specialist who was doing the operation and he said that they might have found a way around things. They may not have to [terminate]. So I was quite annoyed that I had actually agreed. It was just a massive emotional rollercoaster. It was just up and down all the time. You're crying. Felt angry. Felt guilty.

Kathleen's emotional response to the realisation that she should not have had to make the uncomfortable decision about termination shows how essential understanding can be. As Kathleen says, she was annoyed with herself for agreeing to something she did not want, and she was angry and felt guilty that she had let herself make the decision in the first place. Other interviewees also emphasised how not having understood the information given to them led them to make decisions they were either uncomfortable with at the time or regretted later.

Informed understanding is not just a practical concern when making decisions, but is a crucial aspect of autonomous decision-making in bioethics,⁷³ and agency in sociology. Giddens' account of agency requires that the agent “could have acted otherwise”

⁷² These feelings of panic may also be related to the concern interviewees had about needing time to get over the shock of diagnosis. See chapter 5 for further details.

⁷³ As I have previously argued in chapter 3.

(Giddens, 1979, 56), however to act otherwise, the agent has to be aware of what the “otherwise” is. When patients have difficulty understanding the treatment options given to them, or when treatment options are left out of the discussion by the HCPs, these patients are missing out on the “otherwise” that Giddens requires for agency. While Giddens presumably does not require agents to know of all possible “otherwise” scenarios, it does seem reasonable that patients, as a particular category of agents,⁷⁴ be given the opportunity to learn about all possible treatment options available to them. When HCPs withhold information from patients (deliberately or not) they are obstructing patients’ understanding of the “otherwise”, and thus impeding agency.

6.3 Emotional Wellbeing

Another important aspect of informed understanding had to do with patients’ emotional wellbeing. Interviewees seemed to equate having information that they understood with receiving support, which they believed contributed positively to their emotional wellbeing while ill. The more information interviewees understood, the more supported they felt. This support contributed to interviewees feeling more “comfortable” with their decisions; describing being comfortable as not “missing” any possible options for treatment. Interviewees felt that this comfort and support made them more confident about the decisions that they made.

Amy felt quite strongly that emotional support was crucial to decision-making. Having an informed understanding about her mastectomy meant that she was armed against the fear of the surgery. This helped her stay calm about her decision to go through with the mastectomy.⁷⁵

Amy: Like before I had my surgery [support group members] said [...] it’s not as bad as you’re expecting it’s going to be and [...] they all felt terrified and they expected it to be really horrible and they said actually it’s really not that bad and [...] that after you’ve woken up from your surgery and you’ve not got a breast, it’s really upsetting at

⁷⁴ Though there is no reason why this might not occur with other agents.

⁷⁵ This did not always occur in this order. Some interviewees felt that understanding gave them confidence in their decisions, which in turn contributed positively to their emotional wellbeing, while others needed to feel supported before they could make a decision they felt confident about.

first when you look down and you see the scar, it's really upsetting, but actually, it doesn't last that long. And to have that information was actually really good and really helpful because it kind of calmed me down before I went into the surgery and it made me think, OK, I'm scared but it won't last for long. So yeah it was really helpful to have that support group there.

In contrast, many of the interviewees felt that not having the right information, or understanding of that information, contributed negatively to their emotional wellbeing. Anne felt this during her diagnosis for cervical cancer:

Anne: So it's kind of a lot of [...] ifs and buts [...] although they know the answer they don't tell you. So I can remember being told that ten days after the surgery you don't need to come to the hospital because you won't be in any fit state but we'll ring you and we'll tell you [your prognosis]. So I was kind of like banking on that call for that peace of mind and I actually had to ring up myself to get that information, which wasn't how that should work. And I did, rang up and they were like, 'oh yeah well we know everything's alright', and I said "but I don't know". And it's me that's had the surgery and it's me that's sitting here worrying and waiting.

Being left in the dark causes uncertainty and doubt for patients, what Anne calls "a lot of ifs and buts", which can lead to difficult decision-making. Anne linked having information about her disease with her own "peace of mind". For Anne having information contributed positively to her emotional wellbeing. Not having that information contributed negatively to her emotional wellbeing, as she was "sitting here worrying and waiting" on information that had not yet been delivered. Without knowing she was "alright" she was unable to do anything but worry. Because of this Anne lost a lot of trust in her clinicians' abilities to provide her with the support that she felt was necessary as they used a "light touch" and she did not feel they "had her back" (to use her words). Support for her emotional wellbeing was important enough that she went looking for it on her own. When she did find a source of support, what Anne often calls "help", from a cervical cancer support group, she felt they were able to help her properly understand her situation:

Anne: It was just a very light touch I felt, you didn't feel like [the HCPs] had your back I didn't think. And that's why I started looking for places of support and how I came across Jo's Trust because I felt as if I needed somewhere to find out [...] all the things that I didn't know myself. [...] And so when you Google things it's a nightmare trying to find you know good, accurate information [...] when I came across Jo's Trust I realised that actually there was somewhere you could go for help and information.

Informed understanding is also related to the patient's emotional wellbeing as they were often not in a good state of mind when they were diagnosed, and had to make decisions about treatment despite this state. Interviewees felt this state of distress made it difficult to understand information, as it can stop the patient from "hearing" the consultant explaining their diagnosis and treatment options. As Heather explained about her own experience, and what she sees in her job as a counsellor, emotional wellbeing is often neglected to the detriment of patient understanding:

Heather: But I felt like I needed just the basics, but spoken to me like I was a five year old. Because you can't take it in. Working here [...] we get a lot of people that come straight from the hospital [...] and they've just been diagnosed and they don't know what the heck has been said to them [...] because they heard the word cancer and they think *dead*, I'm going to die, shit. And their brain can't take in any more information. And then it's our job [...] to come in and pick up the fear that them people have come with, *death*, *dying*, and kind of explain. We see it all the time. But the hospital really should be putting a rein on that. Nobody should be getting in a car and driving a machine with all them responses in their body [...] There should be someone there that takes them into a side room and gives them a little bit of time and makes sure that they understand, and that they're OK with the information that they got.

As Heather put it, the shock of the diagnosis, coupled with the panic about death and dying can make it very difficult for patients to "take it in" and understand what is being said. For Heather support for the patient's emotional wellbeing should be on hand as

soon as the diagnosis is made to help patients work through these responses without missing any important information that they may need. Amy also expressed a similar concern about how the emotional distress of being diagnosed with cancer can make it very difficult to understand what is being explained:

Amy: [...] it was just crazy and none of it was kind of sinking in, it was all just kind of words really you can't make sense of it. I think that's the thing, your head is just trying to make sense of it and it can't. It was really scary.

All of the interviewees felt that there needed to be more emotional and psychological support throughout the diagnosis and treatment process.⁷⁶ While interviewees did not feel their emotions kept them from making decisions in a stressful time, many expressed that the lack of emotional support made it unnecessarily difficult to make those decisions. As expressed by the interviewees, emotional support can be understood as both Pound and Ebrahim's (2000) "emotional labour" and Strauss *et al.* (1982) "sentimental work", where one aspect of this sentimental work is "the provision of emotional support to patients through their hospital experience to promote patients' wellbeing and facilitate the conduct of medical procedures" (Morgan, 2008, 77). Interviewees felt that having emotional support would help them to navigate the emotional time of diagnosis such that they could "hear" what the doctor was saying, thus enabling them to understand information that was given to them and promote their emotional wellbeing.

As a result of this need for support, all the interviewees took matters into their own hands and had been (or continue to be) members of cancer support groups. Interviewees felt that the level of emotional support provided by the support groups satisfies the support needed, however they all came to the support groups late in their treatment and would have preferred the NHS make patients aware of support groups as soon as they are diagnosed. Some interviewees also felt that having the support groups does not mean that the NHS is absolved of providing additional emotional support, as many of the reasons for the "emotional distress" had to do with being at the hospital and in the

⁷⁶ Interviewees all had different definitions of what emotional support meant, however their explanations had the following in common: that patients have someone to talk to about their disease who would listen. Some interviewees elaborated further, saying that patients should be provided with time with their HCPs to discuss their disease and their emotional response to being diagnosed. Some interviewees also wanted easier access to psychological support through counselling.

care of the NHS.⁷⁷

6.4 The Patient–Healthcare Professional Relationship

The patient–HCP relationship plays a significant role in how patients get information, and understand that information (Siminoff *et al.*, 2006; Martinez *et al.*, 2007; Morgan, 2008; Zikmund-Fisher *et al.*, 2012). The patient–HCP relationship is also particularly relevant to relational autonomy, as social relationships, in particular oppressive ones, influence “an agent’s capacities for autonomy” (Mackenzie and Stoljar, 2000, 22). When making decisions in a healthcare context choices are “affected by concern for a range of relationships that [the patients] value” (Mackenzie and Stoljar, 2000, 222). HCPs should be aware of this influence and attend to their relationship with the patient, as positive relationships will “reflect and enhance the autonomy of those engaged in them” (Mackenzie and Stoljar, 2000, 222; see also Street *et al.*, 2007, 586). In this section I discuss the importance to the patient of the patient–HCP relationship, as earlier data has shown that this relationship is more than a “dispassionate information provider” (the HCP) (Mackenzie and Stoljar, 2000, 225) interacting with a passive recipient of information (the patient). The relationship between patient and HCP can facilitate autonomous decision-making, and therefore warrants a closer look at how that relationship is experienced by the patient. In particular the power differentials that play out in this relationship, within the medical context, influence patient decision-making and ultimately patient autonomy (Matthias, 2010, 200).

Interviewees often described their relationships with their HCPs by explaining their interpretations of the connections they saw between information, understanding, power, control, trust and expertise. How much control is given or taken, the levels of trust between both parties, and the authority given to the expertise of both parties can set or be set by that relationship; in all cases interviewees saw the relationship between patient and HCP as at the heart of how information, understanding and power interacted with, facilitated, or hindered patients’ decisions. I first explore how interviewees experienced the relationship with their HCPs more generally, before turning to the three specific aspects of the relationship that they highlighted as important to them: control, trust and

⁷⁷ As recruitment was done through cancer support groups I have no data on how patients who did not attend support groups feel about the level of support provided by the NHS.

expertise.

6.4.1 *The Patient Experience of the Patient–HCP Relationship*

Interviewees saw the nature of the relationship between patient and HCP as directly related to how well the two parties exchanged information. While it is overly simplistic to link a good relationship with a good flow of information between patient and HCP, many of the discussions that interviewees had about the relationship with their HCPs centred on access to information, and how a good relationship with HCPs facilitates understanding of that information. Many interviewees considered their doctors (in particular) to be the gatekeepers of information, despite access to information through websites and pamphlets.⁷⁸ As a result, there was a power differential⁷⁹ that existed within their relationship which set the doctor up as the busy, well-educated and informed authority figure, while the patient's time was less valuable, as they were less educated, and dependent on the doctor for information. Mary felt that the way doctors are viewed in Britain goes a long way to contributing to the power differential that patients experience:

Mary: I think it's just the sort of long standing attitude of the doctor–patient relationship, that people feel [...] the doctor is very important and there are only certain things that they can talk to them about [...] I have come across a lot of people who said, “oh, I would have liked to have asked about that, but I didn't really think I could”. But it is also [...] the thing that in this country the health services are free at the point of delivery, so you feel a bit [...] like they're doing you a bit of a favour [...] like the doctor is there and he is kindly giving you his time. And he's very busy [...] You don't want to bother them.

While Mary attempted to mitigate this power differential by bringing in her own set of questions, in order to gain some control over the information that the doctor was giving

⁷⁸ Most of the interviewees preferred to receive information from their doctors and nurses as they valued information sourced from HCPs and considered it more trustworthy.

⁷⁹ In this thesis I will use the terms “power”, “power differentials” and “power dynamics” to describe relationships of power, where one person is subordinate to the other, but also to describe how status and authority are used in these relationships, and how status/authority can lead to the formation of a power dynamic in a relationship.

her, she was still setting up the doctor as the main point of access for that information. As she explained, the doctor was “very important” and that importance meant that there are “only certain things” that a patient can discuss with them. The belief that the doctor is “very important” seems patient driven. Mary described how other patients she knows felt that they could not approach the doctor to ask them questions that remain unanswered after a consultation. With the doctor set up as so important and “kindly giving his time” patients feel like they shouldn’t bother them with questions. This seems to imply that the information that the doctor has given the patient is enough, and any further inquiries are just bothering them, to use Mary’s term. This type of behaviour reinforces the kind of power dynamics that patients believe exist, setting the doctor up as the more powerful and knowledgeable of the two, linking power with information and the communication of that information (Matthias, 2010, 206; Morgan, 2008, 61).

This type of power dynamic described above puts increasing importance on the patient–HCP relationship as it becomes a source of crucial information to the patient. Despite this importance, some interviewees felt that there was very little effort from their HCPs to create a relationship with them, which they believe made it difficult to access information. For example, Heather felt her doctor made no attempt to relate to her; he did not even look her in the eye when she was diagnosed:

Heather: [...] my gynaecologist, I don’t think we had any eye to eye contact. He was talking to me scribbling his notes [...] they don’t want to get [...] close with their patients, form a relationship with their patients. [...] But I do think it’s sad that it is that way, because the only comfort and really proper explaining that was done for me was by the nurses on the ward.

Heather felt a good relationship might have helped her understand her diagnosis and treatment. Instead she had to seek comfort and explanation from the nurses on her ward as she could not get that from her gynaecologist.

James felt similarly that a good relationship comes from good communication, and offered a clinician’s point of view as to why patients have experiences like Heather’s. As a surgeon he felt he understood the importance of informed understanding for the patient, and believed the responsibility of ensuring that a patient has both lies with the

HCP:

James: I had on the whole a fairly close, direct relationship with the patients. We did not have nurse specialists in those days [...] But, now, since there has grown a sub group of cancer nurse specialists, and their role is perceived to be liaising with the patient [...] Many consultants and doctors tend to leave it to them to do a lot of the communicating [...] They would say “Fine, this is what you’ve got but now then go and see nurse and she’ll tell you all about it.” [...] So that relationship has changed. I would try to [...] explain things in sufficient, in the detail that I judged the person to need. And I thought I was a reasonably good communicator, but I wasn’t always I’m sure. And I’ve learnt an awful lot about the need to communicate with people since I gave up surgery.

To understand how information, understanding and power come together within the context of the patient–HCP relationship, consider Giddens’ conception of power from chapter 3. Giddens argues that an agent must have the ability to act otherwise (1979, 56). Power is exerted when one individual causes the other to be unable to act otherwise, and thus exerts control over that person’s agency (Giddens, 1979, 91). In the medical context, the doctor is the primary source of information. If the doctor does not give out information (for whatever reason) then the patient is not aware of all available options, and the patient cannot (in Giddens’ words) “have acted otherwise” as they were not made aware of the “otherwise”. This reinforces an existing power dynamic between patient and doctor, where the doctor is the one “in power” as they could have “acted otherwise” by giving the patient all the information they need to understand the “otherwise”, but they do not, meaning the patient cannot act otherwise.⁸⁰

This power dynamic is one that influences the relationship between the patient and HCP, and affects the patient’s experience of the relationship. In addition, little is known about how this dynamic affects HCPs’ experiences of this same relationship. In reviewing the data it was clear that if the relationship between the doctor and the patient was considered by the patient to be a positive and supportive one, then the doctor’s

⁸⁰ Not all patients are as helpless as that explanation makes it seem. As I have previously shown, when the patient comes in with their own list of questions (as Mary did), they are trying to change the power dynamic such that they gather as much information as possible about the “otherwise”.

position as the ‘keeper’ of information was not controversial. Even though the doctor may be more ‘powerful’, in (very) simplistic terms, the patient feels that because of their positive relationship the doctor is approachable and trustworthy.⁸¹ However, if the relationship between the two is felt to be negative and unsupportive, then the doctor is no longer viewed as the ‘keeper’, but as the guard of that information, and the patient does not feel they can approach them for access to the information that they need. In either situation power and information are closely woven together, and thus warrant a further look. I would now like to examine how the subthemes of control, trust and expertise influence the patient–HCP relationship and the power dynamics within that relationship that govern informed understanding.

6.4.2 Control

The theme of control manifested itself in two overarching ways: interviewees’ experiences of how cancer diagnosis removed control from their lives, and how important having control is throughout diagnosis and treatment. Interviewees identified having/losing control with informed understanding about their diagnosis/prognosis. Not having an informed understanding was experienced as losing control and being powerless. The opposite was experienced as being in control and confident, and thus more powerful.

The loss of control was attributed by some interviewees to the gap between what they as patients know and what the doctors know, especially at the point of diagnosis. This was the case for Anne, who travelled all over the city to get her diagnosis, but was never told why she was getting so many tests and seeing so many doctors:

Anne: So then I got a phone call to say come to the General Hospital on the Tuesday. Didn’t really know why I was going up there. I thought I was getting a second opinion [...] and before I went in there was some yellow paper work in the hospital and on the top it’s got General Oncology Centre. So I kind of got at that point why I was there even though nobody had told me why I was there [...] And then we went in and they said “do you know why you’re here” and I said “I

⁸¹ A point I will return to further on in the chapter.

think I'm here for a second opinion but I don't know, to be honest I've had a call and was asked to come up as an emergency and here I am". And they said "oh well we think that it might be cervical cancer".

Anne describes her diagnosis as a shock, as she was not aware there was a real possibility that she had cervical cancer. Not knowing left Anne feeling out of control, and knowing that the doctors did know (while she knew nothing) contributed further to the feeling that she was not in control of her situation. Interviewees articulated that the loss of control should not be an accepted side-effect of being a cancer patient. They equated control with being able to make decisions, and felt that having more information helped them feel more in control. Diane articulated this best:

Diane: Yeah, yeah again it puts you back in—it empowers you. You don't have to ask the question, they're giving you the information. Whether you need it or not. You can decide what you need, often we don't know what we need until its right there in front of us.

Interviewees felt that the responsibility of providing that information should fall on the doctors to ensure that patients have all the information they might need to make decisions. As Diane put it, doctors should be giving information "whether you need it or not", so that it is up to the patient to decide what they "need". Having information provided by the doctors was crucial, as interviewees felt that having information returned some of the control and power that they felt they had lost with the diagnosis.⁸² Amy expressed a similar opinion:

Amy: I think the biggest problem for me throughout the whole thing was the lack of control, because there is nothing you can do about, it's almost like you are picked up and carried along on this rollercoaster and there is no control at all but at least the way they treat you makes you feel like you were at least involved in it, as opposed to just a statistic, you know, you feel like you matter. And they will listen to you and they will talk to you about your concerns, rather than just saying "oh, you need this treatment and get on with it". They took the

⁸² This has been seen in similar studies that look at information and control. In a 2010 study of midwives and mothers Matthias found that information provided by midwives empowered mothers to make informed choices (Matthias, 2010, 206).

time to make sure that you understood it, and that was what made me feel a little bit more in control I guess. Because I had the full facts.

Interviewees felt so strongly about the link between information and control, that when doctors did not volunteer the information needed many interviewees felt that they needed to regain control by asserting themselves and demanding that information:

Diane: I think we pressed for [information about fertility preservation] [...] yeah, I initiated it. Asked the question: what can you do? Is there anything you can do to protect my fertility? [...] my experience has always been unless you have a voice, and quite a loud voice and an articulate voice and a persistent voice you can get a little bit sidelined.

Diane characterised the regaining of this control as “pressing” for information by having a “voice” that is loud enough to be heard by doctors so as to avoid being sidelined. However Diane still confers power and control to the doctor by assigning them the role of information provider, despite being active in gathering information.

6.4.3 *Trust and the Patient–HCP Relationship*

The relationship between control and information is also influenced by the trust that exists in the relationship between HCP and patient (Matthias, 2010, 208). One aspect of the patient–HCP relationship that all the interviewees commented on was that of trust. This trust seems to equalise some of the power differentials that exist between HCP and patient, as the stronger the trust, the more the interviewees felt they could interact with the relationship by asking questions, querying treatment choices and voicing their opinions. Facilitating informed understanding is a crucial part of the patient–HCP relationship, with trust playing a role in how patients view the information they receive from their HCPs. Interviewees expressed similar views, linking informed understanding with trust in three ways:

- 1) Trust in the HCP
- 2) Trust that the HCP was giving them the ‘right’ information (where right is understood by patients as information that is relevant to their particular

situation)

- 3) Self-trust that patients used that information to make the ‘right’ choice for themselves.

All three forms of trust are linked in the data and often one type of trust helped build another. For example, some interviewees felt that if they trusted their HCP, then they could trust that the information their HCP gave them was correct and therefore useful, and so they had self-trust that the decisions they made based on that information were right for them. Conversely, some interviewees did not initially trust their HCP, but were then given correct and useful information, which built up the trust between the two. Once trust was established it often perpetuated a self-reinforcing cycle between interviewees and HCPs. If trust was lost, or was never there to begin with, it created a similar negative feedback cycle whereby interviewees withdrew from their HCPs and looked elsewhere for information.

Before moving on to the data I would like to spend a few moments on self-trust, as it is a crucial element of relational autonomy and patient decision-making. Self-trust and trust in HCPs also go hand in hand. The more trust patients have in their HCP and the information HCPs give them, the more comfortable and confident patients are with their decisions: where comfort and confidence are also barometers for patients’ understanding of the information they must use to make decisions they feel are ‘right’ for themselves.⁸³ Information and understanding are also crucial to building self-trust in its own right, which in turn contributes to autonomous decision-making, as “most of us distrust our decision making capacities in at least some situations, in particular, those in which we know that we lack the knowledge required to make an appropriate choice” (Mackenzie and Stoljar, 2000, 264). The importance of information to self-trust is mirrored in the experiences of the interviewees, as their level of trust in the information they were given influenced their overall comfort level and their confidence in making decisions.

⁸³ Earlier I described comfort as not “missing” any possible options for treatment, thus giving the patient more confidence and control in the decisions that they were making. Here I extend that meaning to include the normative idea that comfort and confidence in decision-making are due to patients feeling they are making the “right” choices for themselves, where these are understood as choices the patient considers to be in line with their values and beliefs. This is not an uncommon characterisation of “right” choice in the autonomy literature. In addition if agency is to be understood as an individual being able to act otherwise, as I have taken it to be, then the “otherwise” implies that there are different choices for agent to take. This further implies that the agent has some kind of criteria for choosing one “otherwise” over another as being the “right” otherwise for them. For further discussion on this please see chapter 3.

In examining the data it was difficult to separate out the three types of trust to consider them individually. Each interviewee had a slightly different understanding of how all three interacted with each other. To reflect this, this subtheme is divided up into instances of distrust/mistrust and trust, as this was how interviewees brought up and discussed the subject of trust.

– *Distrust/mistrust* –

Interviewees initially experienced a mix of positive and negative relationships of trust with their HCPs. Once they got to know their HCPs more, interviewees tended to polarise towards either trusting or distrusting their HCPs, in particular their doctors. For example Kathleen trusted that her doctors were advising her properly, when it later emerged that she felt they were urging her to do the thing that they thought was easiest. Initially she trusted that they had her best interests at heart because she “didn’t know” she had reason not to trust them:

Kathleen: Um, but they had also said [...] they would have to do a sterilisation. Tie me tubes because they felt [...] that would be the best thing for me. Not to be having any more babies, for whatever could go wrong. And I didn’t know, really understand a lot about anything, I think it was pure ignorance, a lot of it. And I just went along with the experts and agreed with what they had said, and I didn’t question it. You just, to me, in them days, they were Gods. The only people you believe in when you’ve been diagnosed was consultants, surgeons and God.

In this example Kathleen viewed trust in her HCP and trust in the information he gave her as wrapped up in each other: She trusted her clinician was giving her information based on what he felt was best for her, because she trusted information that she felt came from experts, who she considers on the same level as “God”. Knowing, information and trust are linked here as well, with Kathleen trusting those who know, the experts, over those who do not know, which in this case is herself. When she later realised that her clinician made a series of errors in her treatment she lost her trust in the clinician, but also lost self-trust in her own decisions, saying she does not *know* if she would have made the same decisions if she had known what she knows now:

Kathleen: I didn't have a second opinion. I assumed I was being sent the best, but really should have asked for a second opinion. I think it was all the panic with time and pregnancy [...] I just wanted to be alright. And again that goes down to ignorance, I didn't know enough. And yes me consultant drew a diagram, but did I know enough about me own body? Did I see photos, no? Would I have made the same decision if I'd seen a bit more? How I was going to be left? I really don't know. It's alright sitting at this age, in hindsight, knowing what you know. But at the time, I mean ignorance. Would I have made the same decision, I don't know. I don't know if I would have agreed. I mean sterilised? I don't know if it was necessary.

Out of all the interviewees, Monica voiced the strongest concerns about trust, as she trusted her clinicians during her first diagnosis of breast cancer, because she thought they were "honest"; however during her second diagnosis she lost this trust because her new clinicians were not as willing to share information with her. Monica's choice of the word "honest" is an interesting one as it lends a degree of normative value to how Monica perceived the importance of giving patients the information that they need; linking the giving of information and patient autonomy in a strong way. In addition to wanting more information to help her trust her HCPs, Monica felt that the clinicians were not communicating properly with each other, so they did not have the right information that they needed. This decreased Monica's trust in her entire treatment team, as she felt they may not have been sufficiently informed of her situation, and so could not give her the best care:

Monica: I had, first time round fantastic, absolutely fantastic, I got on really, really, well with them. I trusted them, I felt like they were really honest. But the surgeon has gone to the North Islands now and Dr XXXX, the oncologist, I don't know where he went but he left the Northeast. This time round, I like them, but I don't feel like I have what I had the first time round. They used to go to each other's appointments, which I thought was really good because I always seemed to have everyone in the same room, I really liked that because they would discuss things between them, rather than, because at the

minute it seems like I speak to one person and then it takes forever for it to get back to the other person, whereas before if they were in the same room it was just so much easier, so much easier.

Monica linked the giving of information to how much she was willing to trust her clinicians. This trust was shattered by her surgeon who, as the quote below shows, refused to answer some of the questions that Monica identified as being most important to her:

Alexis: Why do you think you don't have the trust this time?

Monica: I don't know [...] The oncologist I'm fine with, but the surgeon, not so much. And I think it's probably because when they did the CT scan they found a little nodule in the lung and no one seems to be able to answer the question whether it is or it isn't anything to worry about. Because it's so small. And I asked him the question [...] and he skirted around it so many times it was just ridiculous. And I went at it from every angle I could think of and he just would not answer the question. And that straight away made me think, "Maybe I don't trust him". Maybe I—if he's not prepared to give us a straight answer, even if it's not what I want to hear, that's fine, I can live with that but he just wouldn't. He just kept saying "it doesn't change the outcome". And I said "but it does change the outcome!" Because then you're talking secondaries and that very much changes the outcome. But he just wouldn't acknowledge it. So I ended up speaking to the oncologist about it who said "Yes there is something there. We don't know what it is" [...] But she just said it, like that. But he wouldn't, he wouldn't [...] And I know that he was getting sick of hearing it, but it's my life. It's my life! And my family and my children. [...] Yeah. I'd be reluctant to ask him anything else in the future. I'd probably go the long way round to get me answer, I'd probably go to the oncologist or speak to the breast care nurses and they would probably speak to him. Because I think that if I got that kind of response again I might not be able to hold me tongue so well next time.

Monica had to seek out information from another clinician who she did trust to give her

the information that she needed to understand her situation. It was vital for her to get answers to her questions because Monica was using that information to make decisions about her treatment and future. As Monica asserts “It’s my life!” and she needed information she could trust to make decisions for that life, which in turn would build her own self-trust in her decisions.

While Monica felt that this lack of communication was somewhat solved by the breast care nurse, two of whom she did trust, she was quick to point out that she did not want fake intimacy between the breast care nurse and the patient. The relationship must be a real relationship that is built up over time so that she trusts the nurses. As she put it, the nurses have to “know” the patient, which helps to build the trusting relationship that she felt was necessary to also trust the information being given:

Monica: If I see Dawn or Katie they’ll give me a hug or they’ll hold my hand, or touch my arm. It’s fine because I know who they are. Whereas if it was somebody new that, I might be like, “You don’t know me, don’t do that”.

Monica’s assertion of “You don’t know me, don’t do that” is indicative of her keeping a distance from her new breast care nurse given to her during her second diagnosis, as she was unsure if she should trust them. Monica preferred her old nurses whom she did trust because she knew them and felt they have a track record together. For example, Monica felt that her old nurses knew what type of information she would need to help her cope with her diagnosis and treatment. Her new nurses did not, and gave her information that she did not need and felt she could not use, and so she did not trust the information given to her by the new nurses:

Monica: But the ones at the General Hospital, they didn’t know anything about me, so some of the advice that they were giving me, I was starting to get quite annoyed with. When I was speaking to them about my children this time, saying my little boy [...] he’s having a hard time, Mummy’s hair and things like that. And she said “I’ll order you a book called ‘Mummy’s Lump’”. And I said “I don’t want that. I don’t want him to know about that. He’s too little. He doesn’t need to know there was a lump, he doesn’t need to know any of that”. Whereas

I don't think that Dawn or Katie would have suggested that because they know me and they know my family. It makes a difference when somebody knows of you personally, rather than you just being another patient.

Monica described much of her relationship with the nurses through “knowing” (knowing her, knowing what information is useful for her). This “knowing” was the basis of trust for Monica: she trusted her nurses to give her the right information for her because they *know* her, and so by extension they know what information Monica would want. This was crucial to Monica as she used that information to move forward with decisions that had to be made; again feeding her trust in her HCPs and the information they give her into her own self-trust in her decisions.

– *Trust* –

Monica's lack of trust in her new nurses was in stark contrast to how patients who did trust their clinicians felt about the relationship between trust and informed understanding. For example Angela felt that her clinicians did not give her enough information about her pain relief after surgery, but she had previously mentioned trusting her clinicians and her overall relationship with her clinicians was positive. When she learned new information about pain relief techniques at a support group meeting this information reinforced her belief that her clinicians were trustworthy, as she recognised the treatment described as similar to the treatment she received. If trust is already strong between patient and HCP, then information in retrospect can help to build further trust:

Angela: I'm not in any pain, but it was really fascinating and interesting to learn how that was done. And I remember thinking “why on earth have they only sent me home with paracetamol the rotten sods”, but obviously I'd had that stuff that she was wittering on about and didn't know about it [...]

Angela trusted her clinicians so much that even though she did not actually know for sure that she was given the pain medication that another clinician was “wittering on about”, she assumed that she must have, because to her it was “obvious” that her clinicians would do everything in her best interest. Angela also linked information and

knowing with trusting, as she did not know about the treatment plan, so she did not trust it had happened. However, after she learned about the treatment she trusted that it had happened, and this helped to further build her self-trust in her choice to trust her clinicians.

The way that trust manifests itself and the role that it plays in patient decision-making can be seen not only in how interviewees viewed retrospective information given, as with Angela, but also the way that some interviewees allowed their clinicians to hold information for them “in trust” until a time when they felt they may need to ask for it and use it. This was the case for Amy, who felt that she could ask her HCPs any question and get the information that she needed:

Amy: And so yeah, I didn't ask too much information because it wasn't something that I was worried about. But certainly if I had wanted to then I would have been able to get all the information that I did want to get from them. I had no doubt about that at all.

Amy had “no doubt” that through her clinicians she would be able to get “all the information” she may want. This belief was built on a strong level of trust that Amy had with her clinicians and this trust ran through all of Amy's discussions about her clinicians.

Trust plays a critical role in decision-making. The building of trust can either establish, or is reliant on, a relationship between patient and HCP that facilitates the flow of information between the two parties. Some interviewees needed to trust the information before they could trust the HCP, with others it was the other way around. The lack of self-trust that some interviewees experienced with their own decision-making is one of the crucial reasons why having trust in clinicians, and the information they give patients, is so important. Without some level of trust the patient feels uncomfortable and in some cases unable to make a decision that they feel is right for them.

6.4.4 *Expertise*

Expertise is another aspect of the patient–HCP relationship that concerned the

interviewees. Expertise is one lens through which information is viewed by patients and HCPs. How the expertise of one party is viewed by the other influences decision-making, as it contributes to the overall stock of knowledge that agents use to make decisions. As Weinstein has argued, “Experts have a profound impact on the world. We defer to experts every day to inform us, give us advice, and help us to lead safer and healthier lives” (Weinstein, 1993, 57). In many ways expertise is a type of informed understanding that has advanced to the point that others value input from those with it, making expertise one of the factors considered when making a decision.

Interviewees discussed expertise in a number of ways: how they viewed the expertise of their doctors,⁸⁴ how they used that expertise to make decisions and also how patients themselves can offer expertise. Expertise is also one of the ways of viewing the power differentials that can exist in the patient–doctor relationship, as how the patient views the doctor’s expertise is linked to the level of authority the patient confers to the doctor and the information that doctor has to give (Matthias, 2010, 203). Patients use this expertise and authority to help them make decisions, weighing it up alongside their own expertise in their physical and emotional selves.

Many of the interviewees felt they did not, and still do not, know enough about medicine to challenge a doctor. They often felt that the information that their doctors presented to them was done in such a way as to steer patients towards a particular choice. A choice that interviewees felt was based on the doctor’s expertise. For example, Mary would have preferred to have had her ovaries removed via surgery, but instead she chose to have an ovarian ablation as Mary felt her doctor was leading her towards the ablation:

Mary: And I went with [the radiotherapy] because I could see that that was clearly what he felt was the best option. Because I did sort of experience this thing for a bit where the doctor has sort of fairly clear—what he thinks is the right thing to do [...] That may have just been my perception, but you know for that reason I thought, you know, he thinks that I should do this for some reason so that’s what I’ll go

⁸⁴ In this section I have shifted from the term HCP (healthcare professional) to the term doctor. This is deliberate. Participants in the study had concerns and comments about the expertise of their doctor specifically. Only one participant expressed similar concerns and comments about their breast care nurse, which I have already addressed. For the duration of this section I will use the term “doctor” to reflect their focus.

with.

When I asked Mary why this “some reason” mattered when making her decision, she attributed it to the doctor’s greater knowledge and expertise:

Mary: Um it mattered to me just because I thought that he’s the one that knows all about it, he’s got a much greater knowledge and experience of other people’s survival rates and that kind of thing. So I think that if he thinks that’s the best way to do it, and I’m assuming that he’s basing that on success in the past, then I’d rather go with his view.

For Mary the doctor’s expertise meant that he had a better informed understanding than she did of the procedure, as well as the success rate in other patients. Diane also felt that the expertise of the doctor should be considered because it lends authority to the information that the doctor gives. Diane was one of the most assertive and outspoken participants while she was a patient, however despite this she did ultimately defer to the doctor in her aftercare. She valued the doctor’s expertise and gave authority to their recommendations, helping her to make the decision to suppress her ovaries with drug therapy to keep her cancer in remission:

Diane: They’ve always been really clear to me, the doctors, saying you know we’re trying to stop this coming back [...] I was only in the hospital yesterday having the implant and having the same conversation and them saying we don’t want you to come off this. However bad the side-effects are, we want you to stay on it because it’s in your best interest in terms of the cancer not coming back. It’s as clear as that. So I think, well what should I do? I definitely don’t want the cancer to come back, so I think I’ll carry on taking it.

While most interviewees felt comfortable with deferring to the expertise and authority of their doctor, others felt there were moments when their own expertise in themselves should have been considered. Interviewees felt that when they reported information to the doctors that was incongruent with common symptoms or side-effects, the doctors were reluctant to value the patient’s expertise in themselves (meaning their reported symptoms, and understandings of their wellbeing/health) with the same authority that

the patient viewed the doctor's expertise. This was problematic for interviewees as they felt that while the doctor had expertise in treating cancer, and so knew more and could offer more information to the patient, the patient was the only one who knew if, and to what extent, they were experiencing pain, anxiety etc., and that expertise should not be ignored by the doctor. The move towards acknowledging the patient's own expertise is not unprecedented, with models of patient–doctor relationships beginning to reflect what Morgan calls a “meeting between experts” where the doctor exchanges their expertise in medicine with the patient's expertise in their “experiences and explanations of their illness, and knowledge of their particular social circumstances, attitudes to risk, values and preferences” (Morgan, 2008, 62).

Anne experienced this when her symptoms did not match up to any known set of symptoms. Her doctor argued that there was nothing seriously wrong that warranted exploration, but Anne disagreed (it turned out she had a large cyst growing on one of her ovaries). Anne felt she had to defer to the doctor's expertise, but that the doctor would not accept her expertise in her own body, and so the information she was giving him about her own body was discounted as unimportant:

Anne: You know, you shouldn't have to doctor symptoms to get a reaction and when you're telling them something they should have like listened and I think further down the line they did sort of say yeah, we should have taken that more seriously but we didn't. So it was one of those times when you wish they had been there to listen to you. But they chose not.

With all the interviewees it was clear that the doctor's expertise carried a lot of weight. However, interviewees did feel that their own expertise in themselves should be given more consideration by the doctors, as how they felt and how they viewed the situation also influenced how they make decisions and which decisions they make. While interviewees were willing to consider the information given by the doctor, the doctor was less willing to consider the information given by the patient in the same way. Interviewees wanted more recognition of their own expertise, and those with self-described good relationships with their doctors often felt their expertise was more readily accepted than those with self-described bad relationships. The lack of recognition of patient expertise also raises questions about respect for patient autonomy:

If decision-making in the medical context is premised on theories of autonomy that value patient beliefs and prioritise patient-led decisions, then why is patient expertise not considered with the same respect as other aspects of autonomy in medicine? What is clear from the data is that further examination on how doctors view the expertise of patients is needed to better understand how expertise is used in the medical setting.

6.5 Summary

The influence of information and understanding is not limited to informed consent, extending into all other aspects of the medical encounter and patient–HCP relationship. Emotional wellbeing, control, trust, expertise and communication are all affected by information and understanding, and patients often experience a lack of one feature as a lack of all the others. This chapter has shown how a good relationship with the HCP is central to patient decision-making, as this relationship facilitates autonomous decision-making in the healthcare setting by facilitating informed understanding. In chapter 8 I shall discuss further how the importance of this relationship can be better incorporated into theories to reflect how autonomy and autonomous decision-making are experienced in practice. In the next chapter I will discuss the final major theme, Being Guided.

Chapter 7

Being Guided

Originally this chapter was going to be called “Conveyor Belt” as it aims to capture the loss of control that interviewees reported, especially in relation to their treatment options. The phrase “conveyor belt” comes from Scully *et al.* (2007), where it was used as a metaphor to explain how participants experienced decision-making in the genetic testing context. Participants in that study found that while they made decisions, they were often “submerged in a context of numerous other interventions” and felt they had not “actively” made a decision (Scully *et al.*, 2007, 212). The feeling of not making decisions was one that was also expressed by the interviewees in this study, but I was reluctant to use the phrase “conveyor belt” as that has negative connotations inappropriate to the data. Instead “Being Guided” is a more accurate description of the experience described by the interviewees; while interviewees identified a similar loss of control as those in Scully *et al.*, not all of them felt a loss of power that “conveyor belt” implies. Instead the interviewees described being guided by their healthcare professionals (although not always for the better), and often spoke about *agreeing* with their HCPs’ decisions. The phrase itself comes from one of the participants Mary, who when asked if she felt she was making decisions throughout her treatment responded (emphasis added):

Yeah, I suppose I felt that I didn’t really feel that I was making choices. **I felt like I was being guided** and I felt like they were kind of asking me nicely, but saying this is really what we think that you ought to do.

In this chapter I focus on the different ways that interviewees experienced being guided: by trust, as part of the medical protocol, as a coping mechanism, and “being railroaded”. In this final data chapter there are several overlaps with previous chapters. How interviewees separated decisions they made from those that were guided is closely linked to the relationship they had with their HCP, how much time they felt was available for decisions to be made, and how much they understood the information that they were given. I start by addressing the relationship between “Being Guided” and trust.

7.1 Being Guided by Trust

Trust played a central role in the experiences of the interviewees. Trust has already been discussed in the context of time, information, understanding, the patient–HCP relationship and power, but it also played a crucial role in how interviewees experienced being guided. How much trust interviewees had in their HCPs was influenced by how comfortable they were with being guided. This relationship between trust and being guided is reflected in the language used by interviewees. For example, those interviewees with more trust in their HCPs often saw HCP guidance as suggestions. Other interviewees described instances of lacking trust and feeling not guided at all, while others described lacking trust and feeling misguided or compelled towards a decision.

Stephanie’s experience is an example of how trust interacts with the patient’s experience of being guided, as she was a child when she was diagnosed, and had to transition into an adult patient who could make her own decisions during her treatment. Perhaps because of her young age at diagnosis she placed (and continues to place) a lot of trust in her HCPs, and her interview contained very little narrative about choice or decision-making. Stephanie explained her diagnosis, treatment and aftercare as a series of treatments and consultations, and while she had no conflict with her HCPs, she did not appear to have made any of her own choices about her treatment options. Stephanie appeared comfortable with her HCPs making the decisions for her and this was reflected in the way she described her treatment choices as being decided for her (emphasis added below):

Stephanie: So then I was referred to the teenage consultant at the General and **they decided, well they decided** that with the operation they were going to get rid of [...] and then chemotherapy and then radiotherapy.

While Stephanie did not use the term trust explicitly, because of her age it appears that she took for granted that her doctors were to be trusted. In contrast Robyn, who was diagnosed as an adult, understood trust as a more contentious point in adult reality. However, despite that, she also linked trust with her experience of being guided; describing how her trust in her HCP meant that she trusted his expertise and the

decisions that he made using that expertise:

Robyn: I was certainly being led by a good team and yes I had certain elements of choices, but I have to be guided ultimately by an excellent consultant who knows his job inside out. I don't know his job, but he does, and I've got to just lay down and give him my life really [...] You know he's the boss and he knows what he's doing. And quite coincidentally one of my friends [...] he was a very good friend of hers and she spoke with him and he said "You know she stands a really good chance but she's got to do this now, you know", so there were lots of things. But yes, it was a good team, and yes I had choices and yes I had to be led and in some respects you need to be led because your brain is quite full of other things.

Here trust, being guided and the importance of the patient–HCP relationship are all connected. Robyn previously expressed what a good relationship she felt she had with her consultant, whom she called "excellent" and part of "a good team", and because of her trust in him knowing his job "inside and out" Robyn felt she could "be guided". The importance of trust is emphasised when Robyn states that she had to "give him my life", as well as the value Robyn placed on the "outside" knowledge about him that she gained from a friend, which seemed to strengthen her trust in his judgement and her willingness to take his guidance and "be led".

Like Robyn and Stephanie, many other interviewees described their experience of being guided as strongly rooted in their relationship and trust with their HCP.⁸⁵ These data suggest a different view to the more predominant "conveyor belt" and "professional choice" type language that is often seen in the literature about decision-making in the medical setting (see Scully *et al.*, 2007; Morgan, 2008, 63–67), indicating that patients are not necessarily passively cooperating with the decisions that their HCPs make for them, but actively agreeing to them. While "Being Guided" is not explicitly discussed in the wider literature, there is discussion of the relationship between trust, the HCP–patient relationship, and guidance for decision-making that is similar to what interviewees expressed in this study. Trust has previously been identified as important

⁸⁵ Not all the interviewees had a good experience being guided and I will discuss their experiences in the final section of this chapter.

to patient decision-making as “practitioners were trusted for their perceived specialist knowledge and expertise, but also for their interpersonal skills”, as patients are likely to rely heavily on guidance from their HCPs, and will often defer to the experts (Nelson *et al.*, 2012, 800–801).

Trust is also what helps to distinguish “Being Guided” from being misunderstood as a form of soft paternalism, whereby patient assent to physicians’ decisions takes the place of active decision-making (Emanuel and Emanuel, 1992, 2221; McMullen, 2012, 238). Trust in their HCPs played a key role in how being guided was experienced by interviewees, which in turn influenced the interviewee’s perception of the decisions that they did make, as well as how and why they made them. Unlike patient accounts of paternalism, “Being Guided” was not (for the most part) experienced by the interviewees as a loss of or lack of respect for autonomy, nor as an impediment to making decisions in the medical setting. Instead it was experienced as a process (or for some, a moment in time) where they put their trust in someone else, and the choices that they did make were about agreeing or disagreeing with the options presented. One study described what I call “Being Guided” as a delegation of decision-making from patient to HCP, which was seen as “an active choice in which they described feeling that their views were taken account of” (Nelson *et al.*, 2012, 801). Allowing oneself to be guided (or delegating decision-making responsibilities) is only possible if the patient trusts the HCP, or feels that the HCP has such greater authority over the subject that the patient feels comfortable deferring to it, and in fact feels that deferring to that authority is the best choice for them. What is clear from the data is that very few patients said they felt coerced into a decision, or forced to follow the doctor’s suggestion *all of the time*,⁸⁶ as the concept of paternalism suggests. Instead most interviewees felt that when being guided they had actively made the decision to be guided. Their active choice in allowing themselves to be guided was both an affirmation of their control over their medical decisions, and from a bioethical point of view, evidence that they were exercising their autonomy and that this in turn was being respected.

⁸⁶ Some of the participants did feel that there were instances in their treatment and aftercare where they did not have a choice and would have wanted one, but none of the participants experienced this all the time will all the decisions that they had to make.

7.2 Being Guided by the Medical Protocol

Even with a good consulting team interviewees felt there was an aspect of being guided down an already existing path, and this was due to the medical protocols for treating cancer. Healthcare professionals, as much as their patients, are constrained by the medical protocols ascribed to their patient's treatment. While options do remain available, the medical protocol is a rigid framework within which only limited options are possible. In this study interviewees often made reference to their medical protocols and the restricting effect that these protocols had on the choices available to them, and thus the decisions that they made. The effect that medical protocols have on patient decision-making is also an example of how institutions can interact with and influence the agency of individuals, a point I discuss later.

For those interviewees who were diagnosed with advanced cancer the link between being guided and the medical protocol stood out more prominently. Amy's narrative indicates how the medical protocol can often guide the patient before decisions are even made. When recounting her diagnosis and treatment it is only after chemotherapy that Amy started to discuss the choices that she made, every choice before that was guided by her HCP who suggested chemotherapy as a first course of action. As Amy says "an appointment was made for me" because her medical protocol indicated that she needed to get "the chemotherapy done first":

Amy: After that I was told that I would need to see the oncologist and an appointment was made for me to see her and [...] they sort of explained to me that I probably would have to have chemotherapy, surgery and radiotherapy [...] So she had basically said you're going to need chemotherapy, you're going to need it soon and she explained to me that it was very aggressive and that it really was a case of getting the chemotherapy done first [...] So it was clear that it was big and it was bad and you know they were able to say you need to start this treatment.

Angela's experience is also a good example of this phenomenon, as the severity of her cancer meant she needed a mastectomy to survive, however she was reluctant to accept the mastectomy as the only available treatment option. Angela did not feel that her

HCPs were keeping options from her; instead she felt that the medical protocol dictated the path that she was to be guided down by her HCPs:

Angela: [sighs] Choices, now I was sort of basically told this is what we need to do to cure you. I did at one stage, during the chemo, before the breast was removed I did contemplate not having the breast removed, and saying no, that's it. I'd have the chemo but I would not have the breast off, I was so determined. And actually considering in effect choosing the alternative of no treatment, which is you know, the worst [...] So yes, yeah, I felt that, I could've made that choice if I'd wanted to, but after a few weeks I began to realise that it wasn't a choice that was sensible for me [...] So even though I was particularly miserable about losing my breast I went the full route and followed the suggested treatment. There wasn't a point where it was have this OR this and be cured, it was this and be cured or not do this and not be cured [...] So I didn't have any choices of treatment, just this was the one choice [...] But that was because of my circumstances, they said that if the lump had been smaller then maybe I could have had a lumpectomy.

In Angela's opinion she had a choice to make between being guided by her HCPs and following the "suggested treatment", or she could choose not to have the surgery and receive palliative care. Angela chose to be guided by her HCPs and follow the suggested treatment, which was the only treatment available to her in order to "be cured".

In the literature there is little on the subject of being guided and medical protocol, however one study on decision-making for childhood "normalising surgeries" addressed a similar phenomenon to what my interviewees described, which the authors called "doing something" (Nelson *et al.*, 2012, 799). In this study "doing something" characterised a number of treatment choices that happened after the birth of a child with cleft palate (Nelson *et al.*, 2012, 799). Nelson *et al.* argue that parents did not describe making individual choices for each treatment, but instead recognised a larger choice between "doing something" or "doing nothing" (Nelson *et al.*, 2012, 799). In a sense there is something similar happening when patients are guided by the medical protocol:

they are choosing to “do something” by following the prescribed course of treatment as recommended by their physician. Angela perhaps put it best when she says “it was this and be cured or not do this and not be cured [...] this was the one choice”. As with the Nelson *et al.* study, there is a sense in the interviews that interviewees were guided by the medical protocol, but that they were actively choosing this guidance as they had chosen to do *something* over doing nothing. The choice of something over nothing is significant as it indicates that there is an “otherwise” available when being guided by the medical protocol, which respects the concept of agency as outlined by Giddens (1979, 56).

However the medical protocol is not just an available choice, it is embedded in the overarching medical system as part of the “institutional framework of health care provision” (Mackenzie and Stoljar, 2000, 223) and as such merits some discussion on the relationship between decision-making and structure as well. In particular how structure/institution interacts with the patient’s “autonomous desires” bears further scrutiny, as autonomy and agency can be guided, and in some cases even impeded by “social norms, institutions, practices and relationships that effectively limit the range of significant options available to them” (Mackenzie and Stoljar, 2000, 22). To understand the extent that medical protocol can influence patient decision-making it may be helpful to take a more relational and sociological focus, which highlights the influence that institutions (such as medicine) can have on those making choices within those institutions’ operations (Mackenzie and Stoljar, 2000, 22; Giddens, 1979, 55).

As I argued in chapter 3, agency is not without limit as decisions are made from within the social context of the agent. How is that relevant to medical decision-making? To use the same example from chapter 3, while a person may be free to go for a walk, they cannot go for a walk any way they like, as within their social context of going on a walk there are only certain ways that are considered appropriate (Giddens, 1979, 83; see also chapter 3). “Being guided” by the medical protocol is considered the more appropriate choice in the medical context in the same way that there are certain appropriate ways of going for a walk. Choosing life is encouraged over choosing death, and this choice is not without judgement based on the rules and regulations of the context (Giddens, 1979, 80).⁸⁷

⁸⁷ This is also one way that institution/structure, in the guise of the medical protocol, has influence on agency.

This is not to say that interviewees in this study were not making choices, but instead that those choices were sometimes influenced by the medical system within which they were made. There is choice, but the context of the interaction means that there is really only one “right” choice (the identification of which many of the interviewees described), which satisfies both the medical professional’s need to involve patients in the treatment process, while respecting the autonomy/agency of patients to choose. This type of influence is important to flag up as it builds a picture of the type of atmosphere or environment within which patients must make decisions, adding to an increasingly long list of hidden phenomena that impact on decision-making such as relationships, power dynamics, time and now institution/structure. Whether all of these phenomena can be overcome, or even need to be overcome to better facilitate autonomous decision-making, will be further discussed in the final two chapters of this thesis.

7.3 Being Guided: A Coping Mechanism

Another way that interviewees experienced being guided was to engage in a kind of wilful ignorance (at times) as a form of coping mechanism (to use Heather’s words) against the distress of having cancer. This style of being guided manifested itself in two distinct ways: The first was how interviewees used being guided as a way to cope with emotional distress by choosing to abdicate decisional responsibility to their HCPs. The second way, while similar, was more active, as interviewees solicited recommendations for treatment options from their HCPs to help them make decisions they perceived as difficult to cope with due to distress or complexity of choice.

Heather is a good example of someone who was very comfortable being guided through her diagnosis and treatment. She chose to delegate much of her decisional responsibility to her HCPs as a way of coping with the stress of having cancer. Heather wanted to be rid of her cancer, and she trusted that her doctors would do that, so she chose to follow them almost blindly so that she could achieve her goal of being cancer-free:

Heather: I didn’t care what they did. I just wanted someone to say at the end of the hospital visit “Everything is fine” [...] So my way of coping was I shut off. I didn’t want to know. And I remember saying to my husband “Just don’t ask nothing, we’re just doing what we got to

do.”

While it may appear that Heather was not making decisions about her treatment, she was in fact making very important ones. Her goal was to be cancer-free, so she took steps and made decisions that helped her achieve this goal in a way that made her feel comfortable about her choices. Heather “wanted to be better” and for her the best way to achieve being better was to “shut off” and not know what was happening. Heather actively decided this when she told her husband not to ask questions, making the decision that “we’re just doing what we got to do”. From a relational perspective Heather was actively engaging her autonomy by being in touch with her beliefs, values and desires (“I just wanted to be better”), and making decisions to bring them about (“Just don’t ask nothing”). Heather believed she would have been more uncomfortable had she been confronted with all the information, options and decisions to be made, and so to cope she shut herself off. Heather also used her choice to be guided as a way to safeguard her emotional wellbeing, something that has been previously pointed out as integral to autonomous decision-making.

Monica was even more upfront about her use of being guided as a coping mechanism: If she did not have to make decisions about her cancer then she did not have cancer:

Monica: Because I don’t think I asked any [questions] first time round. I just went along with it [...] I think that I just ignored it. I still went out, go out and do normal things. I just ignored it and hoped it would just go away. And it did.

In contrast some of the interviewees used being guided as a coping mechanism for making decisions by looking to their doctors’ opinions for guidance with the more difficult decisions. Anne, Amy and Diane in particular were guided by the opinions of their HCPs when it came to more difficult decisions that they had to make about treatment and after care. For example Anne asked her doctor outright what she would do in her position to help make up her mind:

Anne: I sort of asked the question, “If it was you sat here what would you do, if you were me what would you do?” And she said “I would go with it, I would get it out.”

Amy also turned to the opinion of her doctor when making decisions about her chemotherapy care:

Amy: [...] but there was a longer waiting list for that and she said “To be fair, you will probably lose your hair anyway and you won’t be able to start your treatment until the end of January, you really can’t afford to wait that long.” She made me aware that the option was there but she also made it clear that she didn’t recommend that I wait that long.

Finally Diane, who strongly asserted her authority to make her own decisions throughout her diagnosis, treatment and aftercare, and who defied her HCPs on a number of occasions as she felt their suggestions were not in her best interest, decided that she needed guidance from her HCPs to help her make some of her difficult decisions:

Diane: I needed, I definitely needed help. Definitely needed help, guidance. Not guidance in the sense of them saying—I just knew that they had seen it all before so I just needed case studies if you like, examples of other women. Because the minute they say it you think, jeez, am I the only person who has ever been through this, and very sadly it becomes obvious that you’re one of many, many, many, many, many, many individuals. And in a perverse way that makes it better. And then you hear of different people dealing with it in different ways. Some well, some not so well. It does put it in context for you. OK I’m going to find my own way, I’m going to find my own way through this to survival.

Diane needed her situation put into context in order to make her decisions. Anne and Amy were also trying to discover this context by asking for suggestions from their HCPs. Anne did so overtly, asking “if you were me what would you do”, while Amy was subtly listening to the recommendations from her doctor that she “can’t afford to wait that long”. By soliciting their HCPs for suggestions on what decision the HCPs would take, interviewees were guided towards what they felt was a better understanding of the context within which their decisions had to be made. This form of being guided has previously been seen in research into decision-making within the context of HCP

recommendations, but it has not been viewed favourably in that research (Frongillo *et al.*, 2013, 70–72). Interviewees from my research identified HCP recommendations as useful, either to guide their decisions, or simply as an additional piece of information to consider while making a decision. However, some of the wider literature has condemned HCP recommendations as restricting patient decision-making, arguing that patients will defer to HCP authority over their own, instead of making an autonomous choice (Frongillo *et al.*, 2013, 72).

This is perhaps the case in some situations, however the overall atmosphere that makes being guided perceived as just that is built on trust, a strong HCP–patient relationship and the sense, at least from my interviewees, that being guided was the best option for them at the time they *chose* to do it. Unlike previous research interviewees did not feel that they were cowed into a decision or that they were simply stepping onto a conveyor belt that led to treatment. Interviewees described being guided with clear goals in mind that they felt being guided would help them reach. Instead of having a choice “happen” to them, as the term conveyor belt suggests (for example), the option of being guided was employed by interviewees as an emotional support system and an aid for making decisions. In particular those interviewees who chose to be guided by their HCPs recommendations conveyed a degree of ownership over the advice and suggestions of their HCPs, thus reinforcing the interviewees’ agency and autonomy in a difficult situation. Exactly how nuanced the use of being guided is requires future research to help understand how being guided occurs and how patients use it.

7.4 Being Railroaded

Many of the interviewees were happy being guided by their HCPs, so long as they felt that the clinician had their best interests at heart, which for many interviewees meant achieving the goal of being a cancer-free survivor. However some of the interviewees described situations when being guided by their HCP became being railroaded; a situation in which interviewees found it difficult to maintain their agency and autonomy. For many of them the experience of being railroaded was closely linked to their concerns about not having enough time or information, as previously discussed in chapters 5 and 6. As with the previous themes, the relationship between patient and HCP was also integral to whether the interviewees felt they were “guided” or

“railroaded” by their HCPs, which in turn changed how interviewees saw the decisions they did, or did not, make.

Kathleen in particular felt that she was “railroaded” into her treatment, and it is from her that the term “railroaded” originates:

Kathleen: And I kind of then started getting quite angry and thinking that I wasn’t kind of given a choice, I was railroaded into this. I didn’t have a second opinion. I assumed I was being sent the best, but really should have asked for a second opinion.

Kathleen felt railroaded as she felt she was not given the time or opportunity to consider the different treatment options available to her, but also that she was not made aware of many of the other options available, only the option her HCPs had chosen for her. Initially Kathleen allowed herself to be guided, but that was based on a level of trust that she eventually lost, shifting her experience from being guided to being railroaded. Kathleen’s reaction to being railroaded is indicative of the link between being guided and decision-making, as the anger that Kathleen expressed was about her lack of choice as a result of misguidance on the part of her HCPs. As she says “I wasn’t kind of given a choice”, which she felt she should have been, given the enormity of the decision she was making (about a radical vulvectomy and sterilisation).

While Kathleen was a very specific case, other interviewees felt that being guided could sometimes briefly become being railroaded, in particular due to the way that HCPs communicated suggestions, which left little room for interjection. Being guided was experienced as being railroaded when the interviewees perceived that the HCPs stopped communicating and working *with* them, and instead were *speaking* to them and working *on* them.⁸⁸ For example, Anne felt that being guided became being railroaded when her HCPs started to tell her what they were going to do without asking her opinion on those choices. The shift between the two is evident in the language Anne used to describe her experience:

Anne: Because it’s all about your business and “we’re going to do this, we’re going to do that, you’ve got to come back and we’re going to

⁸⁸ A phenomenon I will revisit in chapter 8.

look at you”. There’s not any, “well how do you feel about that?” Or you know “is that OK with you?”

The “we’re going to” imperative phrasing of her HCPs treatment decisions is contrasted in her account with the interrogative questioning she would have preferred to ensure she was “OK” with her HCPs suggestions.

Perhaps the most interesting example is that of Monica as she had breast cancer twice, and had experienced being guided both positively and negatively. Monica was “happy” (as she says) to be guided the first time she had cancer, however the second time around she was not comfortable with being guided, and attempts by her HCPs to guide her were experienced by Monica as railroading:

Monica: Not so much the first time. I felt like decisions were made for me, but I was quite happy with that. But this time round because I was more clued up, I wanted a lot more say in what happened. Just little things: like that infection I had in the Hickman line, that’s two bad experiences I’ve had with the Hickman line now, so they took it out and she said “Right, we’ll get another one put in”. And I just said “No, no, no, no, no”. I said “No. I’m not having another one put in”. Whereas the first time around I probably would have just gone along with whatever it is that they told me, whereas this time I think “no, I don’t have to do that” [...] I just think it’s age this time. I think last time, I was really just a kid. I didn’t really give much thought to it and I totally didn’t expect to get cancer and I just went along with whatever the professionals told me to do. They knew better. They knew what they were doing and I just trusted them. Whereas this time, I don’t have that trust. I feel more like I should question everything.

Monica felt she had to question their suggestions as she “wanted a lot more say in what happened” with her treatment. She attributed the difference between the two cancer diagnoses to trust and age: she trusted her HCPs the first time she was diagnosed, but the second time she did not trust them, and so did not want to be guided by their suggestions. She also knew much more about what to expect the second time around, which changed how she needed to make decisions.

The phenomenon of being railroaded is a significant concern for patient autonomy as it shifts the patient from being an autonomous member of her treatment team, to being the passive object of interest of the team. The strong reactions that many interviewees expressed when they felt they were railroaded indicates the importance that they attach to maintaining autonomous decision-making, and thus being railroaded is an example of how autonomy may not always be respected in the relationship between patient and HCP. Railroading impedes the patient from exercising their agency, eroding the trust that they placed in their HCPs when they were being guided. Perhaps as a result, interviewees who experienced being railroaded often did not have a good relationship with their HCPs.⁸⁹

While being railroaded stands on its own as a subtheme in this chapter, it is actually a symptom of the wider issues brought up in chapters 5 and 6, as it is one possible consequence of how information is given to patients. Being guided is also closely tied to the HCP-patient relationship in the contemporary medical context. All of these concerns influence patient autonomy and agency negatively, reinforcing the sense that the overwhelming emphasis on informed consent in medicine means that there exist few standards as to how autonomy should be protected beyond informed consent. The role (or lack thereof) of criteria for protecting and respecting autonomy will be further addressed in the final two chapters.

The phenomenon of being railroaded stands on the very edge of paternalism. In interpreting the data, it was clear that most of the interviewees did not experience a “loss” of their autonomy entirely, nor did they experience being incapable of exercising agency. Instead, many agreed that their HCPs could at times be too heavy handed in their suggestions and opinions, and those moments were difficult to make decisions in. When suggestions were handed down as not just the *only* option, but the option that *had* to be taken, interviewees often reacted negatively, preferring to be asked for their preferences and opinions on their options, and not told what it was that they *had* to do.

⁸⁹ It is however a bit of a chicken and egg problem, as the relationship may not have been good so the communication was poor and interviewees felt railroaded and/or interviewees realised they had been railroaded and so trust broke down and the relationship suffered.

7.5 Summary

Being guided was experienced as a difficult balance between autonomy and paternalism, agency and power, information and ignorance. Interviewees' experiences of being guided were influenced by how they experienced a number of factors coming together, namely trust, the provision of information, and the strength of their relationship with their HCP. From a bioethical point of view this chapter paints a slightly bleak picture for patient autonomy, as it may suggest to some that it is simply not possible for patients to make autonomous decisions in the medical context. That is not the intention, as it is not how interviewees described their experiences of being guided and decision-making. Instead interviewees felt that the choice to allow themselves to be guided was one they actively made, and furthermore they described "being guided" as the best choice for them given their situation. This belief by interviewees that they were choosing to be guided further reinforces the argument that being guided is different from not having a choice. Even in the most extreme version of it (being railroaded) interviewees still felt there was a difference between not having a choice at all and being guided, which they describe as an active decision that they made for themselves. In this chapter I hope to have highlighted the ways that being guided can influence decision-making (positively and negatively). I would also like to bring forward into the academic discussion the phenomenon of being guided, as it may better reflect how autonomy is experienced in practice.

Chapter 8

Discussion

In the final two chapters of this thesis I discuss the significance of the empirical and theoretical findings of my research. In this chapter I look back on what I have found in the data. I discuss the empirically identified concerns and needs of the interviewees, analysing them with reference to the wider literature on decision-making in the medical context, as well as social and bioethical theory. I also use the data to reflect on the appropriateness of the concepts of ‘traditional autonomy’ and ‘relational autonomy’ in the contemporary medical encounter.

I begin by discussing how my research contributes to the existing empirical literature on communication in the medical context, the HCP–patient relationship, and also on the connection between theories of decision-making and decision-making in practice. I then discuss how findings from my research can contribute new ideas to the empirical literature, focusing on the phenomenon of Being Guided, and the importance of time in the data. A similar analysis of how my research confirms and contributes to autonomy and decision-making theory follows. I will examine the recurring concerns about informed understanding, and offer new thoughts on the place of power and emotional wellbeing in those theories.

In the final chapter I will build on the findings here, and discuss how the data can contribute further to theory. I introduce the concept of ‘Facilitated Autonomy’ which I derived from the empirically identified needs of the interviewees. It also builds on, but is distinct from, relational autonomy. By beginning with an examination of the empirical and theoretical needs in this penultimate chapter, I hope to put the development of the concept of Facilitated Autonomy into context by building the argument for reciprocity, relationality and support as key elements of Facilitated Autonomy.

8.1 Contributions to the Existing Empirical Literature

8.1.1 Communication

In my study interviewees discussed in depth how important the communication of information and treatment options were to their ability to make decisions. Interviewees linked communication to informed understanding. They felt that good communication facilitated the exchange of information between their HCP and themselves, which helped interviewees understand that information sufficiently so they could apply it towards the decisions they made.

Communication is a crucial aspect of decision-making in the medical context (Nettleton, 2013, 133). Recent research has highlighted the importance of communication between the patient and their HCP, as this communication is considered by both parties to be the primary source of relevant information. Despite this importance, many studies have found that communication between patients and HCPs is poor (see Siminoff *et al.*, 2006; Street *et al.*, 2007; Martinez *et al.*, 2009; Zikmund-Fisher *et al.*, 2012; Kim *et al.*, 2013). One 2006 study found that communication between both parties was often limited to a data gathering exercise for physicians to gain more biomedical knowledge about their patient, with little opportunity for reciprocal data gathering by the patient (Siminoff *et al.*, 2006, 357). As discussed in chapter 6, interviewees in my study voiced similar concerns to those in the wider literature, often describing communication between themselves and their HCP as difficult, one-sided and laden with perceived assumptions about the patient's informational needs.

This lack of communicative reciprocity (to borrow the term from Street *et al.*, 2007) appears to be alleviated only by the actions of the patient. The positive experiences that interviewees had when they asked directly for information mirrored the findings of several studies, which reported that the more proactive the patient was in participating in a communicative exchange with their HCP, the more likely the HCP was to engage in a reciprocal discussion about the patient's disease and treatment options (Street *et al.*, 2007; Martinez *et al.*, 2009; Moreau *et al.*, 2012; Frongillo *et al.*, 2013). Conversation that engages the patient in a discussion of their preferences, goals and values is characterised as 'patient-centred communication' in the literature. This type of

communication is more likely to happen if the patient is perceived by the HCP to be “involved” by actively taking part in the discussion (Street *et al.*, 2007, 592; Nettleton, 2013, 135). The strongest predictor of whether the physician would engage in a reciprocal discussion with the patient was how actively the patient attempted to engage the physician in discussion (Street *et al.*, 2007, 592).

The experiences of my interviewees, coupled with the findings of wider literature, suggest that patients should ideally take a more active role in those activities they feel necessary for decision-making, such as information gathering, communication, and discussion with their HCP. There is some evidence that being a passive member of the communication partnership may in fact limit available choices, as patients who more actively reciprocate communication are more likely to have treatment options presented to them by their HCP, while less involved patients are given only one recommendation (Frongillo *et al.*, 2013, 71).

In addition, the lack of communicative reciprocity between patient and HCP (regardless of who is less communicative) is problematic given the current focus on patient-centred care in the literature, and in practice. Patient-centred care prioritises patient values, beliefs, preferences and goals so that “full participants” in medical decision-making must be “reliably and explicitly asked about what they want to do” (Zikmund-Fisher *et al.*, 2012, 203). Full participation in decision-making may be difficult to achieve if communication between HCP and patient is confined to a monologue from the HCP on the technical details of a diagnosis (Zikmund-Fisher *et al.*, 2012, 203). Interviewees in this research reported that communication was critical to decision-making, adding further support to findings in the wider literature that one of the strongest indicators of patient satisfaction in treatment decisions is the feeling of being informed (Martinez *et al.*, 2009, 388). The number of studies reporting a lack of reciprocal communication in the patient–HCP encounter raises questions about whether patients are sufficiently informed when they make medical decisions.

– ***Communication and HCP assumptions*** –

The lack of reciprocity may also be due to the influence of HCP assumptions on patient–HCP communication, which is a phenomenon reported in the wider literature, and experienced by my interviewees. Interviewees felt that HCPs made assumptions in their conversations with patients about what information a patient wanted, based on the

HCP's assessment of the patient's needs. Interviewees felt that if their HCP did not know them well enough, then the assumptions made about their informational needs often missed the mark, thus restricting patient access to information.

Interviewees described accessibility to information as largely influenced by the relationship that they felt they had with their HCP. The assumptions made by their HCP were understood as an extension of this relationship, and when wrong, were often viewed as part of the breakdown of communication that occurs in a poor patient–HCP relationship. Interviewees felt assumptions made by their HCPs limited the information available to them as patients, information which may have changed the decisions they took about their treatment.⁹⁰ This opinion was most often voiced with reference to the information they were given about the effects of chemotherapy on fertility, and the availability of fertility preservation techniques.

Previous research in both the substantive field of oncofertility, as well as the wider field of decision-making in the medical context, has identified HCP assumptions as a significant influence on the information communicated between patient and HCP (Cope, 2002; Street *et al.*, 2007, 587; Quinn and Vadaparampil, 2009). A number of studies have reported that HCP beliefs about who should be informed of oncofertility techniques restrict the information that patients receive (Cope, 2002; Nisker *et al.*, 2006; Goodwin *et al.*, 2007; Quinn and Vadaparampil, 2009). As I examined in the literature review, the reasons given by HCPs for not discussing oncofertility are for the most part non-medical and range from the patient being homosexual (or believed to be) to the physician's individual beliefs about the appropriate age to stop having children (see chapter 2). Studies on decision-making outside the oncofertility context have similar findings, with one reporting that the quality of communication between patient and HCP is linked to the HCP's perception of the patient with whom they are communicating (Street *et al.*, 2007, 587). Patient demographics may also influence communication, specifically HCP perceptions about class, education and gender (Zikmund-Fisher *et al.*, 2012; Street *et al.*, 2007, 588; Siminoff *et al.*, 2006, 356).

Communication between HCPs and patients is a vital part of decision-making and autonomy. Theoretical understandings of patient choice, in particular feminist

⁹⁰ For example: Angela was not offered fertility preservation, which she feels was due to her being over 40 years old. However, she wanted to preserve her fertility to avoid menopause and would have liked to have been given the opportunity to discuss this with her doctor.

perspectives on choice in the healthcare context, also highlight that assumptions about information and understanding mean that “women’s options in health care are frequently constructed in ways that limit their autonomy” (Mackenzie and Stoljar, 2000, 217). Communication is one of the key ways that patients get information about their disease, treatment plans and side-effects (Kim *et al.*, 2013, 97). Information about their disease and treatment is highly valued by patients. By holding back information they think would be irrelevant HCPs may be forcing patients to make decisions from a restricted or incomplete set of options. If patients and HCPs can engage in more effective, reciprocal communication the negative influence of HCP assumptions could be minimised. Without these assumptions discussion about treatments, side-effects and fertility preservation would be more comprehensive, and tailored to the patient’s informational needs. More work needs to be done to examine the effect of HCP assumptions on patients in the UK, but the experiences of the participants of this study does provide further evidence that HCPs may have to be careful about not over-restricting the information they give patients based on their own assumptions about fertility.

Access to information, and access to people who could communicate this information to patients, was a primary concern for the interviewees. Given that communication with their HCP is one of the main sources of information, and that informed understanding is considered both in theory and in practice to be a significant part of patient decision-making/autonomy, the gap between theory and practice raises questions. Are HCPs just paying lip service to the informed understanding and patient-centred communication rhetoric, or do they not recognise the gaps that exist between how they communicate, what information they communicate, and how the patient receives those communications? If informed understanding is a criterion for theoretical conceptions of autonomy, what does it mean when that informed understanding is difficult to achieve in practice due to problems with communication? And who is responsible: the patients, the HCPs or the medical institution within which the communication takes place? There is increasing evidence from both the wider literature and my research that a reciprocal approach to communication may be necessary to help support patient decision-making and autonomy in the medical context. I address this point in the next chapter.

8.1.2 *The HCP–Patient Relationship*

The role that the HCP–patient relationship plays in decision-making is complementary to the concerns identified with HCP–patient communication. Interviewees reported that their experience of their relationship with their HCP was directly linked to how well the two parties communicated and exchanged information. In particular interviewees expressed the opinion that HCP–patient relationships influence access to information about the interviewee’s cancer and treatment options. Many interviewees reported that getting this type of information was difficult, making the decisions they had to make difficult as well.

These experiences of the interviewees reflect the wider literature on patient decision-making, where the relationship between HCP and patient is considered influential on patient decision-making and integral to the medical encounter (Annandale, 1998, 264; Nettleton, 2013, see chapter 6). In the literature the HCP–patient relationship is closely linked to the quality of communication between patient and HCP. Research into the connection between communication and the HCP–patient relationship has found that poor HCP–patient relationships lead to poor communication, making “high quality decisions” difficult for patients (Kim *et al.*, 2013, 97). In contrast good communication emerges from positive relationships between the two parties, which results in high treatment decision satisfaction for the patient (Street *et al.*, 2007, 586).

Not only is the HCP still considered the primary source of information, but “medical encounters occur within interactive environments and physicians often dominate these environments” (Siminoff *et al.*, 2006, 360; see also Nettleton, 2013, 128) such that the balance of power between patient and physician can become inequitable.⁹¹ One study on the influence of the HCP–patient relationship suggests that the discrepancies in communication that have been observed in previous studies may be occurring because the relationship between provider (what I call HCP) and patient is not egalitarian (Zikmund-Fisher *et al.*, 2012, 204). Much has been discussed about the power dynamics between HCP and patient, to the point that the patient–physician relationship is often conceived of as “ideal types or categories arranged on a continuum from physician paternalism to patient autonomy” (McMullen, 2012, 238). As a result decision-making theory is often focused on moving power back towards the patient (consider the shared

⁹¹ And in fact is often posited as being inequitable from the start (Nettleton, 2013, 128).

decision-making model for example), with less consideration to the sources of that power (information provision, institutional influence) and how some of the power dynamics observed may be impossible to dissolve (for example, the HCP is always going to be the medical expert).

Recent studies have suggested that the focus be switched to trying to find a balance between “the power of the physicians’ recommendations and the power of patient choice” (McMullen, 2012, 247). However this approach implies that ‘fixing’ the influence of the HCP–patient relationship on patient decision-making is simply a matter of getting two equally powerful members of a relationship balanced so that one is never more powerful than the other. In practice this is not the case as the two sources of power (the patient and the HCP) are not equal in the contemporary medical encounter (Nettleton, 2013, 130). Any attempt to balance power between patient and HCP “fails to acknowledge the potentially imbalanced nature of this interaction when one party is sick and searching for security, and when judgements entail the interpretation of technical information” (Emanuel and Emanuel, 1992, 2221).⁹² This approach also assumes that patients have a freedom of choice (implied by the rhetoric of shared decision-making and informed consent) that in practice is difficult to achieve, as choice can be limited by factors outside patient control (McMullen, 2012, 247).

Achieving any balance of power dynamics is also heavily dependent on how the patient views the importance of their relationship with their HCP, and the authority they give that relationship.⁹³ Not only is it necessary to acknowledge areas where power may be imbalanced, but it is also necessary to consider the deep roots of these power relationships, especially in medicine where “physicians have the authority to act as gatekeepers to healthcare. They control medical knowledge, technology, access to treatment and even norms of behaviour in the medical encounter” (Charles *et al.*, 1997, 686). A number of the interviewees noted that they felt they had difficult relationships with their HCP. This was due in part to their belief that the HCP was “very important” and should not be bothered, or they trusted that they were “being sent the best” (phrases

⁹² Some of the sources here, like the Emanuel and Emanuel one, are older. However I have included them as their findings continue to be true. 22 years from when the Emanuel and Emanuel paper was published fundamental texts, such as Nettleton’s *The Sociology of Health and Illness* (2013), continue to discuss why a power imbalance persists between patient and HCP in the medical context, marking out the influence of power as part of the classical debate in medical sociology literature.

⁹³ A Foucauldian way of viewing power, however none of my interviewees expressed their understanding of power dynamics in those terms.

used by the interviewees). Interviewees did not want to shut down what they considered to be a fragile relationship by questioning or going against recommendations. This phenomenon has been previously reported in the literature, where going against HCP recommendations is perceived as difficult by patients if they feel it “might negatively affect their relationship with their physician” (McMullen, 2012, 247; see also Frongillo *et al.*, 2013, 72). The concern patients have for their relationship with their HCP is indicative of its importance to them, which stems from the patients’ beliefs that the HCP is the primary source of the information that they need to make decisions about their healthcare.

The relationship between HCP and patient is a complex one. I explore it further in the final chapter, looking at how this relationship can be understood against the theoretical backdrop of agency, autonomy and power dynamics, in order to better incorporate the HCP–patient relationship into bioethical concepts of agency and autonomy.

8.1.3 *Being Guided*

One theme from the data that was difficult to find in the wider literature was that of “Being Guided”. This was the term that many of the interviewees used to describe the phenomenon of choosing to follow the treatment pathway recommended by their HCPs (see chapter 7). While there has been research done on similar concepts like the patient “conveyor belt” (Scully *et al.*, 2007), patient assent (Emanuel and Emanuel, 1992; McMullen, 2012) and paternalism (Emanuel and Emanuel, 1992; Charles *et al.*, 1997; Charles *et al.*, 1999), this literature has focused on the negative aspects of HCP recommendations (McMullen, 2012; Frongillo *et al.*, 2013). “Being guided” stands out from this literature for the general lack of negative associations by interviewees with the idea of following HCP recommendations. “Being guided” was also not associated with the passivity that concepts like paternalism and “conveyor belt” imply. Interviewees describe “being guided” as an active choice that they made, where they used the phenomenon of “being guided” to help them achieve goals that they felt necessary to meet for their own wellbeing (mental and physical). “Being guided” is possible when those aspects of decision-making considered necessary (by both the interviewees and existing research) are respected and supported in the medical context, namely a good relationship between HCP(s) and patient that facilitates trust, reciprocal communication,

informed understanding, and discussion.

“Being guided” is a difficult concept to define, but it can in part be defined by what it is not, and I would like to spend a moment outlining why “being guided” is not paternalism in disguise. The key difference between “being guided” and paternalism has to do with two important aspects of patient decision-making: patient preference and informed understanding. In “being guided”, both of these are at the forefront: it is the patient who makes the decision to be guided (because that is their preference), and this decision is made when the patient feels sufficiently informed⁹⁴ of their situation such that they feel they understand the decisions that will be made.

In paternalistic models the patient’s preferences are not elicited or considered (even those preferences to be guided), instead the HCP acts on what they feel would be best for the patient’s medical wellbeing (Emanuel and Emanuel, 1992, 2221; Charles *et al.*, 1999, 652). In contrast, when interviewees in my study chose to be guided their own preferences were always at the heart of the decision, as they felt “being guided” was the correct choice for them at the time. “Being guided” was chosen by the patient as it allowed their preferences and goals to be prioritised and fulfilled. This required a lot of trust on the part of the patient towards the HCP, making a strong HCP–patient relationship a necessity for “being guided” to remain distinct from paternalism.

Information is also a key aspect of “being guided”. Interviewees did not take “being guided” to mean being kept in the dark, and with the exception of Heather, interviewees still demanded to be informed. Once informed they then made the decision to be guided. This phenomenon is not without precedence. Previous studies have observed that while patients want all the information they can get about their situation, their preferences for who participates in the treatment decisions, and how that participation occurs is quite diverse (Charles *et al.*, 1997, 683). Being informed is a vital priority to patients, but this does not necessarily translate into the patient making specific treatment decisions as “patients want information about their medical condition and treatment options without necessarily being responsible for making treatment decisions. An informed patient may prefer to make the decision herself [...], to share the decision-making process, or to delegate this responsibility to the physician” (Charles *et al.*, 1997, 683). I understand

⁹⁴ The level of sufficiency of information is subject to the patient’s need, not any predetermined criteria.

this delegation of decisional responsibility to be similar to what happens when patients choose to be guided. Charles *et al.* also touch on the importance that information plays in “being guided” as they identify the type of patient who can make these types of decisions as “an informed patient”, linking information and “being guided” together; an association interviewees made as well. As with other research on decision-making, information is essential to being guided. Patients who choose to be guided need to first have an informed understanding of their situation, then they can choose whether to delegate some or all of their decisions. If patients are not informed then they are unaware of what decisions are even available to delegate, and this becomes a slippery slope towards paternalism.

Finally the most important aspect of “being guided” that is not present in the more negative paternalistic models is the freedom that choice brings. Concepts like paternalism and “conveyor belt” imply a consistent loss of control and direction that is not found in the interviewees’ accounts of “being guided”⁹⁵. Unlike the conveyor belt phenomenon where patients feel they cannot get off the belt, “being guided” is chosen as it is a form of autonomous decision-making, implying it can be unchosen as well. The power to be guided rests in the hands of the patient. This is a necessary component of “being guided” as the preference for it is contextual, and may change as treatment progresses (for example Monica wanted to be guided with her first diagnosis of cancer, but for her second diagnosis she did not). “Being guided” is an example of how important context and flexibility are for understanding decision-making in the same way that patients understand and experience it. The concept of “being guided” raises concerns about the traditional concept of autonomy that would reject the delegation of decisions by patients, as that delegation may not fulfil the necessary criteria for an autonomous decision. Further work is required to better understand how and why patients delegate decision-making.

8.1.4 *The Importance of Time*

As important as time was to interviewees, there is little literature on the subject of time in bioethics. Some writers, such as sociologist Barbara Adam, would go so far as to say

⁹⁵ This is not to say that interviewees never said they felt out of control. Some did experience “Being railroaded”, however interviewees did not report feeling this all of the time. See section 7.4 for a detailed account of “Being Railroaded”.

that the social sciences do not consider time much, and when they do they tend to ignore the multifaceted nature of time (Adam, 1990, 4). Time exists in the social realm, as a social force. As Adam argues:

“Many more aspects of time [...] form an integral part of our lives. Some have to do with synchronisation, ordering, sequencing or timing, others with control or measurement, and still others with the time aspects of machines and artefacts. All have a bearing on our lives not as separate abstracted entities but as an interconnected whole. If we accept social science to be about studying, understanding and explaining that reality then we can expect social scientists to take account of time in this multiple and connected way, to know and acknowledge the many aspects of time in their relation and not on an either/or basis.” (Adam, 1990, 1)

Time was an important part of the interviewees’ experience. Time and decision-making are interconnected in ways integral to the key focus of this thesis: patient autonomy. In this thesis I am conducting a sociological bioethical inquiry, and so must take account of time in the same way that Adam asks of the social sciences. How an individual understands time is important for understanding his/her autonomy, as their understanding of time “constitutes the difference between having choices and seeing one’s social life as determined.” (Adam, 1990, 5). Seen through the lens of bioethics this distinction can be understood as the difference between autonomy (what Adam calls “having choices”) and non-autonomy (what Adam calls “seeing one’s life as determined”). If autonomy and being autonomous are important concepts in bioethics, then the relationship between autonomy and time should also be valued, and by extension time should be a feature of interest to bioethics as well.

The relationship between decision-making and time/timing that interviewees experienced was as multifaceted as Adam describes above. For interviewees the importance of time was not always about having the time to make a decision, but about how time interacted with their perceived futures, the retrospective narratives of their cancer story and the time spent with their healthcare professionals: all of which patients considered necessary for the decisions that they made.

– *The manipulation of time*–

As reported in chapter 5, interviewees often manipulated their understanding of time

and timing when reflecting on how and why they made their decisions. Manipulating time not only helped interviewees to explain the actions that they took, but it also helped them feel in control, allowing interviewees to claim some ownership over their actions during a difficult period. This control and ownership made them more comfortable about the decisions they had made and the decisions they may have to make. The feeling of control may have also helped avoid any emotional burdens interviewees felt were too heavy and impeding their decisions, making the manipulation of time an example of patients exercising their autonomy in a difficult setting. This argument is supported by Scully *et al.*'s (2007, 215) suggestion that the manipulation of time allows patients "moral space" within which to make their own difficult decisions:

The manipulation of time is not simply about controlling the process of decision making, but also about preserving a 'space' in which moral agency can be exercised.

This space was achieved by breaking up their decisions through time, so that the interviewees gained some control and justification over their decisions, making difficult decisions more manageable and thus possible to make. In all cases in the data manipulating time served to facilitate, justify, cope with, and protect the interviewees from decisions that had to be made. This allowed them to feel as if they were still maintaining some control. In doing this, interviewees were making the necessary "moral space" to exercise their autonomy and make difficult decisions themselves.

– Planning for the future–

Part of the reason why interviewees manipulated time had to do with the difficulty they had in planning for the future. They often had to make decisions about things that had yet to happen or that they had not even thought about yet (for example, whether they wanted to have children). As I have argued in chapter 5, planning for the future is particularly hard for oncology patients as their prognosis is unsure, making it difficult for them to make decisions about their future when they cannot know if they will survive to that future. These decisions were doubly difficult for interviewees considering fertility preservation as they had to make decisions about their future survival, as well as their future fertility, and these two futures were not always compatible (especially for those women with hormone receptor cancers).

Planning for the future was an integral part of moving forward for interviewees, and they focused on how the future affects and influences their present action. Planning for the future had a number of positive consequences for interviewees that helped facilitate their decisions: for example it could be about hope, about attending an event in the future, or be as simple as choosing a cancer treatment based on the future side-effects. Planning for the future was also a way for interviewees to preserve options and choices for themselves in the future that they were not prepared to make a decision about in the present.

Since much of cancer treatment and fertility preservation happens across a period of time, it is necessary to extend the level of choice across this period of time as well, taking what Scully *et al.* (2007) argue is the “longer perspective”. Decisions in cancer treatment are simultaneously decisions for the now and for the future. By this I mean that the cancer patient must make a decision about cancer treatment that affects the decisions available in the future about their future health (for example chemotherapy can cause menopause, which affects future fertility). Cancer patients, and by extension oncofertility patients, must exist in two temporal arenas: their “now” selves and their “future” selves. Oncofertility patients in particular must balance and compromise between the two, as cancer decisions affect the availability of future fertility options. The decisions that oncofertility patients make in the ‘now’ must also help them to “colonize the future”⁹⁶ in such a way that they feel comfortable with the choices they have made. This is the long term framework within which patients make decisions.

Adam describes this process as “the power of the human mind to visit past events, to re-invent them, create alternative versions and plan a multitude of futures. We are able to imagine the world in a projected future-present upon which we can reflect and make out choices” (Adam, 1995, 18). The medical context often truncates this decision framework, requiring decisions that affect the future to be made immediately. This makes the decisional framework suddenly very small and very immediate, when in fact the decision has to be made within the patient’s long term framework (which includes the “projected future-present” that Adam suggests). Bioethical concepts of autonomy focus on this same immediacy in decision-making that the medical context imposes (Scully, 2007, 216). Doing this focuses only on what is needed for the patient to

⁹⁶ The colonisation of the future refers to the process by which individuals extend their consideration of present needs to include consideration of their future needs (Hagerstrand, 1985; see also Adam, 1990). They do this to secure the safety of their futures and eliminate uncertainty (Adam, 1990, 139).

maintain autonomy at the point of decision-making, but not on how the patient can maintain their autonomy within the context of the patient's long term framework.

Uncertainty due to predictive fuzziness about their prognosis was also a key feature of interviewees' experience of time in the decision-making context. Predictive fuzziness occurs when the patient's future is difficult to know, and understand, because the patient's prognosis is unknown or uncertain. Knowing about the future, or not knowing as the case is with predictive fuzziness, was important for the interviewees. "Knowing" their futures was understood by the interviewees as having information on their current condition that they could use to make decisions moving forward through time in a way that made them feel comfortable and in control of their lives. Predictive fuzziness meant that their futures were sometimes impossible to know, as their prognosis was unknown, effectively eliminating a source of information that patients consider important when making decisions.

The importance of having information lies at the heart of why value is placed on planning for the future. Planning for the future is the enacting of patients' decisions based on the information they are given and have understood, while predictive fuzziness is experienced by the patient as a lack of information and understanding. This uncertainty influences patient decision-making as it acts as a road block to achieving the informed understanding that patients feel is critical to decision-making. In oncofertility the combined predictive fuzziness of cancer prognosis and future fertility is impossible to rectify as there is *no* way of knowing with certainty that a patient will survive treatment *with* their fertility intact. Given the importance of informed understanding to patients' experiences with decision-making (and to autonomy theory) the full effects of medical uncertainty like predictive fuzziness require further research to better understand how uncertainty interacts with patient autonomy.

– *Needing time* –

Interviewees also reported wanting more time spent with their HCPs. Interviewees described having difficulty understanding the information given to them, as they did not have sufficient time with their HCPs (mostly their doctors) to be able to understand what they were being told. Without the time to understand, interviewees felt it was difficult to make decisions they felt comfortable with.

While this may seem a small point about information access, it is actually part of a larger issue concerning the facilitation of patient autonomy with regards to time. As Scully *et al.* found, informed consent is built on the principle that patients understand the information given to them, and that they continue to understand the information and have access to this information throughout the decision-making process: i.e. over time (2007, 217). This has been previously reported in the wider literature on decision-making as well. Emphasis has been put on allowing more time for continuous access to information. This emphasis is in recognition of the varied abilities of patients in gaining access to, and understanding, information from their HCPs (Zikmund-Fisher *et al.*, 2012, 199). In particular, research in the wider literature has reported on how time constraints affect the necessary discussion needed to allow for sufficient understanding (Zikmund-Fisher *et al.*, 2012, 199).

The continuous understanding of information over time is also a vital part of maintaining and facilitating patient autonomy, however many theoretical conceptions of autonomy focus only on the point of decision-making, not the moments that precede or proceed from it. As I argued earlier, failure to facilitate patients' continuous informed understanding is a failure to acknowledge the long-term frameworks in which patients make decisions. Clinicians and ethicists often see the decisions to be made as close in time to the clinical encounter, but to the patient the whole process has been going on longer than the point of contact with the clinician, and will continue on after as well. It is important to allow for the patient's long-term perspective (Scully *et al.*, 2007, 217) as it may be necessary for the patient to repeatedly review the information so that they feel they understand it within their long-term framework. Respecting the long term framework in which the patient makes decisions is also important to consider when facilitating patient autonomy. It is not just the clinical encounter, but the patient's whole life story, values, and beliefs for their present and future that inform their decisions. These values and beliefs are aspects of decisions that will be made about fertility preservation and cancer treatment that exist totally outside the clinical encounter, but reside comfortably in the patient's long-term framework, contributing to how she asserts her agency, moral competency and decision-making.

8.1.5 *Autonomy in Practice*

The data from this study contributes to the growing body of literature that explores why current decision-making models/theories are not accurate representations of how decisions are made in practice. Patients, both those in the wider literature, and those I interviewed, expressed concerns about gaining an informed understanding of their disease and treatment options. They stressed the importance of support, the need for a more balanced input of expertise from patient and HCP, and called for a greater understanding of the influence of the HCP–patient relationship. However none of these concerns are new to the literature, and in fact many of the discussions about why these phenomena occur are becoming so common to the sociological study of medicine that they are part of the canon.⁹⁷

Empirical work in the field has gone a long way to addressing the observed disconnection between theory and practice by examining what *is* occurring in practice. Contemporary models of patient decision-making still do not reflect how patients make decisions, highlighting the need to revise those theories that attempt to capture the decision-making process. In the final chapter I try to bring the empirical and the theoretical closer together, such that lessons learned from practice may be woven back into the theory, perhaps moving closer to an understanding of patient decision-making that better reflects the reality that patients experience. However, first I would like to discuss observations from my research that may add to the existing empirical and theoretical work in new ways.

8.2 **Implications of the Empirical Contributions**

The importance of time and the use of “being guided” are related as they are both concerned with supporting patient decision-making. “Being guided” can be understood not only as a way of making autonomous decisions, but also as a form of support for

⁹⁷ The concerns listed above have been cited in classical texts such as Silverman’s 1987 book *Communication and Medical Practice: Social Relations in the clinic*, and Annandale’s 1999 work on *The Sociology of Health and Medicine*. The same issues are continuing to be discussed in contemporary textbooks like Scambler’s *Sociology as Applied to Medicine* (6th edition, 2008) and overview texts like Nettleton’s *The Sociology of Health and Illness* (3rd edition, 2013). All these texts devote whole chapters to discussing the nature of the doctor–patient relationship, and debate numerous theories of how patients make decisions in the medical context.

difficult decisions. Pushing it further, there is a possibility that there would be less need for “being guided” if the concerns regarding reciprocal communication and provision of information were better addressed in practice. “Being guided” may be both symptom and semi-solution to the concerns about facilitating autonomy in the medical setting: being guided happens because patients get overwhelmed with being part of the medical process, but it is also one of the ways that patients choose to cope with the situation so that they can make decisions within this process.

The importance of time is also about creating support in an area where support is perceived as lacking. Patients manipulate time to make space for the decisions they have to make because they perceive that they otherwise will not get that necessary space. They feel this way because the short clinical encounter does not give them enough time with the HCP to help them understand the information they are given. Time with the HCP is necessary as interviewees reported that information was often sparsely given, difficult to understand and given quickly. As a result interviewees wanted more time spent on emotional and informational support to help them deal with making difficult decisions in the short period of time given.

I do not mean to suggest that if patients were provided with more support (informational, emotional etc.) when making medical decisions that more time, or “being guided”, would no longer be necessary. I do not believe the solution is so simple, or that there is a possible solution to all the related concerns.⁹⁸ This is because cancer treatment occurs relatively quickly after diagnosis, and oncofertility treatment even quicker as a result. It is unlikely that the amount of time given to make a decision will be increased, and diagnostic time is more likely to decrease than increase as screening programs become more comprehensive and accurate. Instead, emphasis and effort could be shifted to supporting patients, making areas that cause difficulties for decision-making less burdensome on the patient. In particular there is an identified need for informational support (through discussion with nurses and doctors) that would provide patients with ongoing access to informational resources throughout diagnosis, treatment and aftercare. This ongoing access would help patients feel they have at the very least an informed understanding of their situation, giving them important tools to make decisions they are comfortable with. I discuss the importance of informed understanding

⁹⁸ For example, very little can be done about future planning in terms of support as there is only so much anyone can know about the future and only so much doctors can know about future prognosis, which is why that area needs further research.

to theories of autonomy in the next section.

8.3 Contributions to the Existing Theoretical Literature

8.3.1 *Informed Understanding*

Informed understanding figures prominently in the theoretical accounts of decision-making, agency and autonomy, and was considered a crucial part of making decisions by the interviewees. As so much emphasis is placed on informed understanding in both theory and practice I would like to spend some time discussing it further.

As I argued in chapter 6, interviewees saw information and understanding as necessarily linked. They needed to understand the information they were given within the context of their own lives in order to use that information to make a decision. Information without understanding was considered useless by the interviewees. I have previously discussed the influences of communication, trust, time and the HCP–patient relationship on the provision of this information and subsequent understanding. Here I focus on the theoretical interests in informed understanding.

In theoretical accounts, information and understanding take centre stage either as explicit criteria for achieving autonomous decisions in bioethics (Beauchamp and Childress, 2009; Mackenzie and Stoljar, 2000) or in sociology, as part of the process by which Giddens argues agency is achieved (Giddens, 1979).⁹⁹ These theoretical accounts all argue that information on its own is not enough for an individual to make autonomous decisions, or exercise their agency. However, in practice information provision is patchy and patient understanding of that information is not prioritised (see chapter 2). Interviewees reported various degrees of non-understanding or misunderstanding due in large part to how clinical encounters are structured. Without the time, staff, or support they needed interviewees felt that informed understanding was difficult (though not impossible) to achieve in the medical context.

Both patients and bioethicists advocate for the importance of informed understanding to

⁹⁹ Giddens argues that the agent must be aware of all the “otherwises” when they make a decision. Informed understanding is how the patient, as a type of agent, becomes aware of these “otherwises”.

(albeit different) conceptions of autonomy and decision-making. Yet somehow, 35 years on from Beauchamp and Childress' iconic enshrining of information and understanding as major criteria for autonomy,¹⁰⁰ informed understanding is still difficult to achieve. One possible reason for this is that informed understanding might not in fact be a necessary criterion for autonomy in practice. However, given that interviewees were adamant that one of the things they needed most was information they understood, it is unlikely that those theories of autonomy that require informed understanding are missing the mark. Informed understanding coloured all aspects of interviewees' decisions: they needed it to plan for the future, to allow themselves to be guided, to engage in necessary discussion with their HCPs, and to establish some degree of power in their relationships with practitioners. It is undoubtedly important to the decision-making process.

Why, then, is informed understanding so difficult to achieve in practice? The answer to this may have to do with the medical profession's understanding of autonomy, specifically the role that informed consent plays in the medical encounter. Reducing the process by which patients make decisions to the signing of a consent form may have changed, or at least limited, how consent is understood. Instead of focusing on what patients need to make decisions, it has become standard practice to assume that when a patient signs a consent form this indicates that they understand everything on the form (as Corrigan, 2003, saw in studies of informed consent in clinical trials). However, signing the form is the *only* way that patients can get access to the treatment, whether they understand it or not. Treatment is often considered urgent and necessary in oncology, further emphasising the importance the consent form holds. It is therefore likely that patients sign consent forms without the necessary informed understanding simply so that they can access the treatment they feel is urgently needed.

It would seem that patients *and* autonomy theorists recognise the need for informed understanding, but in practice this need is not operationalised. In order to operationalise this need, emphasis in the medical encounter should be refocused on informed *understanding*, as information provision on its own is not enough.¹⁰¹ One way to achieve this reemphasis may be to consider more carefully the multiple phenomena that influence decision-making, in order to better understand how those phenomena affect

¹⁰⁰ In the first edition of *Principles of Biomedical Ethics*, published in 1979.

¹⁰¹ This may already be the focus in the clinical setting, but further emphasis is needed as patients continue to feel under-informed.

informed understanding. For example, poor communication can result in the HCP not realising that their patient does not understand the information provided. Patient understanding needs to be given as much weight as the information itself, as it is informed *understanding* that is valued by patients and in theories of autonomy, not information on its own.

8.3.2 *Power Differentials and Dynamics: Their Role in Medical Decision-Making*

Exploring the importance of the HCP–patient relationship in the medical encounter, and the power dynamics within that relationship makes up a significant part of the sociological work examining the medical encounter. As I argued in chapter 2, how power is experienced between patient and HCP has been a perennial concern in sociology. In the contemporary medical encounter how patients and HCPs interact with each other may still be reinforcing the asymmetrical power dynamics between them. For example, recent empirical work conducted by Frongillo *et al.*, shows how patients are still “reluctant to challenge a provider’s recommendation, even if they prefer a different option” due to the authority the HCP is given in the medical encounter (Frongillo *et al.*, 2013, 72). In addition, textbooks such as Nettleton (2013) and Scambler (2008) continue to devote time to examining power within the HCP–patient relationship, indicating the extent to which power, and power dynamics, in the medical encounter are recurring areas of concern.

However despite the extensive research done on power in sociology, the role of power does not feature heavily in traditional, bioethical accounts of autonomy. Existing theories of autonomy, especially traditional autonomy, have had the habit of glossing over or ignoring problem areas identified through empirical research (Hedgecoe, 2004, 127; see also chapter 3). In addition, the resources of social theory have been considered irrelevant in the past, and thus left out of traditional accounts of autonomy (Mackenzie and Stoljar, 2000, 4; see also chapter 3). The role that power differentials can play in the HCP–patient relationship, the medical encounter, and decision-making should not be ignored. Given the emphasis that interviewees put on their relationships with their HCPs, I would like to focus on how theories of power can contribute further to bioethical theories of autonomy.

One theory of bioethical autonomy that does consider the role of power is relational autonomy. Relational autonomy is concerned with how people are socially embedded, focusing on the effects of oppressive socialisation that bring about power dynamics that traditional theories of autonomy often ignore (Mackenzie and Stoljar, 2000, 22). In relational accounts of autonomy power/power dynamics are mostly viewed through a feminist lens, and power is often (but not always) viewed as an all-encompassing negative and oppressive force on women. While interviewees in my study did not call themselves “oppressed”, they did identify aspects of power that they felt influenced the patient–HCP relationship, and by extension, their decision-making abilities. The data indicates that there is a power differential that exists between HCP and patient that influences the agency and autonomy of the patient. In principle relational autonomy has ample room for nuance in power differentials, however, this power differential is more multi-faceted than some relational accounts of autonomy allow. For this reason I would like to consider the influence of power through the sociological lens.

In this thesis I have used Giddens’ definition of agency, and his corresponding theory on power (see chapters 3 and 6). Giddens argues that an agent must have the ability to act otherwise in order to have agency (1979, 56). Power influences this agency when one individual causes the other to be unable to act otherwise, and thus exerts power over that person’s agency (Giddens, 1979, 91). I have previously established a link between an agent’s ability to act otherwise and having an informed understanding of this otherwise (their diagnosis and treatment options).¹⁰² In the medical context the HCP is the primary source of this information (Kim *et al.*, 2013, 97), and thus the primary source of the “otherwise”. If the HCP does not facilitate the patient’s informed understanding (for whatever reason), then the patient is not aware of all available options (the “otherwise”). As a result the patient cannot “have acted otherwise” as they do not know what “otherwise” options are available. When communication is poor this sets up a power dynamic within the HCP–patient relationship, and the patient feels they are not sufficiently informed by the HCP. In this situation the HCP is the agent in power, as they could have “acted otherwise” by giving the patient sufficient information for the patient to understand their “otherwise”, but they do not.¹⁰³ Without sufficient

¹⁰² See chapter 6.

¹⁰³ This is of course only the case for those patient–HCP relationships that have poor communication. However given that current empirical research reports that communication is still a major stumbling block to patient decision-making, and that patients routinely feel under-informed by their HCPs, it appears that poor communication between patient and HCP remains a normal part of the medical encounter, which is

information about the “otherwise”, the patient cannot act otherwise. This Giddensian power dynamic is the “recognition of informational asymmetry between patient and physician” (Charles *et al.*, 1997, 683), where the HCP holds the information that the patient needs about their disease and treatment¹⁰⁴. The influence of this power dynamic on the HCP–patient relationship is significant as this is the same relationship which I have previously argued facilitates patient decision-making, supporting patient autonomy through reciprocal communication and discussion.

It is difficult to escape the power dynamic that exists between patient and HCP. HCPs are experts in a field where many of their patients are not, and power is distributed in part through knowledge and information provision. HCPs are also granted power in the medical encounter because of the authority they are given by social beliefs and norms (Charles *et al.*, 1997, 687; Annandale, 1998, 274; Nettleton, 2013, 123–125). This authority is so well recognised in HCP–patient interactions that it is a significant part of many sociological theories of these interactions. For example Parson’s (now quite dated) sick role describes a reciprocal social relationship between patient and doctor, where the doctor must be given authority, power and status over the patient’s health for the patient to fulfil their role as the sick person (Parsons, 1951, chapter 10; see also Nettleton, 2013, 125).¹⁰⁵ There may be no solution to fully eliminate the existing power dynamic. However, there may be possible ways of reducing any negative influence it has on patient autonomy. By putting added emphasis on how sources of information are valued between patient and HCP, and re-emphasising the expertise of both patient and HCP,¹⁰⁶ it may be possible to better balance the power dynamics between patient and HCP.

– *Patient expertise* –

In the medical context the HCP is often considered the expert (Charles *et al.*, 1997, 683; Annandale, 1998, 224), but room should be made for the patient as expert as well. Taking a Giddensian approach to power means that in the medical context whoever has

why I have chosen the negative version of this example of power. It is entirely possible for the patient to be the one in power, it is just not seen in practice very often.

¹⁰⁴ It is also possible for the HCP to be in the position of inferiority if the patient withholds important information about their health and lifestyle (for example, under-reporting how many cigarettes or units of alcohol they consume in a week).

¹⁰⁵ Parsons’ sick role is a classic example of physician power, but it has been criticised over the years (especially with regards to chronic illness). I use it here to show how physician power is so entrenched in our understanding of the HCP–patient encounter that it is a significant part of a major sociological theory.

¹⁰⁶ All the while advocating for a strong HCP–patient relationship.

the knowledge of the “otherwise” has power over the other agent. Revaluing the importance of patient expertise would allow power to shift back and forth between patient and HCP, depending on who was the source of the knowledge in each exchange. This is not to conceive of the patient as a “lay expert” in medicine, but as true experts in themselves, where “themselves” consists of the patient’s values and beliefs, how they experience their body (pain, discomfort, etc.) and how they assess their mental wellbeing.

The patient-as-expert is not an unprecedented view. Much of the literature on shared decision-making, for example, is premised on the early argument by Hurley *et al.* that “while the health care provider possesses better knowledge regarding the expected effectiveness of health care in improving health status, the individual knows best how improvements in health status affect his or her wellbeing” (Hurley *et al.*, 1992, 4). The contemporary medical encounter has moved towards a patient-centred care approach that embodies Hurley *et al.*’s argument of “the individual knows best” (1992, 4). As I argued in chapter 2, the medical encounter of the 21st century is characterised by “the authority of the self” (Annandale, 1998, 254) and increasingly HCP–patient interactions are being viewed as a meeting of experts, where the patient is viewed as one of these experts (Nettleton, 2013, 123).

I would like to advocate for the knowledge described by Hurley *et al.* to be more readily recognised as a form of expertise. If expertise is “the capacity either to offer expert opinions or to demonstrate one or more skills in a domain” (Weinstein, 1993, 59),¹⁰⁷ and the “domain” of a patient is their understanding of themselves (mental, physical etc.), then it follows that it is acceptable to consider patients as experts in their domain. In fact it is necessary to consider patients as such, as HCPs (experts in the domain of medicine) cannot and should not act outside of their expertise (Weinstein, 1993, 59–62). When HCPs ignore or discount the expertise of the patient, they discount an important part of the relationship and interaction that is necessary for a patient to make an autonomous decision. If patients are considered experts in themselves by HCPs (as argued in chapter 6), then this may help put their relationship on a more equal footing and ease some of the tension of the existing power differential between HCP and patient. The power differentials were reported as less restrictive for some of the

¹⁰⁷ While the Weinstein reference is dated, it makes up part of the classic literature on expertise, and his explanation of how expertise is conferred and recognised is useful for understanding how patients and doctors are actually experts in different, but complementary domains.

interviewees who chose to assert themselves strongly within the HCP–patient relationship. For example, Robyn had a list of questions she felt were necessary to help her make decisions. Diane decided for herself when would be best to try for her third child, disregarding advice from her HCPs that she felt did not incorporate her life plan. In both of these examples the interviewees described their HCPs more as equals, and in Diane’s case she referred to all her HCPs by their first name only. Demonstrating and using their own expertise allowed the interviewees’ knowledge of themselves to be viewed as valuable and complementary information by their HCP.

However, even if patient expertise is viewed on a more equal footing with HCP’s expertise, there still exists a power differential between the two. No matter how “equal” the two experts are, there will be times when the HCP knows more than the patient and vice versa. As a result it raises the question of whether it is possible to “resolve” the influence of power dynamics on decision-making in the medical context.

– *“Relational” power* –

A possible solution to this concern is to consider Giddens’ concept of relational power as the basis for how power should be exercised in order to facilitate autonomy. This theory of power interactions fits nicely with the relational focus of my research, taking a reciprocal approach to understanding power dynamics. Power relations are understood as “relations of autonomy and dependence, but even the most autonomous agent is in some degree dependent, and the most dependent actor or party in a relationship retains some autonomy” (Giddens, 1979, 93). As I have previously argued in chapter 3, relational power more accurately captures the flow of power that should exist in the relationship between HCP and patient, as the HCP needs the patient (and thus must convey to them some power) to give them their patient history, symptoms, treatment side-effects and feedback in order to treat the patient to the best of the HCP’s abilities. The patient needs the HCP (and so must also convey to them some power) to use that information to diagnose and treat the patient effectively. Defining the power relationship between HCP and patient as relational (even within the power relationship that I outlined earlier with regards to the source of information and expertise) would help ensure that the patient’s autonomy is respected at all times. The patient’s autonomy is valued in and of itself, but also that autonomy is a necessary element for the HCP to do their job and use their expertise to diagnose and treat the patient. This relational approach to power describes a relationship between patient and HCP that would be co-

dependent in nature, but still to some degree autonomous, as it is also a working relationship that needs both parties to be engaged with each other so that their interactions further the goals of both patient and HCP. Relational power is not an artificial balancing of power between patient and HCP, as seen in many of the decision-making models in the literature review, but instead recognises the different instances of power between the two parties, making the power dynamics (and their influence) more transparent.

Introducing this reciprocal concept of relational power in to autonomy theory is also a move away from the criterion-based approach to autonomy discussed earlier. Patient autonomy is more than a set of tick-boxes to be filled in. In place of static criteria the focus is instead on creating environments where autonomy can flourish. Many of the existing criteria for autonomy have been focused on what *cannot* be done to impinge on autonomy. For example, HCPs cannot make decisions for you, they cannot lie to you or willingly withhold information about your treatment, they cannot tell other people what is wrong with you, they cannot internally or externally constrain you, or coerce you in any way towards a decision they want for you. The criteria for autonomy often assume the patient is passive, needing their autonomy to be protected by outside forces (which is a bit paternalistic in itself). Little time is spent on enforcing criteria that actively support the existing autonomy of patients; instead there is a perpetual fear that autonomy can somehow be lost. Theorisation of autonomy would therefore benefit from moving away from the focus on the passive criteria and the moment of decision-making, and be enriched by a move towards building on an over-all atmosphere that facilitates autonomy in the medical context.

The theory of relational power helps to move towards this facilitating environment, by introducing a dynamic, relational approach to the power differentials between HCP and patient.¹⁰⁸ This change in how power and autonomy are conceived of theoretically reflects the findings of empirical work in the area as well. Reciprocity between HCP and patient is seen as the ideal form of interaction between the two parties, in particular for communication between patient and doctor (Street *et al.*, 2007, 586–588). It also reflects the interviewees' call for a reciprocal respect of patient expertise, values and

¹⁰⁸ This may be why the shared decision-making model has become so popular in recent years as it has elements of reciprocity and relationality that patients are looking for. Unfortunately, as argued in the literature review, when operationalised, shared decision-making fails to occur in practice, necessitating further investigation and research into why it is not a successful model.

beliefs from HCPs. Interviewees generally wanted more consideration from their HCP as they felt they gave their HCPs a lot of respect, considered their opinions seriously and yet the HCP did not reciprocate these gestures. With relational power neither party is “in power” all the time. Instead power flows back and forth during the encounter, facilitating the reciprocity that interviewees want in their interactions with HCPs.

8.3.3 *Emotional wellbeing*

Interviewees linked emotional wellbeing and decision-making when describing how they made decisions. They saw emotional wellbeing not only as a psychological need, but also as contingent in part on the fulfilment of their informational needs. Interviewees felt that when they did not have all the information they needed, or an understanding of that information, this impacted them negatively, making them feel confused, frustrated and angry. As a result they often requested more information as a way of promoting their emotional wellbeing. Interviewees felt that there was no way to fully overcome the impact that emotions have on decisions. Nor did they want to ignore the influence of their emotions, as they were using these emotions as indicators of how comfortable they were with the decisions they made.

The value that interviewees placed on emotional wellbeing, and emotional support, is in contrast to how traditional bioethical theories of decision-making view emotions, with most theories ignoring emotions as interfering with the “disinterested objectivity that is taken to be crucial to moral decision making” (Anspach and Beeson, 2001, 112). Sociological accounts have examined the importance of emotions in the medical context (in particular through emotional labour), however in practice the “emotional aspects of health care are sometimes excluded, or rather devalued, in relation to professional–patient interactions [...] This has been recognized to be an important limitation of medical consultations by both academic researchers and lay people” (Nettleton, 2013, 142). My data add to the recognition of this limitation, reinforcing that the relationship between emotions and decision-making is strong.

Empirical evidence of the influence of emotions on decisions is not limited to my own research. Anspach and Beeson’s empirical work on the role of emotions show that “emotions and values are inextricably intertwined” and as such emotions play a valuable

part in decision-making (Anspach and Beeson, 2001, 114).¹⁰⁹ People attach emotions to their decisions so strongly that pride is often felt for decisions considered right or good, while shame and discomfort are associated with decisions considered wrong or bad (Anspach and Beeson, 2001, 115). Interviewees used similar language to discuss the effects of their emotions on decision-making, or the emotions that they felt as a result of their decisions. For example Diane felt that her HCP's strong suggestion not to try for a third child after remission was wrong. She identified this suggestion as wrong as it made her feel angry and frustrated. Her decision to try for another baby felt right for her as it made her feel happy and hopeful, which she felt validated her decision as right. This does not mean that emotions should be considered the sole arbiter of 'right' and 'wrong' decisions. However, to artificially remove emotions from the decision-making process, as many theories of autonomy do, is to remove an integral part of the process. Emotional wellbeing should be acknowledged as part of the decision-making process, and patients should be supported so that the emotions they feel are manageable and they do not feel overwhelmed by them.

A relational approach to autonomy values emotions as well, and recognises the importance of proper support for patients. Theories of autonomy need to consider the effect of emotions that come with illness, prioritising the provision of support for "people in coming to terms with their altered circumstances as part of the protection and respect for autonomy" (Mackenzie and Stoljar, 2000, 231). The link between support and autonomy is so strong in relational accounts of autonomy that the giving of information without support¹¹⁰ is considered to be an action that does *not* facilitate autonomy (Mackenzie and Stoljar, 2000, 231). O'Neill argues similarly, that consent requires correct information that is accessible to patients under stress (O'Neill, 2002, 158), where support is necessary to relieve the stress that patients experience. This suggests that without external support achieving autonomous decision-making may be difficult, thus prioritising support for patients is necessary to facilitate autonomy in the healthcare context. If this is in fact the case, then current concepts of autonomy used in clinical practice require review to assess how support is currently valued in those

¹⁰⁹ While Anspach and Beeson are looking at more "controversial" moral decisions such as the withdrawal of life support, the choice that the participants had to make (or would have made had they known) between immediate treatment, or pursuing fertility preservation is an ethical dilemma: it is a direct conflict between survival and patient values. Again less dramatic than Anspach and Beeson's examples, but still a trade-off between different values for the individual, making a discussion of the ethics of emotions and decision-making valid.

¹¹⁰ Both informational and emotional support.

theories.

8.4 Summary

In this chapter I critically evaluate the empirical and theoretical contributions of my data. My research adds further weight to the concerns in the existing literature about decision-making in practice, while also offering new observations to that field. In laying out how the empirical work for my research confirms and contributes to the existing literature on decision-making, I hope to strengthen the argument for Facilitated Autonomy that I make in the final chapter. The next chapter addresses the limitations of my research, and then builds on the observations, analysis and arguments made here, moving towards a different way of understanding the concept of autonomy, and how autonomy can be used in practice.

Chapter 9

Critical Reflections, New Directions

In this final chapter I examine how my research challenges the existing literature. From these challenges I develop the concept of Facilitated Autonomy and outline its empirical and theoretical origins. I explain how Facilitated Autonomy differs from existing theories of autonomy, and what the concept of Facilitated Autonomy may mean for medical practice in the future. The limitations of the research, and what they mean for the findings presented here, are also discussed. I comment on how my work has addressed concerns about sociology as part of the field of bioethics, using my research as an example of one way to ‘do’ bioethics through sociology. Finally this chapter ends with a discussion of possible avenues for future research into oncofertility and decision-making.

9.1 Challenging the Existing Literature

Current research on how patients make decisions, along with my own research findings here, highlights two important points about theories of decision-making and autonomy. Firstly, existing theories of decision-making (such as shared decision-making) do not accurately reflect how decisions are made in practice. Secondly, bioethical theories of autonomy may not be comprehensive enough to allow for the multiple phenomena that influence patients when making decisions in practice. Empirical findings are at odds with theoretical accounts of how decisions are made. This is problematic as theories of autonomy and decision-making are theories about behaviour that (currently) fail to accurately describe that same behaviour in practice. This is not just the accepted difference that can occur between an ideal type and reality, but a misunderstanding of how to translate practice into theory, and vice versa. As a result two important issues (one descriptive, one prescriptive) remain about patients making decisions: how do patients make decisions in the medical context? And how should patients make decisions in the medical context? I argue that these two questions are connected: how patients make decisions should inform the theories of autonomy that prescribe how these decisions should be enabled and facilitated in practice.

Much of the literature on autonomy and agency focuses on what the requirements/criteria are for autonomous decisions, implying that those decisions that do not meet the criteria are not autonomous (see chapter 3). In contrast, the focus for interviewees was not on “autonomy” or “autonomous decision-making”, as is often portrayed in bioethical literature. Interviewees did not express any feelings that they were “lacking” autonomy or were non-autonomous, indicating that they did not use the terminology associated with theories of autonomy, nor did they identify with the concept of non-autonomy. While they did not use the terminology, the interviewees did describe trying to gather what they felt was necessary to facilitate their decisions so that they felt comfortable with the choices that they made.¹¹¹

This is not to say that there are no points of commonality between empirical observations of decision-making in practice and decision-making as described in theory. A connection between the empirically identified needs of the patients when making decisions, and the requirements that are (very generally) ascribed to autonomous decision-making in theories of autonomy can be seen when examining those criteria with reference to the data.

When the concept of autonomous decision-making is broken down to its very basic components it requires informed understanding, voluntariness and authenticity. Traditional theories specify a further four main criteria: sufficient information, sufficient understanding, and freedom from internal and external constraints (see Beauchamp and Childress, 2009, chapter 4). When considering the above criteria against the experiences of the interviewees, many of the criteria were not met, suggesting that according to these criteria the interviewees may not have made autonomous decisions. For example, interviewees wanted more support when being given information about their disease and treatment, as they experienced a lack of sufficient information. They also wanted more support that facilitated their understanding of that information, because there was a lack of sufficient understanding. They needed emotional support to help them make decisions, so that they could use that information to the best of their abilities, which could be very broadly construed as wanting freedom from internal constraints. Finally they needed to feel supported in their decision to take time (if they required more) to make difficult decisions, which I broadly

¹¹¹ I will continue to use the same definition of “comfortable decisions” that is used in chapter 6: where comfortable decisions are those decisions that the patients feels are “right” for themselves.

interpret as wanting freedom from external constraints.

All of these failures to meet specific criteria might make a bioethicist question the autonomous nature of the decision, and yet somehow interviewees were not concerned in the same way. Not meeting the theoretical criteria for autonomy does not seem to stop patients feeling that the decisions they have made are autonomous. So are these patients autonomous or are they not? Is this a subset of patients unaware of their own incapacity to make decisions in the medical encounter? It seems unlikely that is the case,¹¹² and much more likely that the criteria for autonomy may be focusing on the wrong things when trying to capture what autonomy is in practice. I would like to suggest that there are two phenomena occurring: The first is a failure to satisfy conventional theoretical criteria in practice, and the second is the failure of conventional theoretical criteria to capture 'real' autonomy. I would like to examine both in turn.

While the theoretical criteria for autonomous decision-making have been put in place to both protect the patient and establish competency, they are difficult to relate to concrete situations. I am less interested in whether the interviewees of this study 'fulfilled' these criteria, and more interested in the similarities that their voiced concerns have with these criteria, which are so strongly associated with autonomy in medicine. In theory these criteria are not only recognisable, but easily achievable and enforceable as well. In practice interviewees described instances of what I interpret as having difficulty finding space to exercise their autonomy, in particular finding an environment where they felt supported and their decisions mattered. The interviewees were more than capable of making an autonomous decision; it was the narrowness of the current concepts of autonomy which made it difficult to recognise these decisions as autonomous.

This failure to satisfy conventional criteria is due in part to those same criteria not reflecting the reality of decision-making in practice. Despite the emphasis on it in textbooks, informed consent laws, and clinical practice, there is evidence from this study to suggest that patient autonomy is still not being respected or considered sufficiently in the medical context. I would like to suggest that existing criteria for autonomous decision-making are focusing on the wrong aspects of autonomy by scrutinising the individual decision, but not the environment within which the decision is made. Instead theories of autonomy should focus more on the criteria for creating an

¹¹² Though it cannot be ruled out for certain.

environment that supports autonomous decision-making. The criteria should not be about determining whether the decision is autonomous, but whether the environment is supportive and facilitates autonomous decision-making. Refocusing in this way assumes the patient is autonomous,¹¹³ and looks to the environment in which the decision is being made to support this existing autonomy. Current theories look only to see if the decision fails the ‘autonomy test’ by not meeting the criteria. Patients do not understand decision-making as a set of criteria to be met in the way that autonomy theory seems to demand.¹¹⁴ None of the interviewees wanted a set of tick boxes to check that their decisions were autonomous; they wanted an environment that facilitated their decision-making by addressing their outlined concerns. Changes in the practice and theory need to be such that they reflect the needs of patients in this regard, and not abstract criteria.

Building this supportive environment means conceiving of autonomy in such a way that there are not just proscriptions on action, but necessary prescriptions as well. This means not only focusing on the things that HCPs cannot do, but also on the things that they *have* to do to help create an environment where autonomous decision-making can occur. For example the identified need for support means that the HCP should provide accessible emotional support, and build a relationship with the patient as a necessary requirement of autonomy. However, the patient must be involved in creating this environment, and they should ensure that the elements they need to facilitate their autonomy are present by actively seeking them out to the best of their abilities. Patients can no longer be seen as passive receivers of autonomy ‘protection’. Autonomy is active, dynamic and *reciprocal*, and as such both parties have to get involved and be active in the facilitation of autonomy in the medical context.

9.2 Facilitated Autonomy

Much of the wider literature on autonomy and decision-making focuses on capturing how people make decisions. In bioethics there are several competing theories (I have focused on two: traditional and relational autonomy) describing autonomy and autonomous decision-making. The social sciences are no different, offering a number of possible theories, from medical sociology in particular, with shared decision-making the

¹¹³ Within reason. Patients that are unconscious, incapacitated or incompetent will always be a point of concern for theories of autonomy.

¹¹⁴ Nor do sociological accounts of agency.

current belle of the ball. The common aspect between all of these concepts is that when studied empirically none of them appear to occur in their entirety in practice. These theories also share a point of concern, the artificial assignment of ‘permitted’ decisions. However, as I argue in chapter 3, patients do not make decisions based on decision-making theories any more than people in general live their lives within philosophical categories, making it difficult to reconcile theory and practice.

Given the plethora of empirical evidence to indicate that these theories inadequately describe decision-making in practice, it may be time to step back and consider a different way of understanding autonomy in the medical context. This different understanding starts with a move away from the focus on single moments of decision-making. As Donnelly *et al.* have argued, “decision-making is not independent from social values and cultural context” (2013, 1010). As a result there are several factors that affect decision-making, and it has become clear that decision-making is dynamic and occurs over time, all the time. My research, and that of others, has shown that patients view decision-making as a process, and while they may communicate decisions to their HCPs one at a time, they are considering multiple decisions at once. Criteria that capture and govern single instances of decision-making are ignoring how patients actually make decisions. Instead the focus should be on building and supporting an overall environment that facilitates autonomy in whatever form the patient feels necessary (for example, Being Guided).

One of the key ways to consider how the environment can facilitate autonomy is to reflect on those aspects that patients have identified as important, as well as those areas they¹¹⁵ have found held them back from decision-making: namely the HCP–patient relationship, the unacknowledged long-term framework within which decisions are made, and the recognition of the patient as an expert in themselves. Because of this I would like to propose an alternative conception of autonomy that builds on the foundations of relational autonomy, as well as the empirical work of my research: that of Facilitated Autonomy. Facilitated Autonomy, as a concept, emphasises the importance that patient–HCP relationships have in facilitating autonomous decision-making, the role that same relationship plays in the medical encounter, and the important role of relationality and reciprocity in building and dynamically supporting an

¹¹⁵ The patients referred to here are both my interviewees and the participants of the many empirical studies reviewed in chapter 2.

environment in which patient autonomy is supported. This is a move away from the traditional focus on the moment of decision-making and towards a more inclusive approach to autonomy. Autonomy and autonomous decision-making are consistently supported because the environment within which autonomous decision-making occurs facilitates this support.

This move is well within the keeping of the relational autonomy spirit, which argues that “by focusing only on the moment of medical decision making, traditional views fail to examine how specific decisions are embedded within a complex set of relations and policies that constrain (or, ideally, promote) an individual’s ability to exercise autonomy with respect to any particular choice” (Sherwin, 1998, 32). Sherwin is mostly arguing about the negative effects of these relations and policies. However I believe the point Sherwin makes can also be understood to mean “that autonomy is not necessarily best protected by evaluating particular decisions, but rather by shaping whole institutional practices such that they give rise to autonomous decisions and decision-makers” (Paton, 2010, 52). Until now relational autonomy has focused on how these relations and policies restrain autonomy, but I’d like to change the conversation by introducing the notion of Facilitated Autonomy and focus on what I believe Sherwin views as the goal: the promotion of autonomy through these same forces.

This focus is driven not only by the possibility of it in theory, but by my empirical research as well. The interviewees in this study did not identify with the terms “autonomous” or “non-autonomous”, nor did they describe moments when they lost their autonomy. Instead many asserted that they knew they could make (what I interpret as) autonomous decisions, but they felt that what was lacking was an environment where they felt empowered to make those decisions. This implies that requiring changes to the environment, so that it facilitates and supports autonomous decisions may be the more appropriate focus of theories of autonomy, and the practices these theories inform. Focusing on how the environment facilitates autonomy also widens the scope of responsibility for supporting and respecting autonomy beyond the individual making the decision, encompassing the medical encounter as well as the practices and people within that encounter.

9.2.1 *What is Facilitated Autonomy?*

Facilitated Autonomy is based in part on the concept of reciprocity. My argument for the need for reciprocity is empirically derived, but also builds on elements from classic sociology (for example Parsons' sick role and Giddens' relational power) and contemporary sociology (for example Street *et al.*'s communicative reciprocity). Reciprocity has previously been considered an important aspect of the medical encounter: Parsons views the relationship between doctor and patient as reciprocal, describing a reciprocal, yet unequal, relationship of power between patient and HCP in order to achieve these social roles (1951, chapter 10). In contrast, Facilitated Autonomy views power as reciprocal because it is also relational (as described by Giddens), and so flows back and forth between patient and HCP, with neither party ever needing to hold power over the other in the way that Parsons suggests. Relational power relies on "communicative reciprocity" (to borrow a term from Street *et al.*, 2007) between patient and HCP, which facilitates information exchange and discussion between both parties and builds the supportive environment necessary for Facilitated Autonomy.

The focus on reciprocity is also a reflection of the importance given to the HCP–patient relationship in the medical encounter. The HCP–patient relationship is at the heart of Facilitated Autonomy and is crucial to facilitating its key requirements: informed understanding and patient support. Both requirements are connected: informed understanding occurs through reciprocal communication, made possible through a fostered relationship between patient and HCP that facilitates discussion and signposts support (emotional, informational etc.) for the patient. Sustaining these key requirements builds an environment that recognises the patient's expertise in their own values/beliefs, and respects their need for self-determination. In addition, different understandings of autonomy/decision-making are accommodated as an extension of the patient's autonomous choice, avoiding the concerns from previous theories that decisions made outside set criteria are not autonomous.

The reciprocity in Facilitated Autonomy also sets it apart from previous theories of autonomy by adding a requirement not normally seen in these theories, a role I call the "active patient". Reciprocity requires all parties to bring something to the table, and thus the patient cannot be a passive receiver of autonomy "protection" (as implied by traditional theories). Ideally the patient should actively engage in building and

supporting the facilitating environment within which they make autonomous decisions. Patients are one part of a multi-part relationship with at least one HCP, and as that one part they cannot expect the HCP to do and know everything. The patient must also be engaged, asking questions and voicing their opinions and concerns. The idea of an “active” patient is one shared by contemporary sociological accounts of decision-making. Facilitated Autonomy is a reflection of the growing trend of patient-centred care where “patients are not simply passive recipients of care; they are also active participants in the process of health care work” (Nettleton, 2013, 135).¹¹⁶

Facilitated Autonomy draws further on sociological theory as it is heavily influenced by Giddens’ agency: specifically the acknowledgement of the institutional influence on agency, and relational power. As I have previously argued, relational autonomy also focuses on those negative instances of power. However, by taking a Giddensian approach to power, which relational autonomy generally does not, it is possible to conceive of power as relational, moving back and forth between HCP and patient, depending on who requires knowledge from the other. Valuing this conception of power removes the role of sole expert from the HCP and shares it between patient and HCP. Doing this prioritises what the patient needs to make a decision as the needs of an expert, forcing the acknowledgment of these needs within the medical encounter.

Facilitated Autonomy draws not just on sociology, but maintains its link with bioethics through relational autonomy, which values emotional support and patient expertise, and recognises the influence of power dynamics in its understanding of what constitutes an “autonomous decision”. Patients are not required to tick a set of static criteria in order to achieve autonomous decision-making. Instead, ideally, they should be making decisions in an environment where autonomous decision-making is only difficult because the choice itself is difficult.

In response to the concerns raised in the data, the environment promoted by Facilitated Autonomy is also more reflexive of the constraints imposed by the nature of medical protocol, where often all possible options are not available to patients as there is only

¹¹⁶ In practice the active patient still remains more an idea than the norm. Despite the increased role that patients have taken in the last 35 years, Strong’s 1979 assessment may still rings true: active patients who challenge the doctor’s authority can be viewed as challenging the ritual of the encounter and threatening the entire “social occasion” (Nettleton, 2013, 141). This may be why the idea of the active patient has been harder to achieve in practice, despite the increased presence of the concept of the active patient in contemporary theory.

one medical protocol suitable for treatment. Theories of autonomy that focus only on the moment of decision-making would view this restriction of choice as paternalistic. Instead, by valuing Facilitated Autonomy in the medical context, the decisions that patients make throughout their diagnosis, treatment and aftercare are considered in a continuum approach, prioritising the patient's long-term framework so that self-determination is understood as more than just individual and distinct decisions.

Finally, the concept of Facilitated Autonomy views an entirely autonomous decision as an ideal type: if there were no constraints or difficult decisions to be made, then there would be no reason to try and safeguard autonomy. Facilitated Autonomy acknowledges the challenges that are often faced when making a decision, and respect and consideration for the context within which people make decisions is considered necessary for autonomous decision-making. In addition, the concept of Facilitated Autonomy considers people as self-determining within a long-term framework. The decisions that they make are done with reference to their own biography and their own life goals. This self-determination is the backdrop against which patients make more specific decisions, and not all of those decisions present themselves as stand-alone, unrelated decisions.

To understand why consideration for the context and long-term framework are important to autonomy I will use an example from the interviews: Angela was “watching” her ovaries as she knew that she was at high risk for ovarian cancer. While she could have avoided the “watching” by having her ovaries removed altogether, she did not want to go into early menopause until absolutely necessary. Her life goals included not getting ovarian cancer, but also not being in early menopause. She had effectively already decided that she was going to remove her ovaries. That decision had been made when she established a goal not to die from ovarian cancer (which was part of her long-term framework). She was waiting for the appropriate time to finally “pull the trigger” on the removal of the ovaries, which was a decision made against the overall backdrop of her desire not to die of cancer, but also to remain fertile for as long as possible (the context). It may appear to be a series of singular decisions, but in fact the original choice to “watch” her ovaries led to a series of related decisions further in her future, and was made with the idea of keeping her options in the future open as well.

By valuing an overall atmosphere of reciprocity, support, and self-determination, Facilitated Autonomy recognises all the decisions that patients make as autonomous and valuable: not just those made when signing consent forms, or those that fall within a prescribed set of criteria. This means that if at some point (even for just a short time) the patient decides that they believe what is best is to follow what the HCP says (e.g. Being Guided), because this facilitates their self-determined life goals (as it did with Heather, for example), then this decision is still a valid and autonomous decision. The patient has *decided* to follow the advice of the HCP with whom they (hopefully) have a supportive, nurturing and trusting relationship that facilitates autonomy. By promoting an overall environment where autonomy is respected and supported, the patient's long-term framework in which they make decisions is also respected and supported. The patient is not forced to justify their choices through a set of linear decisions, but is free to make decisions with an eye to their future and their future options. Furthermore, decisions restricted due to medical protocol are no longer viewed as paternalistic, as they would be by more traditional theories of autonomy, but are contextualised within the patient's long-term framework.

9.2.2 *Facilitated Autonomy in Practice*

For Facilitated Autonomy to work in the medical context, a number of changes to current practice may be necessary. HCPs and patients need to take a different approach to fostering relationships with each other. In particular HCPs may need to make it more obvious that they welcome discussion from their patients to help them do their jobs, thus making it clearer to patients that communication is valued. To accomplish this requires a shift in the belief that the HCP is the sole expert, and better recognition (from patients and HCPs) of the value and importance of the patient's expertise in themselves. More time should be spent on offering and making the patient aware of support available through the medical community, in this case the NHS. There are several services, support groups etc. available, however support is currently undervalued, and access to support is often unclear. Finally there needs to be wider recognition of the long-term framework within which decisions are made, so that the choices offered are discussed with reference to both the short-term and long-term goals of the patient. This is particularly important for the field of oncofertility where the patient's decision to preserve their fertility is often a decision they make in order to preserve their choices in

the future, when they are able/ready to make decisions about reproduction.

All of these recommendations require changes to individual practice (of both HCPs and patients), but also institutional changes to how HCPs and patients are viewed, and how time and support are currently undervalued in the medical context. The switch from “relationship” to “encounter” that Potter and McKinlay (2005, 476) argue has occurred is due in large part to the increase of one-off/drop-in style interactions that increasingly characterise medical encounters in the 21st century (Nettleton, 2013, 124). This switch discourages the kind of reciprocal relationship between patient and HCP that is necessary to facilitate autonomy. It is within these institutional changes that Facilitated Autonomy must be operationalised. At this time it is not appropriate to provide detailed recommendations of how to make these changes within the NHS, as the research for this project has focused on the experience of a small group of patients.¹¹⁷ Further work is needed to investigate how HCPs experience patient decision-making, which may shed light on those specific areas of practice that need to be changed.

9.2.3 *Facilitated Autonomy in the Wider Context*

Facilitated Autonomy not only captures how patients make decisions “on the ground” so to speak, but it also embodies the version of bioethics that I have presented in the theoretical framework: one where sociology is a constitutive, contributing member of the theoretical fields that make up interdisciplinary bioethics. The concept of Facilitated Autonomy draws from sociological accounts of agency, decision-making, power dynamics, and the medical encounter, but also on bioethical theory, specifically traditional and relational autonomy. The use of these sociological theories is not novel, in fact they have always been applied to examining questions of agency and decision-making, they have just been previously neglected in bioethical inquiry of these same phenomena.

The theory of Facilitated Autonomy also addresses the current criticism of bioethics that it neglects the social and uses the empirical only as a handmaiden to prove already existing theories. In this thesis, Facilitated Autonomy has been developed by looking to the empirical to help inform and reshape existing theories about autonomy so that these

¹¹⁷ Nor was it the goal of this research to provide this type of policy recommendation.

theories better reflect how decision-making is experienced and carried out in practice. By incorporating both empirical work, as well as social and philosophical theory, I hope to have mapped out one route for how sociology can further contribute to the field of bioethics with both qualitative research and useful theory.

9.3 Critical Reflections on My Research

In this section I critically reflect on the research process and findings. I will start by addressing what I perceive to be possible limitations to my research. I will then reflect on the research findings, while also commenting on how those findings help to address my original research questions (outlined in section 3.7).

Before I begin I would like to address how I am evaluating my research, and also what I mean by ‘evaluating’ it. There is extensive debate in the social sciences about how to evaluate qualitative research (see Lincoln and Guba, 1985; Whitemore *et al.*, 2001; Mason, 2002; Morse *et al.*, 2002; Silverman, 2010), and I will not be engaging with that debate here. Instead I will follow Mason’s approach to assessing qualitative research, which focuses on the researcher providing a transparent account of the research process, in particular the data collection and analysis (Mason, 2002, 188). For Mason the validity of qualitative research is a judgement about “whether [the researcher is] ‘measuring’, or explaining, what [they] claim to be measuring or explaining” (Mason, 2002, 188). Instead of fixed criteria, qualitative research is evaluated on its conceptual and ontological clarity, and how successful that clarity is for helping the reader understand the “meaningful and relevant epistemology” of the research (Mason, 2002, 188). I have already explained in detail the processes of data collection and analysis in chapters 4 and 5. In this section I will focus on evaluating the process and findings, reflecting on how effective the methods laid out in chapter 4 were in illuminating my identified area of interest, and answering the research questions of my project.

9.3.1 Research Limitations

First, I discuss some of the possible limitations of my research, namely the small number of interviews, the failure to recruit HCPs to the study, and the fact that the

empirical data I collected suggested that two of my research questions were less relevant, or less prominent, than I had originally thought they would be. I will start by discussing the small number of interviews.

Originally I had planned to interview approximately 20 breast cancer patients and 20 HCPs. Due to initial problems with recruitment (see chapter 4) I had to devise alternative recruitment techniques which presented barriers to making contact with eligible participants. As a result only eleven patients expressed interest in participating, and all eleven were interviewed. The changes to the recruitment process used also meant that the demographic profiles of the interviewees differed from the originally intended profiles. Interviewees were for the most part in their late 30s to late 40s and many of them already had children. It is entirely possible that younger, childless patients would have different priorities to the women I interviewed, but this is a question I cannot answer without further research. The participants interviewed were comprised of a mix of women with different cancer diagnoses, and included those who were still cancer patients and those who considered themselves to be post-cancer. The women mostly came from the Southeast and Northeast of England, and interviewees from other parts of England were not actively pursued. My study was an exploratory one that focused in part on establishing primary knowledge, so I am not as concerned with achieving “representativeness” of the sample, as not enough is known about the current population of premenopausal female oncofertility patients in the UK to know what is and is not representative of that group.

Despite the interviewee sample being smaller and less homogeneous than originally planned, the analysis still provided rich and previously unknown insights. Flyvberg (2004) and Silverman (2010) have both argued for the value that “even a single case” can contribute to qualitative research (see also Flyvberg, 2004, 421; Silverman, 2010, 270). Qualitative research seeks to provide “depth over breadth”, again emphasising the importance of sample size to the quality of the research (Whittemore *et al.*, 2001, 524). While my sample was small, it did provide ‘sampling sufficiency’, a term Morse *et al.* use to describe research samples that consist of “participants who best represent or have knowledge of the research topic” (Morse *et al.*, 2002, 18), which they argue is an important feature for establishing the quality of qualitative research (Morse *et al.*, 2002, 18-19). In addition, the focus of this study was not on achieving a high recruitment rate, but on striving to come as close to thematic saturation as possible, while acknowledging

that, realistically, the time and resource constraints of a PhD meant that it was unlikely the study would reach thematic saturation regardless of sample size (see chapter 4, section 4.2.2).

Furthermore, several of the findings from this research were very similar to current research (though not on the same topic as this thesis) in the literature, allowing me to contribute to the wider field by confirming/reinforcing those findings with my own research. The alternative recruitment strategy allowed me access to a wider range of patients that offered rich and interesting data. It has also highlighted areas not seen in the literature that require future study, such as the experiences of older fertile women. This gap may not have been obvious had I only used the narrower recruitment criteria originally devised for the project. In these ways my research on patient experience has allowed me to move from the data (what Morse *et al.* call the micro), to a better theoretical understanding (what Morse *et al.* call the macro) (2002, 18–19).

Another limitation to this research is that it only examines the experiences of patients. Because of this at times I have had to speculate on how HCPs might handle the same encounters as the interviewees. As the concept of Facilitated Autonomy is strongly premised on the HCP–patient relationship, it will be central to the further development of Facilitated Autonomy to know more about how HCPs experience this relationship. Observations of HCP–patient interactions while information is communicated, and decisions are being made, would also offer insight into how that relationship influences the practices of both patients and HCPs.

However, whilst HCP interviews would have added to my analysis, their absence meant that I was able to focus more clearly on the patient experience. The richness of the interviews from the patients, suggests that, had an equivalent amount of data been collected from the HCPs, it would have been necessary to treat important findings very superficially, or even leave them out, in order to accommodate the volume of data in the restricted space of the thesis. By focusing only on the patient interviews I have been able to conduct a thorough analysis of the data that can contribute meaningful findings to the field. This understanding of the patient experience, when added to future research on the HCP experience, and to clinical observations of the HCP–patient relationship in practice, should help shed further light on decision-making in the medical context.

The final limitation I would like to discuss is the finding that two of the research questions were not as relevant as I had originally expected. The two questions were:

- 2) How are these experiences shaped by other biographical elements?
- 5) Do female cancer patients feel differently about the potential effects of treatment on their fertility at different stages of their treatment?

I will start by addressing question two. During this research I was not able to take as broad a view of the interviewees' wider biographical circumstances (except to the extent that they invoked these in their interviews) due to the limitations on the number, types and locations of interviews conducted. It is possible that interviews from a wider range of patients at the same clinic, or an in-depth ethnography of a cancer patient self-help group (such as the one I recruited interviewees from), might have allowed me to comment on the influence of biographical circumstances on patient decision-making. However, as I already discussed, practical circumstances inhibited that wider recruitment.

The fifth research question was intended to reflect awareness that decision-making is not a one-off event. Different aspects of treatment might change patients' views about fertility over time, which may change patients' opinions about the decisions they make. However, the interviewees were reporting their experiences retrospectively, and often their current feelings about fertility were at the forefront of their interview. In addition, interviewees did not discuss how they felt about their fertility at *different stages of their treatment*, but instead they discussed how they felt about their fertility *before, during and after cancer*. For this reason it is quite difficult to reflect on how cancer patients feel about their fertility at different stages of their treatment, as that is not how my interviewees understood their experience. It may be that patients do feel differently about fertility after surgery but before chemotherapy (for example), and that interviews done with patients at different stages of treatment may reveal different and changing attitudes towards fertility throughout diagnosis, treatment and aftercare. In some ways it is a measure of the success of the interviews that interviewees' comments changed my perception as a researcher about what is relevant to understanding their world view.

9.3.2 Critical Reflections on the Findings

Several research questions drove this research (see section 3.7) and here I revisit and reflect on them by addressing how the research has helped to better understand the oncofertility patient experience; the healthcare professional's role in oncofertility (and the medical encounter as seen in practice); the role of autonomy in medicine; and the role of Facilitated Autonomy.

– *The oncofertility patient experience* –

In responding to the first research question of this thesis I found that oncofertility patients' experiences of decision-making are strongly influenced by their encounters with their HCPs. One important finding of my research is that power differentials and dynamics continue to play a significant role in the patient experience. Despite efforts to move towards patient-centred care, patients are still influenced by the power differentials/dynamics between the HCP and patient (Annandale, 1998, 274; McMullen, 2012, 243). These power differentials are problematic as different conceptualisations of autonomy perceive different problems caused by power differentials for the exercise of autonomy, and there are similar concerns for notions of informed consent and understanding. Power differentials impact on the quality of the relationship between the HCP and patient, and consequently the quality of communication between the two parties. Poor communication is a problem as patients (in this study and others, see chapter 2) are very clear about the importance and value they place on having an informed understanding of their disease, treatments and prognosis. The primary way that patients identify achieving this informed understanding is through communication with their HCPs (Kim *et al.*, 2013, 99). Due to persistent norms of power and behaviour in medicine, many patients feel it is difficult to initiate and maintain the quality and style of communication they feel is necessary for informed understanding to happen.

Informed understanding also continues to be a necessary component of many prominent concepts of autonomy, and is a cornerstone and goal of Facilitated Autonomy. Examining the experiences of oncofertility patients making decisions highlights how informed understanding is still a priority for patients, even though they find it difficult to achieve in practice. Further work needs to be done to examine whether informed understanding is genuinely valued in the medical context, or if it is merely part of the rhetoric around informed consent.

Consideration of how informed understanding is achieved is also vital. Power, relationships, context, support and communication all contribute to helping (or hindering) the patient in achieving informed understanding. Patients' experiences of illness and medicine are contextual and unique to them, and influence how they make decisions. Interviewees in this study made it clear that a one-size-fits-all approach that ignores the patient's context is not an effective or successful way to transfer health information to patients¹¹⁸ and, I argue, risks impeding autonomous decision-making. By requiring more emphasis be placed on the consideration of the patient's context, as well as the building and promotion of relationships and support, the concept of Facilitated Autonomy takes into account the influence of phenomena like power differentials and institutional structures, procedures and environments on decisions. Facilitated Autonomy provides a new perspective that better captures these important aspects of autonomous decision-making, turning away from the traditional focus on using universalizable/generalizable criteria to test for "autonomous" decisions. Facilitated Autonomy is premised on the recognition of the importance of context and the unique needs of the patient when making decisions. This refocusing may allow concepts of autonomy to better reflect how patients currently experience making decisions in the medical encounter.

– The role of the HCP in oncofertility and the medical encounter –

In addressing the fourth research question it became clear that the medical encounter does have an influential role in patient decisions about cancer treatment and fertility preservation. Despite the move towards patient-centred care, the interviews show that the power of the HCP in the medical encounter is still very present. As a result the influence of the HCP on patients is something that may require further consideration and scrutiny. It may also be necessary to make clear to HCPs the influence that they have on patients so that HCPs pay closer attention to this influence in their practice. By encouraging patients to engage in discussion and ask questions through reciprocal communication (as promoted in Facilitated Autonomy), HCPs could help compensate for the influence of these power differentials by making it even more obvious to the patient that the decision power is in the patients' hands.

¹¹⁸ Thus addressing research question three and six: "What is important to patients when they are making decisions?" and "With regards to oncofertility services, what are the needs of adult female cancer patients in the UK?"

One way that this reciprocity may be achieved is through reframing autonomy and the associated processes of informed consent and decision-making through the lens of Facilitated Autonomy. No theory of autonomy is currently ‘fully’ incorporated within medicine as such; instead particular theories underpin a concept of moral agency that has been incorporated into specific, practical notions and processes of consent and decision-making. Adopting Facilitated Autonomy in medicine in an analogous way would mean modifying the theories that currently underpin consent and decision-making in medicine. In practice, doing this would require fostering a supportive and facilitative environment that promotes strong HCP–patient relationships, where relational power flows between the two parties, and both are considered with respect by the other. However, whether these theories and practices can be changed, and what that means for future clinical practice remain unanswered questions. Changes in the 21st century to how Western medicine is practised (Potter and McKinlay, 2005) are making it more difficult to foster the relationships that patients, at least in my study, want with their HCPs: time restraints, care rationing and, in the UK, NHS funding restrictions in particular may be altering how patients and HCPs interact and build relationships.

– *The role of autonomy in medicine* –

Throughout this thesis I have argued against the use of traditional concepts of autonomy in medicine. This is not to say that all the components of the traditional concepts of autonomy (namely information, understanding, individuality and freedom from constraints) are wrong, but rather the understanding of how those components are valued in practice may be misunderstood by traditional accounts. For example, constraint takes on a different meaning from that in traditional accounts when understood alongside the persistent norms of power that continue to be present in the medical encounter. Patients are aware of these norms and many interviewees described their experience of making decisions within the constraints they produce. Traditional accounts would consider these decisions constrained by external forces and thus invalid. However, decisions continue to be made in what traditional concepts would consider difficult, if not impossible conditions within which to exercise one’s autonomy. What is clear from this, albeit limited, research is that these patients have a different understanding of how they want to make decisions (that is, exercise their autonomy) than is found within the traditional concepts of autonomy that seem to dominate current policy and practice in medicine.

Theory and practice need not be at odds in this way. As I suggest above, by adopting Facilitated Autonomy in a similar way to those theories that currently inform medical practice, it may be possible to bring a central pillar of bioethical theory closer in line with patient needs. Facilitated Autonomy opens up the concept of autonomy so that it is likely to better reflect the needs of patients when they are making a decision. It addresses important concerns about how patients make decisions within the *current* experience of the medical encounter, and the importance of communication, reciprocity and relationships to decision-making within this encounter. It also recognises that how medicine is practised has considerable influence on these decisions. Theoretical understandings of autonomy, but also clinical practice, may have to change to better facilitate patient decisions in the medical encounter.

The concept of Facilitated Autonomy now needs to be developed and evaluated to ascertain its versatility outside of oncofertility, as well as its scope to change practice in medicine. Facilitated Autonomy is an attempt to better reflect the changes in medical practice (as well as social changes such as patient rights) that have occurred since the original theories of autonomy in medicine were first developed. When developed further Facilitated Autonomy may prove to better reflect the contemporary medical encounter and the needs of the contemporary patient. This is not to say that Facilitated Autonomy will be the *best* theory for all medical situations: that also remains to be further researched and evaluated. However, I argue that the relevance of Facilitated Autonomy may be further strengthened by adding empirical and ethical insights from other fields of medicine, where research (modelled on my own research design) can bring to light how decisions are made and how autonomy theory is used in different areas of medical practice.

9.4 The Future Research Agenda

One of the most interesting findings was what “fertility preservation” meant to the women interviewed. For the interviewees, oncofertility, and in particular fertility preservation techniques, was not just about having babies. The women in this study understood “fertility” to go beyond childbearing; preserving fertility was about choice preservation for the future, but also not going into menopause. Both goals were very important to the women, more so than preserving their fertility just so that they could

have their own children. Research on oncofertility that only focuses on patients who wish to preserve fertility for childbearing reasons might therefore overlook an oncofertility patient-base who may not want to have children, but do want to preserve their fertility: in particular women who are pre-menopausal but considered too old to have a viable pregnancy. More research needs to be done on how older pre-menopausal women experience cancer and fertility decisions, as well as how fertility is understood and valued by women who do not want to have children.

One of the reasons why the above is important to consider for future research is that more needs to be known about why and how HCPs decide to discuss fertility preservation with patients. As seen in the literature review, HCPs do not discuss fertility preservation with all oncology patients. This decision is based on reasons that the HCPs determine themselves. There are few set guidelines as to who should receive fertility preservation information; NICE 2013 guidelines only state that the effect of cancer treatment on fertility should be discussed with the patient, and there would appear to be no national monitoring to ensure that these guidelines are followed.

Future research could also examine HCPs' experiences of communication and discussion of oncofertility decisions with patients, and how HCPs experience the HCP–patient relationship, including how they value that relationship. Clinical observations of discussion about treatment decisions between oncofertility patients and HCPs may also help to open up the black-box around how these decisions are made within the medical encounter. Given the importance that the HCP–patient relationship has to patients, it is equally important to examine the other side of that relationship.

The future research agenda suggested here is best served by examining the above outlined questions through the sociological bioethics that I have advocated for in this thesis. The future research agenda is not just about exploring the experiences of different groups (i.e. healthcare professionals and/or older women who are still fertile) but also about examining whether those experiences reveal bioethical concerns about autonomy in practice. Exploring these bioethical concerns using sociology offers sociological theory, methods and methodology with which to interrogate the subject and data, which, in turn, can contribute to those bioethical theories that currently influence clinical practice.

This thesis has focused on bioethical understandings of decision-making, while recognising the role of sociology in bioethics. Taking a sociological approach to bioethical inquiry may also offer fresh insight into the efficacy and relevance of other bioethical concepts that influence medical practice, such as justice and healthcare rationing. Bioethics incorporates a number of disciplines, but sociology has been by far the least recognised. Exploring the future research agenda through a sociological approach to bioethics would also serve to reinforce sociology's position within the quartet of disciplines that constitute the field of bioethics.

Appendices

Appendix A: Biographies of the Interviewees

Cancer Patient Interviewees

Kathleen:

Kathleen is from the North East. She is 54, divorced with two children. She was diagnosed with aggressive vulval cancer when she was pregnant with her second child and advised to terminate her pregnancy so that her surgeon could perform a radical vulvectomy to remove the cancer. She and her husband initially agreed, but were later given a second opinion and found that Kathleen could keep her pregnancy and have the radical vulvectomy performed. After her surgery was performed Kathleen's doctor was found to be doing inappropriate surgeries on patients, as well as doing his own pathology work, for which he was not trained. Kathleen was not told about fertility preservation during her time as a patient. Kathleen is cancer free.

Stephanie:

Stephanie is from the North East. She is 23 years old, single with no children. Stephanie was diagnosed with brain cancer when she was turning 18, and so she started her treatment on the paediatric ward, and remained a patient on that ward until she completed all her treatment. She had radiotherapy and chemotherapy to treat her tumour and has had one relapse since that treatment. Stephanie suffers from memory loss due to the aggressive treatments she underwent, so she asked that I also interview her mother so that nothing was left out. Her mother is Brenda. Stephanie was told about fertility preservation but chose not to pursue any fertility preservation techniques while a patient. She is in remission.

Robyn:

Robyn is from the Midlands. She is 50 years old, married with two children. She was diagnosed with breast cancer when she was 46 years old. She was treated with a mastectomy, and drugs to stop her production of oestrogen. She has since had a breast

reconstruction. Robyn was not told about fertility preservation during her time as a patient, and she is now in early menopause. She is now cancer free.

Amy:

Amy is from the South East. She is 33 years old, single with no children. Amy was diagnosed with aggressive breast cancer when she was 32 years old. She was treated with chemotherapy and a mastectomy. Amy was offered fertility preservation, but chose not to pursue it. She is currently in remission and believes she is still fertile as her periods have returned post-treatment.

Mary:

Mary is from the Midlands. She is 52 years old, married with no children. Mary was diagnosed with breast cancer when she was 46 years old. Mary was treated with chemotherapy, a mastectomy and then radiotherapy. She was not offered fertility preservation. Mary did not want to have children. She is now cancer free.

Angela:

Angela is from the South East. She is 48 years old, married with two children. Angela was diagnosed with breast cancer when she was 44 years old. Angela was treated with chemotherapy and a mastectomy. She also has a family history of ovarian cancer and chose to have her ovaries removed in 2012. She was not offered fertility preservation. She is now cancer free.

Diane:

Diane is from the South East. She is 46 years old, divorced, but living with a long-term partner and has three children. Diane was diagnosed with oestrogen receptor positive breast cancer when she was 40 years old. She was also pregnant at the time of diagnosis. Diane terminated the pregnancy in order to undergo surgery on her breast, followed by chemotherapy and radiotherapy. Diane was not offered fertility preservation. Two years after her diagnosis she conceived her third child and gave birth to a girl. After the birth her oncology team asked her to shut down her ovaries either

through surgery or drugs as they feared she would have a relapse. Diane agreed and continues to take injections to keep her ovaries from working. She is now in early menopause. She is in remission.

Monica:

Monica is from the North East. She is 32 years old, married with two children. Monica has had breast cancer twice, once when she was 24 years old. At that time she was offered fertility preservation in the form of embryo freezing, which she refused. At 28 years old she had a preventative double mastectomy after finding out she carries the BRCA 1 gene. She was then diagnosed with breast cancer again when she was 32. Between her two diagnoses she gave birth to her two children. She was offered fertility preservation with her second diagnosis, which she declined. At the time of writing she was still in the final stages of treatment.

Anne:

Anne is from the North East. She is 35 years old, married with two children. Anne was diagnosed with cervical cancer when she was 32 years old. She was treated with a hysterectomy, but also had an ovary removed due to a cyst. She is taking drugs to help boost her remaining ovary to keep her out of menopause. Anne was not offered fertility treatment. She is cancer free.

Heather:

Heather is from the North East. She is 38 years old, married with two children. Heather was diagnosed with cervical cancer while she was pregnant. She chose to wait to have treatment until after she gave birth to her child. She then had a partial hysterectomy. Heather is a health professional who works with people who have cancer, are in remission, as well as with family and friends who have lost someone to cancer. She is cancer free.

Family and NHS Staff Interviewees

Brenda:

Brenda is from the North East. She is 54 years old and the mother of Stephanie. Stephanie asked that I interview her mother as well as herself as Stephanie suffers from memory loss around the time of treatment due to the radiation and chemotherapy prescribed for her brain tumour. Brenda does not have cancer but has a family history of cancer with several members of her family having died from the disease.

James:

James is from the North East. He is 73 years old and is a retired surgeon who specialised in “waterworks” cancers (bladder, urethra, etc.). He is now a consulting member of a cancer support group in the area and worked for a number of years in the NHS on projects related to patient support and satisfaction.

Rebecca:

Rebecca is from the North East. She is 25 years old and a nurse on a chemotherapy ward. She has a special interest in how reproduction is affected by chemotherapy treatment.

Appendix B: Aide-Memoires

Patient Aide-Memoire

INTRODUCE MYSELF AND EXPLAIN THE STUDY

For my project I am interested in hearing about how female patients experience the relationship between cancer treatment and fertility before and after cancer. There are no right or wrong answers, especially as I am really interested in hearing about your individual experience.

CONSENT FORM PROCESS

DEMOGRAPHIC QUESTIONS

- I thought we'd get started with a few warm up questions about yourself, is that OK?
- Are you from the Northeast originally?
- Do you mind if I ask your age?
- Are you married? Do you have children?
- What was your cancer diagnosis?

TRANSITION: Depending on what they say about diagnosis, segue into the cancer discussion.

THE CANCER STORY

- I thought we could start by asking if you would tell me the story of your diagnosis?
- Primary concerns after diagnosis. Why?
- What was going through your mind when discussing/choosing treatment options? Why?
- Experience/Relationship with doctors and nurses. Why?

TRANSITION: Into fertility discussion. Depends on the type of cancer, since with reproductive cancers it will already have been discussed a little. So use prior information about cancer for the segue.

THE FERTILITY STORY

- Was fertility a concern or issue that was raised during your diagnosis or treatment?

-GET AT THE WHYS AND WHY NOTS

-Was timing right for that discussion. Why?

-Who should have discussion about fertility and cancer. Why?

-How did you feel about the effect [their cancer treatment] might have on your fertility?

-Had you thought about having children/having more children prior to the diagnosis?

TRANSITION: Use what they have told you about their feelings on fertility to bring the discussion round to questions about fertility preservation techniques.

FERTILITY PRESERVATION

-I wanted to shift focus if that's OK and speak a little about fertility preservation techniques. Do you know anything about fertility preservation or have you heard anything about it?

-explain fertility preservation

-So to start: Do you think that FP might have been something you would have been interested in knowing about it if it was available? Why/Why not?

-If we had it here in the UK, when do you think would be the best time to discuss FP with a patient/ Why?

-And who do you think would be the best person to have that discussion? Why/

-What other resources or sources of information do you think might be useful? (If they aren't sure give examples like a website, brochure, dedicated nurse etc. to help discussion)

GO BACK TO ANYTHING LEFT HANGING/LOOSE ENDS

ENDING REMARKS

-I'd like to thank you for taking the time to tell me about your experiences. Your story is incredibly helpful to my research. Before we wrap up I was wondering if you had any questions you'd like to ask me about the interview or my PhD project?

SAY THANK YOU AGAIN AND END RECORDING

Healthcare Professional Aide-Memoire

INTRODUCE MYSELF AND EXPLAIN THE STUDY

-For my project I am interested in hearing about how female patients experience the relationship between cancer treatment and fertility before and after cancer. There are no right or wrong answers, especially as I am really interested in hearing about your individual experience.

CONSENT FORM PROCESS

DEMOGRAPHIC QUESTIONS

- I thought we'd get started with a few warm up questions about yourself, is that OK?
- Are you from the Northeast originally?
- Do you mind if I ask your age?
- Are you married? Do you have children?
- What type of medicine do you practise/did you practise (if retired)?
- How often do you see cancer patients?

TRANSITION: Depending on what they say about diagnosis, segue into the cancer discussion.

THE CANCER STORY

- I thought we could start by asking if you would talk me through the kinds of interactions we would have if I was a patient: Why would I be seeing you, for how long etc.?
- After diagnosis, what are your primary concerns for the patient?
- What typically are the primary concerns that the patient has?
- How do you decide which treatments to discuss with patients?
- How much consideration for "life after cancer" goes into discussions about treatment plans?
- What do you think are the major "life after cancer" issues that must be considered for survivors during treatment? After treatment?

TRANSITION: Into fertility discussion. Depends on the type of cancer, since with reproductive cancers it will already have been discussed a little. So use prior

information about cancer for the segue.

THE FERTILITY STORY

-Do you typically discuss fertility with patients?

-GET AT THE WHYS AND WHY NOTS

-After diagnosis do patients have concerns about fertility?

-Who should have discussion about fertility and cancer with patients? Why?

-How is the topic of fertility most often brought up? Is it the patient or the doctor?

FERTILITY PRESERVATION

-I wanted to shift focus if that's OK and speak a little about fertility preservation techniques. Have you heard about fertility preservation? Is this something that patients know about or want to know about?

-Are patients typically well informed/know about fertility/FP before you discuss their options with them?

-Are there certain patients you don't discuss fertility concerns and fertility preservation with? Why is that?

-What other resources or sources of information do you think might be useful? (If they aren't sure give examples like a website, brochure, dedicated nurse etc. to help discussion)

GO BACK TO ANYTHING LEFT HANGING/LOOSE ENDS

Final question: If the roles were reversed and you were the patient, what would you like to know about cancer, fertility and fertility preservation?

ENDING REMARKS

-I'd like to thank you for taking the time to tell me about your experiences. Your story is incredibly helpful to my research. Before we wrap up I was wondering if you had any questions you'd like to ask me about the interview or my PhD project?

SAY THANK YOU AGAIN AND END RECORDING

Appendix C: Information Sheet (Patients)



Participant Information Sheet

Research Project:

Oncofertility: The Experiences of Premenopausal Cancer Patients and their Health Care Professionals with Regards to Fertility Preservation Discussions.

Chief Investigator

Alexis Paton

You are being invited to take part in a research study. Before you make a decision, it is important that you understand why the research is being done and what it involves. Please take this information sheet and read it carefully. If you have any questions, or anything is unclear and you would like further information, please let me know before you decide to be part of the study.

What is the purpose of this study?

I am a PhD student at Newcastle University and as part of my thesis I am investigating the experiences of female cancer patients and their health care professionals in the Newcastle area. I am interested in female patients' experiences with regards to their fertility and reproduction before and after cancer treatment. I am particularly keen to investigate how patients and their health care professionals make decisions about fertility and cancer treatment during this difficult time. I will also be talking to health care professionals from the Northern Centre for Cancer Care and the Newcastle Fertility Centre who are treating cancer patients. In addition to patient experiences I would like to gain an insight into how health care professionals understand the relationship between cancer treatment and patient fertility. By hearing accounts from both patients and health care professionals, I hope to gain an in-depth picture of the key issues in the areas of fertility and cancer medicine.

To do this, it is vital to hear the perspectives of patients and health care professionals involved in cancer treatment so that I can identify ways that support may be offered in the future. I would therefore like to invite you to take part in this important study.

My aims are:

- To explore the experiences of female cancer patients and the health care professionals who treat them, with regard to fertility choices.
- To explore the ways in which oncology and fertility clinics interact in the UK.

- To identify sources of support valued by patients and health care professionals, as well as identify what types of support and/or policy should be implemented to address the needs of patients and health care professionals.
- To explore female patient and health care professionals experiences with fertility preservation techniques.

Do I have to take part?

Whether you decide to take part is entirely your decision. If you **do** wish to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. If you decide to take part you are free to withdraw from the study at any time, without giving a reason. Your decision to take part or withdraw will not affect the standard of care that you receive from your doctor, as your doctor will not be told of your involvement.

What will happen if I decide to take part?

If you decide to take part, then I will interview you once, over a period of 8-12 months, appropriate to your situation. These interviews will take place either at your home, the university or the hospital, whichever is most suitable, at times that are also suitable to you. They will explore relevant issues with regards to your cancer treatment and fertility concerns. Each interview will be approximately 1-2 hours, depending on how much time you have available and how much you wish to say. With your permission the interviews will be audio-recorded and then transcribed. If you prefer I can take notes during the interviews. Full copies of the transcripts or notes will be available for viewing at your request.

What is the next step?

This information has been given to you to look at before deciding whether you would like to hear more about the research. Please have a close look at it before considering whether you wish to hear more about the study. If you do want to know more please contact me in the following ways:

Through email: a.paton@newcastle.ac.uk

Website: www.onconfertilityinthenortheast.co.uk

By mobile: 0778 984 8226

By Post: Alexis Paton
Policy, Ethics, and Life Sciences Research Centre
4th floor Claremont Bridge, Newcastle University
Newcastle Upon Tyne, NE1 7RU

If you have further questions I can arrange a time suitable for you to meet with you at a suitable venue to discuss any issues and questions you may have. Any information given at this initial meeting will not be used for the purposes of research. You will not be considered a participant until you choose to fill in the consent form.

The aims of this initial meeting are:

- To discuss any issues relating to the research, before you consider whether you would like to be involved or not.
- To give you the consent form to sign if you decide to take part.
- To arrange a time to carry out the first interview if you decide you would like to participate in the study.

Will my taking part in the study be kept confidential?

All information collected over the course of this study will be kept confidential. Audio recordings will be destroyed at the end of the research. All transcripts and notes will be anonymized, meaning your name and identifiable details will be changed. Your participation will not be discussed with any health care professionals, including your own doctors. I will not discuss anything you tell me with people known to you; however you are free to discuss any issues covered by this research with your family members, friends and doctors.

Is there any time when disclosure might occur?

If you were to say something that potentially indicated that you or someone else was at risk of harm I would be obligated to disclose this information to the relevant authorities. If you do something of this type I will indicate it to you and you may choose to continue the discussion or end it. I would also discuss what the next steps would be in this case.

Can I talk to other people about the study?

I will always keep your participation and personal details confidential. However, if you would like to discuss your involvement in the study with your doctor, family and friends you are welcome to do so. In addition should you feel you would like to speak with a councillor about your involvement in the study a councillor has been made available. If at any time you wish to speak to her please contact Karen Verrill at 0191 2139201.

What will happen to the results of the research study?

The results of this study will be used in materials I am writing about cancer patients' and health care professionals' experiences with regards to fertility. The material will be primarily used to write my PhD thesis, as well as be presented at academic and professional conferences and in academic journals. At all times the information from the study will remain anonymous and confidential. Some findings may also be shared with the Northern Centre for Cancer Care and the Newcastle Fertility Centre if they are relevant to their policies and procedures. A final report will be produced for patients and health care professionals and sent to everyone involved in the study, should they desire it.

Who is organizing and funding the research?

The research is being done in collaboration with the School of Geography, Politics and Sociology and the Policy, Ethics and Life Sciences Centre at Newcastle University as part of the

PhD program. The study is funded by Newcastle University and the Susan Channon Breast Cancer Trust, covering the costs of interviews and observations.

Appendix D: Information Sheet (HCPs)



Participant Information Sheet

Research Project:

Oncofertility: The Experiences of Premenopausal Cancer Patients and their Health Care Professionals with Regards to Fertility Preservation Discussions.

Chief Investigator

Alexis Paton

You are being invited to take part in a research study. Before you make a decision, it is important that you understand why the research is being done and what it involves. Please take this information sheet and read it carefully. If you have any questions, or anything is unclear and you would like further information, please let me know before you decide to be part of the study.

What is the purpose of this study?

I am a PhD student at Newcastle University and as part of my thesis I am investigating the experiences of premenopausal cancer patients and the experiences of oncology health care professionals in the Newcastle area. I am interested in health care professionals' experiences with regards to patient fertility before and after cancer treatment. I am particularly keen to investigate how patients and their health care professionals make decisions about fertility and cancer treatment during this difficult time. In addition I would like to gain an insight into how health care professionals understand the relationship between cancer treatment and patient fertility. I will also be talking to premenopausal cancer patients about their experiences with cancer and fertility. By hearing accounts from both patients and health care professionals, I hope to gain an in-depth picture of the key issues in the areas of fertility and cancer medicine.

To do this, it is vital to hear the perspectives of patients and health care professionals involved in cancer treatment. I would therefore like to invite you to take part in this important study.

My aims are:

- To explore the experiences of cancer patients and the health care professionals who treat them, with regard to fertility choices.
- To explore the ways in which oncology and fertility clinics interact in the UK.

- To identify sources of support valued by patients *and* health care professionals, as well as identify what types of support and/or policy should be implemented to address the needs of patients and health care professionals.
- To explore patient and health care professionals experiences with fertility preservation techniques.

Do I have to take part?

Whether you decide to take part is entirely your decision. If you **do** wish to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. If you decide to take part you are free to withdraw from the study at any time, without giving a reason.

What will happen if I decide to take part?

If you decide to take part, then I will interview you once, over a period of 8-12 months, appropriate to your situation. These interviews will take place either at your home, the university or the hospital, whichever is most suitable, at times that are also suitable to you. They will explore relevant issues with regards to your medical practice and patient cancer treatment and fertility concerns. Each interview will be approximately 1-2 hours, depending on how much time you have available and how much you wish to say. With your permission the interviews will be audio-recorded and then transcribed. If you prefer I can take notes during the interviews. Full copies of the transcripts or notes will be available for viewing at your request.

What is the next step?

This information has been given to you to look at before deciding whether you would like to hear more about the research. Please have a close look at it before considering whether you wish to hear more about the study. If you do want to know more please contact me in the following ways:

Through email: a.paton@newcastle.ac.uk

Website: www.oncofertilityinthenortheast.co.uk

By mobile: 0778 984 8226

By Post: Alexis Paton
Policy, Ethics, and Life Sciences Research Centre
4th floor Claremont Bridge, Newcastle University
Newcastle Upon Tyne, NE1 7RU

If you have further questions I can arrange a time suitable for you to meet with you at a suitable venue to discuss any issues and questions you may have. Any information given at this initial meeting will not be used for the purposes of research. You will not be considered a participant until you choose to fill in the consent form.

The aims of this initial meeting are:

- To discuss any issues relating to the research, before you consider whether you would like to be involved or not.
- To give you the consent form to sign if you decide to take part.
- To arrange a time to carry out the first interview if you decide you would like to participate in the study.

Will my taking part in the study be kept confidential?

All information collected over the course of this study will be kept confidential. Audio recordings will be destroyed at the end of the research. All transcripts and notes will be anonymized, meaning your name and identifiable details will be changed. Your participation will not be discussed with any of your colleagues, friends or family. I will not discuss anything you tell me with people known to you; however you are free to discuss any issues covered by this research with your colleagues, friends or family.

Is there any time when disclosure might occur?

If you were to say something that potentially indicated that you or someone else was at risk of harm I would be obligated to disclose this information to the relevant authorities. If you do something of this type I will indicate it to you and you may choose to continue the discussion or end it. I would also discuss what the next steps would be in this case.

Can I talk to other people about the study?

I will always keep your participation and personal details confidential. However, if you would like to discuss your involvement in the study with your doctor, family and friends you are welcome to do so. In addition should you feel you would like to speak with a councillor about your involvement in the study a councillor has been available.

What will happen to the results of the research study?

The results of this study will be used in materials I am writing about premenopausal cancer patients' and health care professionals' experiences with regards to fertility. The material will be primarily used to write my PhD thesis, as well as be presented at academic and professional conferences and in academic journals. At all times the information from the study will remain anonymous and confidential. Some analytic findings may also be shared with the Northern Centre for Cancer Care and the Newcastle Fertility Centre if they are relevant to their policies and procedures. A final report will be produced for patients and health care professionals and sent to everyone involved in the study, should they desire it.

Who is organizing and funding the research?

The research is being done in collaboration with the School of Geography, Politics and Sociology and the Policy, Ethics and Life Sciences Centre at Newcastle University as part of the PhD program. The study is funded by Newcastle University and the Susan Channon Breast Cancer Trust, covering the costs of interviews and observations.

Appendix E: Promotional Material

The following shows the brochure that was used to recruit participants to the study:

Introduction

This study seeks to increase knowledge and understanding about how cancer treatment and fertility preservation are dealt with in the UK.

Why?

More needs to be understood about how patients and health care professionals make decisions about cancer treatment and fertility preservation after diagnosis.

Research Aims

- To determine how patients and health care professionals make decisions about cancer and fertility treatment in the UK.
- Use this information to inform knowledge and guide future policy.
- To explore the ways in which oncology and fertility clinics interact in the UK.



Listed below are a few useful links:

- CancerHelp UK:
www.cancerhelp.org.uk
- Breast cancer and fertility specific page of CancerHelp UK
<http://www.cancerhelp.org.uk/type/breast-cancer/living/pregnancy-and-breast-cancer#treatment>
- Fertile Hope
<http://www.fertilehope.org/>

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Further details of the project are available at:
www.oncofertilityinthenortheast.co.uk

Or contact us directly:
Alexis Paton
Mobile/Text: 0778 984 8226
Email: a_paton@newcastle.ac.uk
Web: www.oncofertilityinthenortheast.co.uk



Premenopausal Cancer Patients' Experiences with Cancer and Fertility

Background

I am a researcher based at Newcastle University doing a study on the experiences of premenopausal female cancer patients, with regards to their future reproductive health, as well as the experiences of the health care professionals who treat them.

This research will help identify those areas where further support and information may be required for patients, as well as health care professionals, with regards to fertility preservation for cancer patients.

Aims

To investigate how cancer patients and their doctors make decisions about fertility and cancer treatment after a cancer diagnosis.

Objectives

My main objectives are:


- To explore the experiences of cancer patients and the health care professionals who treat them, focusing on fertility choices.
- To explore the way in which oncology and fertility clinics interact in the UK.
- To identify sources of support valued by patients and health care professionals, as well as identify what types of support and/or policy should be implemented to address the needs of patients and health care professionals.
- To explore patient and healthcare professionals experiences with fertility preservation techniques.

...

Please take the time to consider whether you are interested in this study and let me know if you would like to hear further information, and/or discuss any issues you may have.

Contact information

Please get in touch if you would like to know more about this project by contacting me either through:



PhD Student,
Alexis Paton

Email at: a_paton@newcastle.ac.uk

Mobile/Text: 0778 984 8226

Post: PEALS Research Centre
4th floor Claremont Bridge
Newcastle University
Newcastle Upon Tyne, NE1 7RU

Any information given will be treated with strict confidence.

...

Appendix F: Consent Form

Consent Form



Oncofertility: The Experiences of Premenopausal Cancer Patients and their Health

Care Professionals With Regards to Fertility Preservation Discussions

Chief Investigator: Alexis Paton, Newcastle University.

Please initial:

I have read the information sheet.

I have been given a copy to keep.

I have had an opportunity to ask questions and discuss the study.

I have received satisfactory answers to all of my questions.

I have received enough information about the study.

I understand that my participation is voluntary and that I am free to withdraw from the study:

- At any time
- Without having to give a reason for withdrawing
- Without affecting my medical treatment

I am happy for interview/s to be audio-recorded and transcribed.

I agree to my personal data being stored on a secure database, to be accessed by Alexis Paton and her research team.

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Newcastle University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I agree to take part in the study.

NAME IN BLOCK LETTERS

Signed..... **Date**

Signature of Chief Investigator

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