

RE-THINKING THE DISTINCTION BETWEEN THERAPY AND ENHANCEMENT:

A STUDY IN EMPIRICAL ETHICS

Alexander James McKeown

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Seventy Nine Thousand, Nine Hundred and Ninety Six Words

ABSTRACT

My aim in this thesis is twofold: to advance philosophical understanding of the contested therapy / enhancement distinction and its ethical implications; and to achieve this via the integration of empirical data into the philosophical and ethical debate. Despite its implications for justice in healthcare, and despite the abundance of theoretical literature, little is known about how human enhancement is understood within its own context.

The division between therapy and enhancement is nominally defined by whatever is identified as 'normal' health. This seems unproblematic, however it is extremely difficult to offer a clear, non-relative account of normality that is not beset by logical and semantic difficulties, or modified by historical, socio-cultural, technological, economic, and geographical contingencies.

This raises a challenge: if what is 'normal' cannot be clearly identified, how can we clearly identify the difference between therapy and enhancement? If we cannot clearly identify the difference between therapy and enhancement, how can we ensure that our medical policies are ethically appropriate in distinguishing between who may and may not receive assistance?

The empirical data communicate relevant views held by medical professionals whose work involves a prominent 'enhancement' drug, recombinant human erythropoietin (EPO). I use the insights gained from analysing theory and data to develop a refined account of the therapy / enhancement distinction which integrates the two. I use this as the basis for developing normative conclusions and policy recommendations in response to the ethical challenges posed by any future proliferation of enhancement technologies.

I use the philosophical approach of Critical Realism for integrating the theory and data and constructing the normative conclusions developed. This is the first time critical realism has been used in empirical bioethics, and this thesis therefore also makes an original methodological contribution to the field.

DEDICATION

To my father, John McKeown. For inspiring a love of argument and showing me from an early age how much can be achieved just by thinking, and thus inadvertently lighting the philosophical touch paper. He lived long enough to see me decide to do this, but not long enough to see me start or finish it, and I therefore dedicate this thesis to his memory.

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AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the requirements of Regulations of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED:

DATE:

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FOREWORD

The idea for this thesis was motivated by two inter-related observations. Firstly, medical science and technology are moving increasingly rapidly. Secondly, to the extent that what is technologically possible influences our abilities, norms, expectations, and the social context in which we live, this influence will increase as development accelerates.

One aspect of this of particular contemporary significance is the contested relationship between therapy and 'human enhancement'. Human enhancement, which captures the idea of using medical science to go '*beyond therapy*' to *improve* on normality rather than restore it is an ambiguous concept precisely because it implies a norm. If norms are changing increasingly rapidly, how is it possible to gain a clear understanding of it?

The prospect of human enhancement raises numerous philosophical questions. The potential to dramatically extend or add to our capabilities, or to go further and fundamentally change our nature, invites ontological and epistemological reflection on what it means to be human. It also brings to the fore serious ethical issues. How should we respond to these technologies? Is it morally desirable or acceptable to modify ourselves in this way? If so, who decides? How should this potential be managed? Is there a limit beyond which it would be morally unacceptable to enhance? Perhaps it is morally *obligatory* for mankind to enhance, if to do so would confer significant enough benefits.

Visions of enhanced humanity – or indeed a *posthumanity* - have roots in myth and science fiction. However man's history has been one of overt and relentless technological advancement. In the present, mankind's increasing biotechnological power is now bringing many of these previously hypothetical questions into the present. To this end its potential socio-ethical impact should be considered, with reference in particular to its own context – that of medicine and health policy.

Notwithstanding antecedents from inside and outside academia, the history of explicitly bioethical scholarship in human enhancement is only around 20 years

old. In this time, however, it has migrated from the margins into the centre ground and the philosophical and ideological battle ground has been staked out. Positions have been established and the theoretical terrain has been comprehensively mapped.

Now that the terms of the debate have been set out, what is missing is information concerning how the various positions are understood, comprehended, agreed with, or disputed from within the extant social context in which biomedical enhancement technologies are emerging. Medical practitioners and scientists will inevitably be involved in negotiating ethical dilemmas concerning enhancement if they are to arise, and knowledge of their views is thus crucial.

Despite the relevance of these views for dealing with the ethical challenges raised by enhancement technologies, little is known about them at present. It is in response to this lack of information when compared with an abundance of theory that I devised this project. In the thesis I build on existing theory with qualitative data that I have collected which give an insight into how human enhancement is understood within contemporary clinical and research practice.

I use the insights from these data to refine our understanding of human enhancement and its ethical implications. The products of this analysis are a refined theoretical model of enhancement and its ambiguous relation to therapy, and preliminary policy proposals for how the ethical challenges could be met in practice. The proposal makes recommendations that both defend what is valuable about enhancement, and uphold what is central to the ethical integrity of medicine.

In keeping with philosophical tradition, bioethical scholarship of enhancement is characterised by a divergence of opinions. Disagreement is ubiquitous. Whilst not theoretically problematic, this poses problems for applying ethical conclusions in practice. The work in this thesis is therefore important. In adding data to a theory-heavy field I advance ethical conclusions that ground a negotiation of opposing positions and thus identify a way forward for future research.

Chapter One: Introduction

1.1) Overview

In this chapter I introduce the therapy / enhancement distinction and explain why the delineation of these two concepts represents a complex philosophical and moral challenge. I will outline the concept of human enhancement itself and explain why its relationship to therapy is problematic and more ambiguous than it appears. I will show how the integrity of the therapy / enhancement distinction turns on the integrity of the underlying concept of 'normal' health. I will then explain why the concept of 'normal health' is ambiguous, and thus broadly frame the problem to be considered in the rest of the thesis. I will also very briefly provide some historical and scholarly context for human enhancement that will be expanded in more detail within the literature review of the following chapter.

Having outlined the problem I will go on to describe the imbalance between philosophical theory and empirical data within bioethical scholarship on enhancement. I will explain why the collection of relevant data is necessary for advancing the field, and justify how these data may be integrated with the currently inconclusive theoretical debate in order to provide a basis on which to develop appropriate and practical normative conclusions.

I will conclude with a summary that explains how the thesis will proceed overall. In particular I will outline the conditions that must be satisfied by the exemplar for enhancement that I select for the empirical component, in view of the preceding explanation of what is needed and currently missing from the literature. Finally I will suggest that the interdisciplinary methodology of Critical Realism is a useful, appropriate and original analytic frame for the investigation, in view of its ability to successfully integrate philosophical theory and social scientific data.

1.2) What is Human Enhancement?

At its most basic the verb 'to enhance' is synonymous with improvement; the heightening of a certain characteristic; an increase or elevation in value; or the

magnification of something's qualities¹. Thus, when the prefix 'human' is attached, the term 'human enhancement' captures the idea of improving ourselves.

Human enhancement as a field of bioethical scholarship in its own right is a recent phenomenon, although it has several historical antecedents. These include the idea of the radically upgraded 'trans' or 'post-human' (More, 2013; Kurzweil, 2005; Bostrom, 2009); the related concept of the 'cyborg' which emerged in the mid-to late 20th Century (Halacy, 1967; Haraway, 1985); and the eugenic movements of the first half of the 20th Century (Resnik, 2000; Agar, 2008). The broader idea of improving on the 'given' human also extends much further into history than this. The modern roots of 'enhancement' can be traced beyond the Enlightenment and the Scientific Revolution – for example through the work of Nietzsche (1895), Bacon (1620), and Picca della Mirandola in the 18th, 17th, and 15th Centuries respectively.

Still further back in Antiquity prototypical mythic accounts of an enhanced human can be found, for example in the Epic of Gilgamesh (Bostrom, 2005); or in the story of Prometheus, the 'shaper' of mankind (Raggio, 1958), who stole fire from the Gods and gave it to humans, enabling them to exert control over their natural destiny in the world. Of particular relevance to medicine within this myth is the idea of self-repairing and re-generating internal organs (Ankoma-Sey, 1999; Taub, 2004).

The verb 'to enhance' can thus be used in any number of contexts and it is not self-evident that human enhancement should be understood as a phenomenon in medicine alone. For example, my abilities have been greatly increased via cognitive enhancements such as language acquisition and education, although these are not medical enhancements. Equally 'enhancement' does not by itself specifically refer to patients, since someone is only a patient once they fall under the concern of the medical profession. While one is receiving medical assistance one is a patient, and before or after this one is not.

¹ <http://www.oed.com/view/Entry/62342?redirectedFrom=enhance#eid>

Despite these observations the context to which the term 'human enhancement' typically refers in the philosophical and bioethical literature is that of contemporary medicine, and frequently within biomedicine more specifically. This thesis investigates human enhancement within a biomedical context, which is the predominant sense in which it is used within the literature. For this reason I will therefore also restrict my usage to this sense of the term. Savulescu et al (2006) endorse the view that the word 'enhancement' necessarily connotes an increase in value. John Harris (2009, p. 131), a trenchant advocate of human enhancement defends this unambiguous characterisation:

'If it wasn't good for you it wouldn't be an enhancement. In terms of human functioning an enhancement is by definition an improvement on what went before.'

An account of human enhancement of this kind defined in relative abstraction does not, however, take into several important ethical considerations, for example: how the definition might apply within a specific context such as the institution of medicine; the clinical and research knowledge and practices necessary for succeeding in human enhancement; the wider implications for society if technological options for enhancement were to proliferate; or the practical ethical challenges associated with it. Whether or not the desire to improve ourselves using medical technologies should in reality be judged positively in this way is therefore a more complex question than is suggested by Harris' account (Bostrom & Savulescu, 2009; Kamm, 2009; Lin & Alhoff, 2008).

1.3) The Therapy / Enhancement Distinction

Biomedical enhancement necessarily entails some conception of improvement via means identified as 'medical' in nature. More specifically, however, it denotes the idea of improvement from and above 'normal' health, rather than improvement by remediation to 'normal' health. It is the latter form of 'improvement' here - the restoration of normality - which largely determines the institutional structure of medicine and its decision making criteria (Friedson, 1970).

Reflection on medicine and its goals has led philosophers and bioethicists to posit a difference between therapy and enhancement on the basis that the two concepts appear distinct. Given a standard account of ‘what medicine does’, those interventions described as ‘enhancements’ appear to represent a form of medical assistance that is distinct from the usual ends of the medical enterprise insofar as they aim at supranormality rather than the restoration of normality. Numerous similar accounts of the distinction exist, all of which are variants on the central idea described by Bostrom & Roache (2008, p. 1):

‘In broad terms, therapy aims to fix something that has gone wrong, by curing specific diseases or injuries, while enhancement interventions aim to improve the state of an organism beyond its normal healthy state.’

A philosophical ambiguity presents itself, however, when we try to clearly delineate ‘therapy’ from ‘enhancement’, as they are conceptually linked by a shared goal of conferring improvement. Thus, despite the apparent clarity of the distinction, the relationship between the two concepts is in fact more ambiguous than it appears. After all, a standard desire or expectation of medical assistance is that it will increase, improve, or enhance our health to a normal or otherwise acceptable state. A problem of conceptual separation thus emerges, since a key goal of therapy is that it ‘enhances’ one’s health (Juengst, 1997; Pellegrino, 2004; Scripko, 2010). Consequently if it is a condition of a therapy’s effectiveness that it enhances, the category of interventions known as ‘therapy’ is logically reducible to the broader concept of enhancement.

Given the semantic difficulty of clearly separating the meanings of therapy and enhancement we can begin to see a traditional philosophical problem of vagueness coming into view (Hempel, 1939; Fine, 1975). Whether or not we accept the reducibility of therapy to enhancement at face value, there is an irremovable conceptual connection between the ‘therapeutic’ assistance that we receive from a doctor to return us to normal health, and those ‘extra-therapeutic’ measures which we do not typically receive from a doctor that are nominally captured by the concept of ‘enhancement’.

Thus, therapy and enhancement share a conceptual anchor in both having a goal of improvement, and yet they appear to refer to different phenomena. How, then, do we clarify them more specifically? To what extent are the concepts similar? To what extent do their meanings differ? Moreover, given that medicine has normative ends, what implications do different answers to these questions have for making morally justifiable decisions in practice, within the socially embedded institutional structure of medicine?

A range of opposing positions has been advanced concerning the separability of therapy and enhancement. To frame the argument broadly, however, two poles can be staked out. At one extreme there is the claim that the therapy / enhancement distinction is logically incoherent because it dissolves under analysis once we realise that therapies aim to 'enhance' in some way. A further contribution to this argument is made by the related difficulty of giving a clear account of the 'normal'. An appeal to 'normal' health also grounds the opposing argument, however, which defends the integrity of therapy / enhancement distinction by virtue of real differences between normal and ill-health.

The two poles can be represented using the following quotes. The first comes from Savulescu (2006, p. 304), who highlights the weakness of an attempt to clearly delineate therapy from enhancement:

'Enhancement is, indeed, a wide concept. In the broadest sense, it means "increase" or "improvement." For example, a doctor may enhance his patient's chance of survival by giving the patient a drug.'

By contrast the second, from Sandel (2004, p. 2), implies that the distinction is real and defensible:

'...enhancement employs medical means for nonmedical ends—ends unrelated to curing or preventing disease or repairing injury.'

As I will show throughout the thesis, however, the debate concerning the reality of the therapy / enhancement distinction is more complex than is evident from these two positions alone.

1.4) Therapy and Enhancement as a Heuristic

In extreme cases the therapy / enhancement distinction is a useful heuristic² for distinguishing between ‘medical’ and ‘non-medical’ applications of technology (Pellegrino, 2004). There is, for example, a significant empirical difference between administering chemotherapy in order to try and prevent death from cancer on one hand, and providing a performance enhancing drug to an athlete so that he or she can win a race on the other.

The fact that this heuristic is generally effective for ranking needs into a hierarchy of severity means that the distinction is an effective ‘rule of thumb’ which has a ‘useful, if modest, bearing’ (Daniels, 2000, p. 309) on determining who may and may not receive assistance. In cases where the heuristic can distinguish clearly between instances of therapy and enhancement it has practical efficacy for making decisions appropriate to the biomedical model of health. This is model underpins the structure and diagnostic rationale of western medicine and, as Gillett (1994, p. 1127) writes:

‘...attempts to isolate distinct and identifiable diseases which are causally produced by some underlying patho-physiological condition...Medicine then produces a technological solution to the problem of nullifying the threat posed by this condition...The medical model is reductive. It works most comfortably where there is a biochemical and/or structural defect that provides a simple key to understanding the disease being studied.’

The medical model is thus effective within clearly defined empirical parameters in which detectable defects determine and nominally limit the boundaries of medical

² <http://www.oed.com/view/Entry/86554?redirectedFrom=heuristic#eid> – the Oxford English Dictionary describes a heuristic process as a ‘method for attempting the solution of a problem’. An informative reference that it also provides from the field of computing studies is: ‘A process that may solve a given problem, but offers no guarantee of doing so...’

practice. According to the criteria that it employs, to provide assistance for states that do not fall under the purview of the medical model is to 'enhance' rather than to 'treat', and such practices are thus deemed external to the concerns of medical professionals.

The situation becomes complicated, however, when we note Juengst's (1997, p. 126) argument that a clear line cannot be drawn between the two to the extent that 'enhancement' may contribute to the achievement of the goals of 'therapy'. He makes the following observation with respect to genetic enhancement, which is a candidate for potentially radical enhancements in future, should the relevant technologies become sufficiently advanced:

'...to the extent that disease prevention is a proper goal of medicine, and the use of gene transfer techniques to strengthen or enhance human health maintenance capacities will help achieve that goal, then the treatment/enhancement distinction cannot confine or define the limits of the properly medical use of gene transfer techniques...'

In view of an ambiguity such as this, scrutiny of the therapy / enhancement distinction entails questions concerning the identification of an appropriate threshold for medical assistance, given that the goals of these two apparently different kinds of intervention may share certain goals. Moreover given that these are not only theoretical dilemmas but applied ones, we may reasonably ask further ethically pertinent questions concerning their resolution, as Bostrom & Savulescu (2009, p. 3) indicate:

'Precisely what capacity is being enhanced in what ways? Who has access? Who makes the decisions? Within what cultural and sociopolitical context? At what cost to competing priorities? With what externalities? Justifiable ethical verdicts may only be attainable following a specification of these and other similarly contextual variables.'

We will see in the following chapter that a considerable and diverse literature exists concerning these complicated issues. For the time being, however, we can

roughly sketch out the means by which this remit is defined and the ethical principles which pertain to it.

Firstly, let us assume that it is a moral responsibility of the medical profession to minimise as far as possible or eliminate the suffering and harm caused by different threats to and limitations of health. This principle is consistent with both ancient and modern conceptions of medical responsibility (Moravcsik, 1976; Gillon, 1994; Fleischauer & Hermeren, 2006). Since the amount of resources available is always finite and health needs differ in severity, some way of fairly apportioning the former according to the latter must be decided upon (Daniels, 2001; Brulde, 2011).

The heuristic judgement implied by the therapy / enhancement distinction is that people in 'normal' or 'good' health do not need assistance, but those people in states of 'subnormal' or 'poor' health do, and this in turn helps to calibrate the system of resource allocation for reducing the harm and suffering caused by biological or physiological states which deviate beneath the norm (Kamm, 2002). 'Normal' health generates no need for assistance, whereas 'poor' health does (Capps, 2011). Medical assistance in instances of 'abnormal' health constitutes 'therapy', whereas in cases of 'normal' health it constitutes 'enhancement' (Bostrom & Roache, 2008). 'Therapy' is a proper goal of medicine, whereas 'enhancement' is not (Kass, 2003).

The nominal distinction made between therapy and enhancement according to the biomedical model is recognisable to us because we view it from within a social context in which this model prevails. It is expected that assistance should be granted once health falls beneath a certain threshold, and the level of expectation thus tapers off correspondingly the further that we move above this threshold, relative to the amount of resources available (Holtug, 1999; Savulescu, 2006).

This account thus broadly frames the character of the modern western medical system (Mechanic, 1973; Baronov, 2008). It also supplies the criteria according to which: medical professionals acquire specialist knowledge and are subsequently licensed to practice (Parsons, 1975); (fluid) diagnostic assessments and treatment

decisions are made (Blaxter, 1978; Conrad, 1992); decisions are made about policies that sanction, legalise, and licence medical techniques, products, and applications (Stevenson & Scambler, 2005); and, consequently, society's expectations are raised of what it can and cannot expect in terms of medical services (Creuss & Creuss, 2008).

1.5) Professional Ethical Practice and the Hippocratic Oath

Freidson (1970) and Zola (1973) highlight the considerable degree of power and autonomy enjoyed by the medical profession in adjudicating between reasonable and unreasonable uses of its resources in a way that affects the whole society that it serves. Despite the institutional power of medicine, however, Juth (2010) and Stevenson & Scambler (2005) observe that a reorientation in favour of awarding more autonomy to patients has taken place in countries such as the UK and USA in recent decades.

This reorientation away from a historically paternalistic approach to medical decision making (Schwartz, 1992; Cohen, 2000) has taken place in recognition of the ethical importance of respecting autonomy, since to do so reduces the risk of medical coercion occurring and action being taken that is against a patient's wishes. Whilst such a reorientation may have been necessary (Graber & Tansey, 2005; Entwistle et al, 2010), controversy still exists over what constitutes the appropriate balance between respecting patient autonomy on one hand, and the clinical expertise of a doctor on the other, in terms of what it means to act in the patient's best interests (O'Neill, 1984; Graber & Tansey, 2005; Loewy, 2005).

This tension is significant with respect to enhancement. If an individual seeks assistance to 'enhance' themselves in some way by virtue of having no medically recognisable need to do so, then a doctor may refuse it on the basis that to do so would fall beyond his professional competence and duties. In this respect to refuse is to thwart the autonomy of the individual seeking help. This is despite that, as the quote from Juengst indicates, it may be in the individual's interests to enhance him or herself irrespective of whether any 'medical need' is present and in a way that

may be consistent with the harm prevention goal of medicine. Given that human enhancement procedures are defined as those which may be beneficial to the individual but for which there is no 'medical need' according to institutional criteria, the balance between individual patient autonomy and professional responsibility is of central ethical relevance to the debate.

An early codification of the ethical responsibilities of a physician is the Hippocratic Oath, whose usage dates back to the 4th Century BC (Fleischhauer & Hermeren, 2006, p. 20). According to a recent survey medical students trained according to the principles of western medicine must still swear on a formulation of this Oath (Sritharan et al, 2001, p. 1440). It therefore continues to constitute a part of the normative underpinning of medical practice, and Antoniou et al (2010, p. 3077) pay tribute to its 'time enduring character'. Given the technological and societal differences between the 4th Century BC and the 21st Century AD, however, opinions diverge as to the extent of its normative appropriateness in the present day. Jotterand (2005, p. 109), for example, adopts the sceptical view that:

'...the extent to which the Oath has been, or still is, a basis for medical ethics is rather controversial and unclear.'

If the normative demands of the Oath do accurately inform the institutional character of medicine in the 21st Century, however, then it should be possible to infer from these something about the services that should and should not be sanctioned in practice. This relationship can also be viewed in reverse: if the institutional character of medicine properly realises the normative prescriptions of the Oath, then there will be a correspondence between the actual boundaries of practice in the former, and the theoretical professional ethical responsibilities outlined in the latter. In many respects this correspondence exists. For example, the physician's continued responsibility to treat the sick and prevent harm is reflected by the Oath's declaration that (Markel, 2004, p. 2028):

'I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.'

On the other hand, however, historical declarations exist within the Oath which, in contemporary liberal societies, are more ethically controversial given socio-ethical norms which now prevail. As Markel (2004, p. 2028) also indicates, this early version of the Oath promises that:

'I will not give to a woman an abortive remedy...'

Clearly, disapproval of abortion still exists and is widespread in certain communities, for example by followers of some religions. Disapproval is not unanimous, however. In those societies in which abortion is legal and tolerated, legality and tolerance highlight disparities between ancient and modern conceptions of the appropriate boundaries of medical practice. Moreover Kao & Parsi (2000, p. 886) note that there is no single version of the Oath used by all of those who enter practice, and find that oaths '*vary in substantive content*'.

These disparities indicate that a direct correspondence may not always obtain between the practices of medicine, and the normative goals which they are meant to represent and which it is incumbent on physicians to deliver. To this extent, what constitutes a proper actualisation of the goals of medicine, and therefore by extension what would count as their transgression, is contestable. As Parens (1998, p. 2) writes in relation to the issue of therapy and enhancement:

'The treatment / enhancement distinction is often used in the context of conversations about what falls within and what falls outside the proper goals of medicine. But as anyone who has participated in or observed such a conversation knows, there is no universally accepted conception of the goals of medicine. The lack of such a consensus has much to do with the fact that there is no one universally accepted conception of what health is. And thus neither is there a universally accepted definition of what "going beyond health to enhancement" means.'

This commentary thus identifies both the significance and the problematic nature of conceptions of 'health' and 'normality' for providing a way of distinguishing between therapy and enhancement. Therapy and enhancement are only clear to the extent that 'normal health' can be identified, and it is the identification of

‘normal health’ upon which the integrity of the biomedical model of health depends. The identification of ‘normal health’, however, is not straightforward.

1.6) Normality and the Therapy / Enhancement Problem

Although therapy and enhancement are conceptually linked by a shared goal of the improvement of health and / or functioning, on a basic reading of the distinction the difference between them is that they seek improvement from empirically different starting points, as we saw in the earlier quote from Bostrom & Roache (2008). According to this view therapies seek to improve from subnormality to normality, whilst enhancements use normality as their starting point to achieve supranormality. Thus, they are distinguished from each other by a threshold of normality. The distinction is, as Bess (2010, p. 647) notes, ‘pegged’ to a definition of normality. This carries a problem, however, since norms of health are not necessarily static:

‘The treatment/enhancement distinction, therefore, presents us with a moving target because it is pegged to the concept of “health”—and the meanings of this latter word tend not only to vary between the positive and negative definitions but also to shift from culture to culture and epoch to epoch.’

To the extent that what normal health ‘is’ is statistically defined relative to a population, many indicators that are used to give an account of the normal are in a state of flux. This is to say that what ‘is statistically normal’ for a given population may be statistically abnormal, relative to the same population a hundred years in the past or future. De Vito (2000), for example, offers a very recent and rapid example of this in the increase of average life-span in the West by around 25 years over the past 50.

Alternatively there may be geographical differences, since something may be statistically abnormal in one population relative to a different population elsewhere. For example, the ‘normal’ haemoglobin content of the blood differs relative to altitude according to corresponding fluctuations in the oxygen content of the air (Brookhart et al, 2008). These two examples demonstrate that a

permanent and non-relative account of 'normal' health can be difficult to identify. Insofar as there is ambiguity in identifying 'normality', there is a corresponding ambiguity in distinguishing between therapy and enhancement. Further examples of this difficulty can be seen in the diversity of accounts of 'normal health' within the relevant literature outlined in chapter two.

The examples given here are just two instances in which the identification of a fixed account of normal health according to biological indicators is problematic, even within limited historical or geographical parameters. If we take a broader view we will see that change in norms also occurs on a much larger scale. This can be seen particularly acutely if we consider the causal influence of technological innovation upon the generation of new norms of health and illness. Ellul (1962), Mechanic (1973), and Stempsey (2006), for example, argue that new technological capabilities generate new functional norms with increasing rapidity by persistently altering expectations about what is possible. Stempsey (2006, p. 234) writes:

'If health is a goal of medicine, it is not a static goal precisely because technological development forces us to expand our thinking about the very nature of the body, its limitations, and what it might possibly be able to do. Technology creates the possibility of new ends that can only be met by means of technology. Once this dynamism is begun, it can proceed toward an ever-expanding set of ends for the human. What is needed to accommodate this way of thinking is a dynamic conception of health.'

This observation is particularly relevant within the context of medical technology in the 21st Century insofar as it is norms of health which nominally determine what and what should not be treated by way of medical assistance. As Babich (2007) and McGinn (1980) note, similar hypotheses are also evident in earlier observations about technology such as those advanced by Bacon (1657), Nietzsche (1886), and Heidegger (1950). Heidegger (Ibid, p. 4) uses the concept of 'enframing' to describe a process of continual re-categorisation by humans of what is available to them in the world. According to this characterisation the world is

understood as *'standing reserve'* which is *'revealed'* differently according to the ways in which he is able to manipulate it technologically. In this way man's relationship to technology is understood as one of a constantly changing set of norms:

'What is modern technology? It too is a revealing. Only when we allow our attention to rest on this fundamental characteristic does that which is new in modern technology show itself to us...Agriculture is now the mechanized food industry. Air is now set upon to yield nitrogen, the earth to yield ore, ore to yield uranium, for example; uranium is set upon to yield atomic energy, which can be released either for destruction or for peaceful use...that expediting is always itself directed from the beginning toward furthering something else...'

Warnock (2003) and Canton (2004) develop this line of argument in relation to modern medicine. According to Warnock's argument (Ibid, p. 459) the deliberate alteration of nature by mankind cannot be prevented, as it is inevitable that humans will seek to manipulate it in ways which enable them to transcend the limitations that it imposes:

'Nature has an intrinsic value...But we also value the power that the new biotechnology may have to provide medical science with the means to cure or alleviate conditions so far without remedy...there is one sense in which the use of the new technology whether in agriculture or in medicine is far from contrary to the grain of Nature. For man is a part of Nature and his role in the natural world is to improve his environment and to try to ameliorate the ills that threaten the whole species...'

We can apply these arguments to the context of developments in medical practice and research. If they have correctly apprehended the logic of innovation then fluctuations in normality according to what is technologically possible will influence the position of the threshold that delineates 'therapeutic' applications of technology from ones that 'enhance', according to the categorisations that we presently employ.

1.7) Enhancement Present and Future

The debate on human enhancement has increased in both breadth and depth over recent years. The recent surge of interest and scrutiny has occurred partly in response to rapid developments in medical technologies and the societal and utopian expectations of what may be realised by present research trajectories in future.

Bostrom (2005) notes that human enhancement is now a mainstream concern in bioethics, having over the past two decades migrated from the margins of scholarship into the centre ground. Two interconnected reasons for this can be identified: firstly, biomedical technology is advancing rapidly; secondly, it is a tendency of humankind that it seeks improvement of the conditions in which it finds itself. As Hauskeller writes (2011, p.1): *'Progress has often been driven by utopian dreams of a better world'*. A level of technological modification of ourselves and the world, described in myth as mentioned previously, and more recently in science fiction, may be moving increasingly from the potential to the actual, as our ability to manipulate and exert control over biological and physical processes grows.

One salient prediction of the biomedical engineering of mankind and society can be seen in Aldous Huxley's canonical work *'Brave New World'* (1932), to which Francis Fukuyama makes frequent reference in terms of present developments in biotechnology in *'Our Posthuman Future'* (2002). More recently, in his novels *'Atomised'* and *'The Possibility of an Island'* Michel Houellebecq has explored a number of transhumanist, posthuman and enhancement themes such as mind uploading, immortality, and human reproductive cloning. The first two of these are fields in which science and engineering research is visibly proceeding (de Grey, 2005; Hayworth, 2012; Rothblatt, 2012), and third is one in which research is –

controversially – ongoing³, despite its widespread illegality (Zavos & Illmensee, 2006).

Interest in the hypothetical ‘posthuman’ end of human enhancement (Fukuyama, 2002; Kuzweil, 2007; More, 2013) has now extended beyond the initial confines of futurist philosophical speculation to related spheres of bioethical interest such as sociology and anthropology (Rose, 2010; Pyyhtinen & Tamminen, 2011; Conrad & Potter, 2004), law (Kolber, 2006; Bostrom & Roache, 2010); and policy studies (Greely et al, 2008; Bostrom & Sandberg, 2009). Interest has also filtered into the public arena, in the form of non-academic news⁴; exhibitions and public events⁵. In 2003 the President’s Council for Bioethics in the USA carried out an early engagement with the ethical issues at stake in human enhancement⁶, and more recently a range of policy-orientated consultations have been carried out both in continental Europe⁷, and the UK^{8,9}.

Debate is growing concerning what the appropriate response should be to an acceleration in enhancement technologies (Bostrom & Savulescu, 2009; Coenen et al, 2010). Although this growth has been propagated by observations of actual occurrences in science and technology, the growth of the debate supports the observation that as yet no clear, settled normative policy response exists to guide decisions about enhancement that would be in society’s interests (Juengst, 2009; Greely, 2010; Drabiak-Syed, 2011).

One reason for this is that despite the widespread ethical significance that an expansion in human enhancement may have, contemporary options are very limited. Rosoff (2012), for example, contends that despite the eugenically motivated concerns about genetic enhancement and the possibility of altering the

³ http://zavos.org/zavosportal/index.php?option=com_content&view=article&id=107/
<http://news.bbc.co.uk/1/hi/world/asia-pacific/4554704.stm>

⁴ <http://www.bbc.co.uk/search/news/?q=human%20enhancement>

⁵ <http://www.wellcomecollection.org/whats-on/exhibitions/superhuman.aspx>

⁶ <http://bioethics.georgetown.edu/pche/reports/beyondtherapy/index.html>

⁷ http://www3.nd.edu/~mlee20/NBR_Enhancement.pdf / <http://epochproject.com/>

⁸ http://www.nuffieldbioethics.org/sites/default/files/files/Novel_neurotechnologies_Chapter_8_Non-therapeutic_applications.pdf

⁹ http://royalsociety.org/uploadedFiles/Royal_Society_Content/policy/projects/human-enhancement/2012-11-06-Human-enhancement.pdf

downstream genetic constitution of future generations, the knowledge and technology required for its realisation is currently so distant from us that we should think in more immediate terms.

At present effective enhancement extend to only a limited range of aesthetic, cognitive, and physical interventions and is thus relatively modest in its capacity to improve or transform (Bostrom & Roache, 2008; Bostrom & Sandberg, 2009), relative to some of the radical predictions being made about what may be achievable in future such as mind-uploading or immortality (de Grey, 2005; Kurzweil, 2005; More, 2013)

Despite the presently limited range and potency of current enhancements, the ethical issues that they raise indicate what will be of moral significance if knowledge and research advances such that powerful enhancement technologies do emerge. This is true not only for policy at a society-wide level, but also in the more parochial context of everyday clinical and research practices, and incremental changes to medical procedures that may occur from the emergence of new norms of new technologies and the new norms of health which correspond to them. Bioethical debate on these issues is currently defined by a range of inconclusive theories concerning what constitutes enhancement, and within which there is little agreement.

If the enhancement potential of medicine proliferates, and the desire for enhancement grows amongst the general population it is not clear what, institutionally speaking, medicine ought to do in terms of its obligation to balance: i) the duty of care that doctors bear to their patients; ii) recalibration of the concept of 'medical need' if norms of health change increasingly rapidly; and iii) demands of justice relating to the equitable distribution of finite medical resources. These responses can in many cases be mapped onto many broader and pre-existing debates within moral and political philosophy, for example as a reassessment of historical oppositions in the philosophy of justice such as Rawlsian liberalism (Allhoff, 2005; Selgelid, 2013) and Nozickian libertarianism (Harris, 2010; Capps, 2011), within the context of enhancement.

1.8) Enhancement and Empirical Bioethics

As a field of scholarship no longer in its infancy the epistemological and moral 'battle lines' circumscribing the human enhancement debate have now been staked out (Greely et al, 2008; Berghmans et al, 2010). There is, however, an imbalance within the field relating to its weightiness towards theory against the relative scarcity of empirical data (Hotze et al, 2011; Wasson et al, 2011).

Relatively few products exist which have a significant history of both therapeutic and enhancement use according to the biomedical model of health. This lack of a relevant history contributes to the largely speculative nature of the field (Jones, 2006; Rosoff, 2012). Notwithstanding for the time being the apparent difficulty of deriving normative claims from states of affairs - namely the 'is / ought' problem – (Hume, 1739) little systematically obtained empirical data exists which investigates how enhancement is perceived and understood from within its own context.

The practical context of the enhancement debate is medical professional practice in the 21st Century. It is those working within this context who will have to make decisions about what would constitute a balanced ethical response to the possibility of an expansion in enhancement technology. It will therefore be valuable to gain insight into how medical professionals conceive and negotiate the issues in view of their responsibilities for the health of those within their care. These responsibilities are not incumbent on those engaged in philosophical speculation about enhancement, and the rational ethical debate in which philosophers are involved will therefore be enriched by data that arises from this material context.

Although the idea of improving the body and extending its capabilities is not new, the means by which we may be able to realise these ideas within the context of modern medicine are entirely new. Few substantial historical examples exist which can be used to advance the theoretical and ethical discussion in a way that is tractable with policy or can meet the pressing demands of justice in healthcare. If

relevant empirical data can be collected that brings to the surface pertinent practical ethical concerns, it will be possible to refine our theories and advance the debate.

Taking this into account a clear path forward is visible. If we require some way to make the theoretical debate more tractable with practice, then we must identify and analyse an example or examples of the purported and problematic therapy / enhancement distinction. It will then be possible to collect relevant empirical data and apply it to the theoretical positions outlined in the debate. We will then be in a better position to recast the therapy / enhancement distinction in a way that achieves a balance between theory and data.

The nuances that data informed by context can offer to the philosophical and ethical debate are essential for developing normative conclusions and recommendations that are ethically consistent with medical practice and health policy. Empirical information that can provide insight into how enhancement is perceived and understood by medical professionals, and which can be examined in the light of the numerous theories which populate the field, is therefore what is needed at this stage of the enhancement debate.

In order to achieve these objectives an appropriate methodology is required. This project is one of empirical bioethics, and therefore combines philosophical (i.e. normative, conceptual) analysis with social scientific (i.e. qualitative, empirical) data. The investigation is interdisciplinary, and an analytic approach that can bridge philosophical and social scientific approaches to ethical issues is required.

Given the aims of this project I advocate the use of Critical Realism (Bhaskar, 1974). This is a philosophy of social science which provides a way of coherently integrating the insights and approaches of both. Critical realism is an approach which has hitherto been little used in bioethics. In chapter three I will show that it constitutes a robust and useful methodology for normative and conceptual analysis which seeks to draw on the valuable empirical data that social scientific research can provide.

One final methodological point should be made before continuing. Given that this is a piece of ethics research, a range of moral theoretical perspectives could have been used as an analytic frame for the work. For example deontological, consequentialist, and virtue ethics analyses would undoubtedly yield useful results. That I attempt to generate 'practical' ethical conclusions rather than ideal ones, however, merely reflects my belief that success in applied ethics consists in acknowledging that moral theoretical approaches conflict. In view of this optimal progress depends instead on balancing these approaches and negotiating a path between them towards the 'best possible' available solution.

1.9) Conclusion

From this broad sketch of the therapy / enhancement distinction and the challenges that it poses, I will draw some preliminary conclusions. The challenge presented by the ambiguous therapy / enhancement distinction is in one respect not new, since it is one of conceptual clarification between concepts whose boundaries overlap, and it is thus a recapitulation of the traditional philosophical problem of disambiguating overlapping concepts. Moreover the idea of 'enhancing' the human is not new either, as antecedents of the contemporary idea can be found in pre-scientific antiquity and myth, when the practical technological means to realise a vision of the enhanced human were not available.

Thus in one sense we are dealing with ancient problems and ideas. On the other hand, however, the contemporary context of rapidly evolving medical technology in which the question of enhancement presents itself indicates that these issues require detailed consideration. In view of the wide ranging ethical implications that enhancement technologies and potential policy responses to them may have, some way of anticipating these implications and formulating normative conclusions that are ethically sound is required.

Given the historical depth of the concept of enhancement, and the recent rapid expansion in scholarly scrutiny and analysis about its possible implications within the context of 21st Century medicine, the main theoretical positions have now

been staked out and established. Persuasive arguments exist both for and against the therapy / enhancement distinction and a range of ethical views have been put forward on either side. However, the debate is inconclusive.

Although appearing unproblematic, under examination the therapy / enhancement distinction is unstable. The first reason for this is that it is logically vulnerable to the claim that therapy is a species of enhancement, since both share the fundamental goal of improving health, functioning, wellbeing, or some combination of the three. If this is true and therapy is logically reducible to enhancement, the erosion of the distinction has problematic implications for the fair allocation of resources: if no clear line can be drawn between therapies and enhancements, why should enhancements not be accessible from a doctor both in principle and in practice? To discriminate against enhancement on the basis of such a logically weak distinction is vulnerable to claims of arbitrariness.

Secondly, the distinction is empirically vulnerable. The integrity of the distinction relies on a convincing account of 'normal' health and / or functioning, since normality is the line according to which a judgement is made about whether an intervention is therapeutic or enhancing in nature. Norms of health, both statistical and perceived, are influenced by a range of historical, geographical, social, cultural, economic, and technological contingencies, however. Given that 'normality' is a concept in a state of permanent flux, the location of the line between therapy and enhancement is correspondingly impermanent.

Thirdly, the combination of these ambiguities has implications for justice in healthcare. Resources are limited and health needs differ in severity. Medicine nominally treats the sick rather than the well, and the well are thus *prima facie* excluded from most decisions about the allocation of healthcare services. If the category into which the constituents of each are put depends on a set of norms that are in flux, however, how is this heuristic for the allocation of resources to be retained in a way that is useful and ethically sound? It is these questions which motivate the research carried out in this thesis and which we will now begin to investigate, starting with a review of the relevant theoretical literature in chapter

two, which will help to show in greater detail where gaps in knowledge presently exist.

1.10) Summary

In this chapter I have introduced the therapy / enhancement distinction and explained why it represents an important practical ethical challenge that should be addressed. I have outlined some of the difficulties associated with using concepts of health and disease for distinguishing effectively between therapy and enhancement. I have also explained the challenge posed by factors such as historical and cultural variation in norms of health which influence how the distinction is understood. I have emphasised the powerful impact of medical technology on definitions of health and disease. I have also raised the issue of ethical relevance entailed by this concerning the fair allocation of scarce medical resources.

I have outlined the current imbalance between theoretical literature and empirical data within the current bioethical debate about human enhancement, and explained why more empirical information is required in order to resolve this imbalance. I have stated my aim to collect relevant empirical data about how the philosophical and ethical challenges of human enhancement are perceived from within the context of contemporary medicine in order to clarify the ambiguous therapy / enhancement distinction and produce a refined account of the relationship between the two.

Having broadly sketched out the problem to be investigated within the thesis, in chapter two I will provide a review of the relevant literature. This will help to identify what information is required to assist in the achievement of the aims of the thesis as a whole. Following this, in chapter three I will justify the use of critical realism as an effective philosophical methodology for combining the theoretical and empirical components of the research, prior to describing and explaining the empirical component in chapter four.

Thereafter in chapter five I report the main findings of relevance which emerged from the empirical study. In chapter six I carry out a philosophical analysis of these findings in light of existing theory towards refining our understanding of the therapy / enhancement distinction. Finally in chapter seven I develop philosophical and ethical conclusions on the basis of the preceding analysis and I make policy recommendations for how the refined understanding of therapy and enhancement can be applied.

Chapter Two: Literature Review

2.1) Introduction

The purpose of this chapter is to identify the main issues of relevance within the theoretical debate about human enhancement and how it can be distinguished from therapy. The review will highlight those aspects of the debate that require further investigation, and how the understanding of these can be advanced by the research to be presented in this thesis. Given the interdisciplinary nature and context of the research, the review will include not only philosophical but also relevant social scientific literature. This will offer a wider conception of the ways in which the relevant concepts can be understood. Moreover, since medicine and healthcare are socio-cultural institutions and this project is one of applied moral philosophy, we require a suitably interdisciplinary approach to the relevant theoretical literature.

Human enhancement is a broad subject and it is not possible to deal with all the relevant literature which exists in the space available. For example the review excludes fields such as disability studies within which relevant work about enhancement has been written. Despite the relevance of accounts of disability to the enhancement debate, the concept of disability itself is not the focus of this project, and hence is not included within the literature reviewed. This review concentrates on those aspects of the debate which are of greatest relevance to understanding the therapy / enhancement distinction in general, and the ethical implications of enhancement within a medical context in particular.

Prior to investigating human enhancement itself we need to examine the various conceptualisations of health that have been advanced within the literature. This is necessary because the therapy / enhancement distinction turns on an understanding of what is understood by the term 'normal' health, and its difference from subnormal and supra-normal states. Following the review of health concepts we will examine changes in norms of health, and the relation of these changes to enhancement. We will also briefly consider the hypothetical

transformation which may represent a final end of enhancement, that of the posthuman.

We will consider various ethical arguments for and against human enhancement. In particular this analysis will include those which appeal to 'naturalness', since these are of great relevance to understanding the therapy / enhancement distinction. Following this I will present an overview of the state of the art in existing technologies for human enhancement and situate the contemporary debate relative to what is possible at the present time. The review will cover the relation of these various themes to clinical and research practices in medicine, and highlight what is missing from the ethical debate at present.

2.2) Concepts of Health, Disease, and Illness: Philosophical Literature

2.2.1) Biostatic vs Evaluative Theories

It is a tautology to state that normal health is normal. As Canguilhem (1989, p. 137) observes, however, *'one could say that continuous perfect health is abnormal'*. Implicit in this observation is the judgement that ill-health and disease are aspects of normality. Thus, in order to use and understand the concept of normality we must first carry out an analysis of health, illness, and disease.

Philosophical conceptions of health, illness, and disease are numerous and diverse. They range along a spectrum from 'value-free' descriptive biological and statistical accounts at one end, to evaluative psychological and sociological accounts at the other end. This distinction can be understood as opposing claims concerning the nature of health states as fundamentally objective or subjective. Between these two poles there exists a range of alternative accounts which attempt in different ways to reconcile the difficulties with the polar accounts and derive utility from the relative benefits of each.

The first kind is the descriptive or 'biostatic' model espoused by Boorse (1975). It is supported to different degrees by Lennox (1995), Wakefield (1995), and Harris (2001). This theory is also known as the 'medical' model, as it corresponds closely

to the diagnostic criteria and rationale used within the context of western medicine. Boorse (1975, p. 542) offers the following summary:

'...health is normal functioning, where the normality is statistical and the functions biological....on our view disease judgements are value-neutral...if diseases are deviations from the species biological design, their recognition is a matter of natural science, not evaluative decision.'

Boorse's argument has been widely criticised, despite its implicitly widespread use in western medical practice. In view of this Khushf (2007, p. 24) asks why it is that Boorse's account remains influential *'if he is so obviously wrong'*, and goes on to answer his question by suggesting that Boorse's model must accurately capture at least some aspects of health. In terms of treating disease, for example, he argues that *'it would be very hard to find anyone who does not see some role for descriptive, fact-based considerations'*.

Opponents of Boorse have attempted to improve on his model. Opposition is frequently grounded in a disagreement with his claim that judgements about states of relative health are value-neutral. De Vito (2000) and Nordenfelt (2006) argue that judgements of health are inescapably value-laden because the deficiencies in functioning that diseases generate tend to limit our capabilities, and these capabilities are, as Toulmin (1975, p. 61) suggests, *'preconditions for almost any other imaginable human good'*.

Consonant with this view Thomasma & Pellegrino (1981, p. 8) suggest that *'a fundamental need of a living organism's health can be said to be an absolute, intrinsic value'*. Hence, within this category of views it is argued that discussion of health necessarily precludes the disaggregation of implicit value judgements, even from those accounts which allege to be purely descriptive. Following this Nordenfelt (2001) insists that health must be judged as relative to goals.

Since goals are subjectively desired because of the value that they hold for the person seeking them, Nordenfelt argues that it is impossible to separate discussion of these from implications of value. He suggests that this is reflected by our day-to-

day use of terms such as health, disease and illness, of which any accurate theory must take account. Agich (1983, p. 38) concurs, arguing that Boorse *'oversimplifies the complex entanglement of descriptive and evaluative elements in disease language'*:

'The conceptual purity which is gained for theoretical health and disease on this account is purchased at the exorbitant price of excusing medicine from the concrete social cultural world. But it is in this world that disease language functions and to this world that philosophical accounts of the language of disease must be relevant.'

The statistical and evaluative positions stand in opposition to each other and are each partially successful in providing a comprehensive account of health. Although they are both plausible positions to some extent, neither supplies a full explanatory account in every possible case. Boorse holds that health is equivalent with physiological functioning that can be described as statistically normal, and yet this characterisation leads to inconsistencies, as Nordenfelt notes (1993, p. 279):

'Many bodily or mental states which are intuitively considered to be diseases or signs of ill health, need not involve any statistically abnormal function. Given a certain very harsh environment, for instance a very hard climate, a certain reduction of function can in fact be the statistically normal one.'

Despite these deficiencies, however, Boorse's biostatic theory is able to criticise evaluative accounts because of their inconsistencies. If it is true, for example, that the primary characteristic of ill-health is impairment of goals, rather than deviation from a statistical species-norm of functioning, then a great many physiological states that do not correspond to our everyday use of the term 'disease' could be considered as such. For example Boorse (1975, p. 544) observes that one may be impaired by being below average *'in any valuable physical quality, e.g. height, strength...'* and indeed that it may also be undesirable to have normal human frailties *'such as a need for sleep and regular access to food and water'*. It does not follow from these limitations that they are diseases, however, simply because they are negatively valued.

Wakefield (1995, p. 237) agrees, arguing that objections to a biostatic explanation of disease can be dealt with by rejecting the claim that apparently value-laden terms such as 'goals' are truly 'value-laden' at all. He suggests that terms such as this are in fact descriptive, and their use in health discourse is misconstrued by those propounding a relativist or evaluative explanation:

'...the fact that one might say that survival is the "purpose" of a certain naturally selected mechanism does not at all imply that one attributes a value - the desirability of survival - to nature. Rather, one is using intentional language to assert that a certain kind of complex non-intentional and non-value-laden causal relationship exists among the mechanism...'

Wakefield argues that to construe health as an evaluative concept is to mistake apparently subjective aspects for objective ones, and hence that explanatory accounts of this kind are reducible to a more basic, mechanistic, explanation of the difference between normal and abnormal functioning.

The two opposing positions are each partially effective, but neither encompasses all of the aspects that are relevant to health discourse. Boorse's biostatic model does not give weight to the subjective negative experience of ill-health, whilst Nordenfelt's evaluative model opens the door for a great many subjectively negative but statistically normal physical states to be considered as diseases. On this reading almost anything could be a 'disease'. Various attempts have been made to reconcile or integrate these positions in order to give a fuller account of health. I will now examine some of these in more detail.

2.2.2) Reconciliations

Although Boorse's model has relatively few strong adherents, conditional support for it is evident in theories which also incorporate evaluative components. Lennox (1995) proposes a synthesis of evaluative and biostatic elements on the basis that some value-based metric for successful functioning is inevitable in judgements of health. He suggests that the invocation of values cannot be avoided in making these judgements. Lennox (1995, p. 500) concedes that Boorse's 'reductionist' account

has significant explanatory power in successfully distinguishing between the relative adequacy of functional states, since:

'The judgement that 'health' refers to a state of successful functioning requires a standard of value, by reference to which organic functions may be judged successful or unsuccessful.'

Lennox points out that despite the difficulty of disaggregating value judgements from a concept of health, the reductionist is entitled to ask how a relativist can seriously defend severing completely the empirical link between health and statistical normality. If there is no necessary connection between the two, the reductionist is entitled to demand a more persuasive account of the reasons for their correlation. Margolis (1976, p. 246) defends the deep connection between the descriptive and the normative in the following way:

'The notion that human beings have a natural function is essential to the eudemonism of Plato and Aristotle and it is, in a way, presupposed by the claims of somatic and psychiatric medicine insofar as they suppose themselves to be value-neutral sciences.'

Alternative accounts contend that the problem inherent to reductive accounts of health as, for example, statistical normality is that they cannot explain different kinds of ill-health. For example, Young (1982) and Marinker (1975) propose a tripartite model. Marinker (Ibid, p. 82) explains:

'The first mode of unhealth is disease. This is a pathological process...The quality which identifies disease is some deviation from a biological norm....The second mode of unhealthy is illness. Illness is a feeling, an experience of unhealth which is...interior to the person of the patient. Often it accompanies disease, but the disease may be undeclared...Sometimes illness exists where no disease can be found...The third mode of unhealth is sickness...Sickness is a social role, a status, a negotiated position in the world, a bargain struck between the person henceforward called 'sick', and a society which is prepared to recognize and sustain him.'

Marinker's approach is intuitively appealing as it corresponds to our everyday use of the terms, and to this extent it satisfies the condition that Nordenfelt suggests any adequate explanatory system must meet. Nevertheless, conceptual 'fuzziness' remains. Sadegh-Zadeh's (2000, p. 607) acknowledges the ambiguity of the concepts 'health', 'disease' and 'illness' and argues that the different states cannot be dealt with by *'yes or no principles'*. As such he suggests that all three must be subject to the *'principle of graduality'*.

This, again, corresponds to our everyday use of the terms health, illness and disease: we understand that it is possible to feel very ill or only slightly ill, to have a disease which is either mild or serious, and to feel fluctuations in our health. He describes the model that he wishes to construct as one which is *'lifeworldly grounded'* (Ibid, p. 621), capturing what is conceptually significant about health, and incorporating both the empirical reality of pathology, and the subjective experiencing of illness. Hofmann (2002, p. 653) offers a related account, and suggests that despite their differences, the concepts are interdependent. Insofar as *'they represent different perspectives on human ailment'*, they require correspondingly different responses.

Hare (1986), Lewis (1953), and Boyd (2000), also argue that a full conceptualisation of health must incorporate both the descriptive and the evaluative components that come to bear upon the relevant terms and their usage. For example, although Hare (1986, p. 176) states that his account *'rests heavily on the notion of natural function'*, he also notes that some degree of evaluation is unavoidable when talking about health, since the judgement that something functions 'badly' entails the implicit judgement that it ought to be repaired (Ibid. p. 178):

'To call a thing bad is to imply that it has qualities which, other things being equal, ought to be avoided or remedied in things of the kind in question. If I have bad eyesight, for example, I ought to go to the oculist and he ought to prescribe spectacles if they will make my eyesight better.'

Similarly, Boyd (2000) characterises health as metaphor for the concept of 'wholeness', adducing the ancient etymological connection between the two words in support of this characterisation. He argues that health can only be fully understood by taking into account the extent to which a person is physiologically able to fully realise a vision of the kind of life that he or she wishes to lead. This account is appealing; however the re-characterisation of health as wholeness does not produce a substantial clarification of the concept of health as such.

One way of resolving this conceptual imprecision might be to formulate a theory away from an ideal of absolute health, towards one which more explicitly explains the relationship between our (objective) capabilities and our (subjective) goals. Pörn (1993, p. 296) offers such a model, proposing an account of health understood in terms of 'adaptedness':

'...does the combination of the ability with a set of environmental circumstances constitute a capacity that is sufficient for the realization of a goal of his? If the answer is affirmative, there is an agreement between his capacity and his goal, a kind of balance...I shall use this kind of generalized adaptedness in my characterization of health.'

Notwithstanding the differences between Boyd and Pörn, the two accounts share an acknowledgement of the epistemic difficulties associated with providing a complete theory of health. Although Pörn believes that this difficulty can be overcome by equating health with adaptedness, he also concedes that 'adaptedness' is a personal matter and not one which can be generalised. In this respect, despite Pörn's attempt to reduce the ambiguity of the concept of health by substituting it with 'adaptedness', it shows itself to be equally as enigmatic as Boyd's substitution of health with 'wholeness'. An analysis of these accounts thus suggests that a fully comprehensive account of health remains elusive.

In spite of the persistent conceptual imprecision, variations of Pörn's account of health as a kind of agreement between one's goals, environment, and capabilities

are found elsewhere. For example, Kovacs (1998, p. 36) offers a heuristic conceptualisation of health '*as somatic and mental ability to adapt to reasonable social norms*'. There is also some parity between Pörn's account and that proposed by Canguilhem's principle of '*biological normativeness*'. Since to talk of goals is to imply a value judgement of certain courses of action, Canguilhem (1975, p. 186) regards health as a state which is '*normative in relation to the fluctuations of the environment*'.

Hesslow (1993) proposes a different solution, however. In view of the inherent complexity of health concepts he gives an account which removes reference to the labels disease, illness, and sickness completely. He contends that in view of the failure of other theories to clarify the meaning of these terms, any correct account must find a different way to explain the relationship between illness, disease, and sickness, and the healthy state from which they deviate.

Hesslow's theory is grounded in the assertion that it is only of secondary relevance to those who provide medical assistance how kinds of ill-health or dysfunction should be ontologically categorised. Rather, what is of primary importance is whether and how the 'fault' can be repaired. Employing a similar reductive characterisations to Veatch's (1981, p. 539) account of health professionals as '*technically competent experts*', and Bayles' (1981, p. 665) '*physicians as body mechanics*', he uses the analogy of a mechanic fixing a car in illustration of this argument, claiming that it is not important to the mechanic what kind of fault has occurred, but simply that a fault has occurred at all.

In this respect Hesslow appears less concerned with which procedures should or should not be considered as appropriate to medical practice and administered under its remit. Instead he argues that we cannot rely on the fact that something is administered within a medical context to tell us whether or not it is a disease or an illness.

Some evidence in support of this is available in the case of cosmetic plastic surgery, which is one of very few historical instances of medical enhancement. If Pertchuk

et al (1998), Gimlin (2000), Henderson-King & Henderson-King (2004) Delinsky (2005), Brown et al (2007) are correct, the key motivation for seeking cosmetic plastic surgery is dissatisfaction with 'normal' appearance, rather than the clear presence of a disease or illness. Hesslow (Ibid. p. 7) suggests that the salient factor determining whether someone requires medical assistance is not whether they are 'ill' or 'diseased' as such, but whether it is possible to remedy whatever the ailment they have - or perceive themselves to have - that is negatively affecting their life:

'Cosmetic surgery is growing in importance and will probably continue to do so. Sex change operations are not motivated by the conviction that gender can be a disease. If and when 'cures' are found for, say, male baldness or normal intelligence, they will become major medical articles. Many physicians are occupied with attempts to give people supernormal functions or capacities, as illustrated by sports medicine and research on longevity.'

Implicit in this argument is the view that the social context in which an individual finds themselves partially determines their relative health. Given that societies and the norms embedded within them change over time, and given also that health improvement is temporally conditioned, several authors have rightly pointed out that norms of behaviour, practice or states of being can change in their social acceptability over time, and in either direction.

Infanticide, for example, has not always been considered an unacceptable practice (Barilan & Weintraub, 2001); and masturbation (Bullough, 1987) and homosexuality (Margolis, 1976) were at different points in the past incorrectly classified as diseases. Hesslow believes that the emphasis within the study of clinical practice is not what constitutes a state of health or disease, but what is medically or technologically possible in terms of sustaining or improving the functioning of the body.

Despite the philosophical orientation of the accounts examined so far, many of them invoke other humans, society, technology, and the environment as influences upon an accurate definition of health. Insofar as health beliefs are tied to prevailing

medical cultures, if the beliefs underpinning these cultures differ then conceptualisations of health are also likely to differ. Given the significance of socio-cultural influences on health and how it is understood, we will now move on to examine theoretical accounts found within relevant literature from the social sciences.

2.3) Concepts of Health, Disease, and Illness: Social Science Literature

Albrecht (2006, p. 268) contends that philosophical questions play an ‘*undergirding*’ role in the construction of social scientific theories within the study of health and illness. One implicitly philosophical view is the widely held position across the social sciences that health concepts cannot be understood in abstraction from their context. That their definitions are subject to changes in this context is thus a central assumption of the social and anthropological studies of medicine. Fabrega (1981, p. 493) writes:

‘It is a truism that conceptualisations about disease have important social implications. Medicine, an institution of society, is defined in terms of its concern with disease. The very definition of disease... is a product of historically determined social happenings. Medical activities, thus, are rooted in socially structured categories.’

Siebers (2001) objects, however, that a purely social model will not do all the work necessary for providing a full account of health, illness, and disease because the intrinsically harmful and life-threatening nature of certain pathological processes cannot be empirically refuted. Consistent with a recognition of the influence of both internal and external influences on health, Engels (1981, p. 599) advocates a ‘*biopsychosocial*’ account:

‘...a medical model must also take into account the patient, the social context in which he lives, and the...system devised by society to deal with the disruptive effects of illness, that is, the physician role and the health care system...By evaluating all the factors...rather than giving primacy to biological factors alone, a biopsychosocial model would make it possible to explain why some individuals experience “illness” condition which others regard merely as “problems of living”...’

What is captured by this account is the claim that a full account of health and those states identified as deviant from it are determined by a mixture of factors that encompasses not only disease pathology, but socio-cultural contingencies as well. The suggestion that these socio-cultural contingencies may be considered as determinants of health to the extent that they promote or inhibit one's ability to live a normal life is one which also appears in the philosophical theories of Toulmin (1975), Agich (1983), Pörn (1993), Lennox (2003), and Nordenfelt (2006). Thus, some degree of interdisciplinary parity is evident in this respect. In addition it follows from these accounts that once society's norms change, definitions of health will also change correspondingly.

2.3.1) Anthropological & Sociological Theories

Although differences exist between accounts of health found in medical anthropology and sociology, they tend to share a key feature. This is the conviction that health cannot be understood in abstraction from the network of which it is a part. Millard (1992, p. 3) offers the following definition of this disciplinary view:

'Medical anthropology takes up the analysis of health in the context of culture, social behavior, economic systems, and human biology...the examination of health issues extends to include knowledge, meaning, social behavior, and biology generally related to well-being, suffering, misfortune, the life cycle, and survival.'

Thus, anthropological accounts view the meaning of 'health' as fluctuating in correspondence with changes in the social, cultural, economic, historical, and technological network of which it is a part. Adherents of this view point out that what is considered 'normal' for a human will be at least significantly constituted by the norms that happen to prevail within that person's particular culture or society at a given time. Hence Benedict's (1934, p. 286) claim that:

'A normal action is one which falls well within the limits of expected behaviour for a particular society. Its variability among different people is essentially a function of the variability of the behaviour patterns that different societies have created for themselves.'

Similarly Unschuld (1978, p. 54) claims that '*medical thought...is specific to a particular world view*'. The relativity of health concepts is also a key theme in the work of Kleinman (1978, 1997, 1999), Kleinman & Sung (1979), Frake (1977), Hahn & Kleinman (1983), and Good (1977). The authors defend their position with evidence from ethnographic studies carried out in regions of the world where 'western' medicine does not dominate. These studies draw attention to the fact that in many pre-industrial regions '*there is nothing which could be called a "professional" sector...*' (Currer & Stacey, 1986, p. 117). Consequently the traditional or folk medicine practices that dominate in these areas (Jiang-Bao, 2000) are, as Press (1980, p. 45) describes them '*largely magicoreligious and cannot be analysed in universal terms which could include Western medicine*'.

This represents a sharp contrast to the biomedically-orientated form of healthcare that dominates in industrialised western nations, one whose structure is acutely rationalist, empirical, '*precisely definable by its scientific stringency*' (Wiseman, 2004, p. 327), and whose '*technological triumphs are its defining image*' (Kleinman, 1997, p. 320). This structure represents a model that '*works most comfortably where there is a biochemical and / or structural defect that provides a simple key to understanding the disease being studied*' (Gillett, 1994, p. 1127), but equally one whose values are informed by '*a narrow technical agenda of professionally defined principles*' (Kleinman, 1997, p. 320).

From a bioethical perspective, medical anthropologists have argued (perhaps understandably, given the necessarily cross-cultural remit of their work) that a weakness of high-tech western medicine is that disease pathology is its '*paradigm object*' (Sadegh-Zadeh, p. 607). From this viewpoint medical decisions may give insufficient weight to the subjective, evaluative, and moral concerns of persons experiencing ill-health, which can come in forms other than the pathological. Good (1977, p. 28) claims that this aspect of healthcare cannot be ignored if it is to be effective, claiming that '*...human illness is fundamentally semantic and meaningful...all clinical practice is fundamentally interpretive*'.

Among the more trenchant anthropological criticisms of western medicine and its account of health made is the accusation that the high commercialism and profit motive of the model distort the true picture of a plurality of conceptions of health, for which one model of treatment alone may not be appropriate. Frankenberg (1980, p. 198) argues that the dominance of this model, as a function of its economic success and identification with '*the high status attributes of Western science*', obscures the therapeutic legitimacy of alternative accounts.

Frankenberg (1980, p. 198) is especially critical of the dominance of the western medical model, claiming that it represents '*a characteristic overstatement of the merits of Western technology including medicine*'. The distorting effect of this dominance is also claimed by others in different ways (Han, 2002; Wolff, 1964; Young, 1981), all of whom criticise the explicitly scientific empiricist bias which characterises the model. Kleinman (1979, p. 7) claims that:

'For researchers in clinical medicine, healing is an embarrassing word. It exposes the archaic roots of medicine and psychiatry, roots which are usually buried under the biomedical science facade of modern health care. It suggests how little we really know about the most central function of clinical care.'

The suggestion here is that the explicitly rationalist bias of western medicine creates distance between the pathological and existential aspects of health, disease, and illness. These elements could, if combined, contribute to a richer and holistic model more able to deal with the qualitative aspects of the experiences of '*the sick person, since it is what happened to him that must be explained*' (Lewis, 1976, p. 120).

The disjunctive aspect of the rationale of western biomedicine identified by Kleinman is consistent with the earlier observations of the sociologist Max Weber, who argues that the ultra-rationalism of modern medicine will inevitably entail circumstances whose outcomes are contrary to fundamental ethical principles of health care. In his 1918 lecture '*Science as a Vocation*' (1996, p. 128) Weber argues that what is most fundamentally at stake, '*Whether life is worth living and when*',

becomes subordinate to the assumption that more life must be necessarily good simply because this is the goal towards which medical practice aims:

'...the general "presupposition" of the medical enterprise is...that medical science has the task of maintaining life as such and of diminishing suffering...Yet this is problematical...the medical man preserves the life of the mortally ill man, even if the patient implores us to relieve him of his life, even if his relatives...grant his redemption from suffering.'

The view articulated here is that 'health' has a multiplicity of subjective, normative, aspects and is not necessarily equivalent or reducible to the technological control of human biological systems. Indeed, given the plurality of interpretations of health found across human cultures and societies, Idler (1979, p. 728) argues that it is simply *'empirically false'* to claim understanding of a concept such as illness without taking into its broader context into account.

Bakx (1991, p. 26) writes that although 'folk' beliefs about health can be found in technologically advanced societies, in these societies such beliefs have become less widespread, viewed increasingly as *'residues from some pre-modern past'*. This change in perception is, as Davies (1997) argues, correlative with increasing urbanisation and technological sophistication in general. Consistent with this account, Gursoy (1996, p. 578) suggests that in the west the biomedical model has over the past 300-400 years become the social orthodoxy:

'The scientific paradigm was born in the 16th and 17th centuries when Newtonian physics and Cartesian rationality replaces the softer and more organic logic of a world view based on religion and an Aristotelian respect for nature. A displacement of paradigms was realised when a desire to predict and control events gradually replaced a less intrusive quest for meaning and significance.'

Hewa & Hetherington (1995) also argue that the developments which occurred during the Scientific Revolution of the C16th and C17th have been particularly influential on the contemporary understanding of health, given modern medicine's *'self-consciously systematic'* (Jordanova, 1995, p. 374) approach to the rectification

or reversal of adverse or undesirable biological, physical, or cognitive processes. This is true whether such dysfunctions are instances of objectively identifiable pathological deviation beneath a statistical norm, or subjectively perceived shortcomings that are not pathological but are nonetheless limiting in some way.

Objective medical conditions of the first kind (e.g. heart disease, diabetes, cancer, Parkinson's disease) are frequently (though not always) relatively straightforward to classify. To describe procedures within the second category, however, as ones which are medical by virtue of addressing a legitimate 'medical' need can be more problematic. Some examples of these include: the prescription of hormone treatment to restrict the height of tall teenage girls (Rayner et al, 2010); cosmetic plastic surgery to reverse signs of ageing or enhance attractiveness (Rogers, 1976; Sarwer & Crerand, 2004; Delinsky, 2005); 'off-label' competitive use of neuropharmaceutical stimulants (Coveney et al, 2008; Williams et al, 2008); and cryonic freezing for extreme, or eventually indefinite, life extension (Romain, 2010; Underwood et al, 2008).

In cases such as these a species-typical characteristic is perceived to confer some disadvantage in need of amelioration or rectification. It is this subjective identification of 'faults', whether or not they should genuinely be understood as diseases or states in need of rectification that contributes to the blurring of the concept of 'health'. The examples given in the previous paragraph all relate to a further issue of relevance within theories of health, namely changes in perceptions of what constitutes normal health and the factors which influence them.

2.4) Norms of Health

Moravcsik (1976, p. 344) offers a historical analysis of health concepts from antiquity to the present day. On the basis of this he concludes that our fundamental understanding has neither undergone any radical advance nor increased in sophistication:

'We do not seem to have a better answer than the one Plato proposed: we must assume a conception of natural bodily functioning and regard as medical treatment those efforts that aim at the preservation or restoration of this functioning.'

Consistent with this assertion, and despite significant differences between the theoretical explanations of health advanced, Mordacci (1995, p. 478) makes the observation that they are largely united by some conception of 'normal' health, whether this norm is expressed in statistical or experiential terms:

'The fundamental feature of the concept of health seems to be the reference to a 'norm', in both the bio-statistical and the normative-ideal sense. Many of the definitions of health that have been given refer to one or both of these two meanings of 'norm.'

On the other hand Amundson (2000, p. 36-43) is critical of adherence to 'normal functioning' and considers it misleading, since biological life is characterised by diversity. Consequently he is also critical of theories which valorise the normal, and implies that such valorisation may be implicitly sinister:

'Variation is ubiquitous...Ian Hacking dates the origin of the concept of normality to the rise of statistics in the nineteenth century. He says that normality ...uses a power as old as Aristotle to bridge the fact/value distinction, whispering in your ear that what is normal is also right'

Thus, opposing views exist concerning the value of 'normality', and by implication the acceptability of altering it. The concept of 'normal health' has, as we will see, significant implications for the therapy / enhancement distinction. Stempsey (2006) and Mechanic (1973), for example, argue that innovation in and increasing integration with medical technology generates new norms of functioning, and these arguments are relevant to theories of human enhancement.

Scholars of science and technology studies and medical sociology have argued that new social norms and norms of health will emerge that are increasingly characterised by the 'cybernetic' union of human biology and technology (Dunbar-

Hester, 2010; Verbeek, 2008; Ihde, 2003). Franklin (2006) develops Haraway's famous claim in 'A Cyborg Manifesto' (1991, p. 168) that 'we are all chimeras' because:

'...the extent to which biological knowledge, biotechniques, and biology "itself" reshape each other, and co-evolve, may never before have been made so explicit as today, through the redesign of the biological in the context of bioscience, biomedicine and biotechnology.'

This question of the potential for technology to create new biological or physiological norms is of significant interest within philosophical analyses of health. Stempsey (2006) for example, examines the changing relationship between medicine and technology via a synthesis of the philosophy of Heidegger (1950), Jonas (1984) and Canguilhem (1975). Stempsey's argument (Ibid, p. 227) is that:

'...one of the characteristics of emerging medical technologies is that these technologies lead to new conceptions of health. When technologies enable the body to respond to more and more challenges of disease, we thus establish new norms of health.'

Stempsey argues it is inevitable that over time medical technology will alter humankind. Moreover given that medical research aims at understanding the mechanisms of the body such that they can be brought under our control, the level of control and successful manipulation that we can exert creates these new norms. Vos & Willems (2000) argue that these norms will in turn change our expectations about the degree of control to which we are entitled in the form of access to medical services or procedures.

Ellul (1962, 1976, 1978) makes a similar argument in relation to technological change more generally, and develops a critique grounded in a question over the end point of continuous development. He argues that the growing technologisation of human life presents an increasingly technologised further set of goals and possibilities towards which human activity can be directed, resulting in a characterisation of *'technology as man's new environmental order'*. Consequently he

identifies technology as possessing a degree of autonomy of its own insofar as it has the capacity to direct the nature of its own existence as well as that of others.

This is of relevance to presently unconventional interventions which may become more common medical practices in future, assuming a sufficiently successful research trajectory. One extreme example of this is cryogenic freezing, wherein a human individual or his or her head is frozen and preserved immediately after death until such time as medical technology is able to reanimate the body and enable the person to continue living indefinitely. There are several cryonic preservation facilities throughout the World - the Cryonics Institute¹⁰, for example, founded by Robert Ettinger in 1964, currently maintains 103 bodies in cryogenic stasis.

Similarly, institutes such as SENS, led by the gerontologist Aubrey de Grey, are carrying out research into regenerative medicine with the aim of enabling humans to reverse ageing and live indefinitely. This is significant in view of the observation that ageing itself is not typically considered a disease at present (Caplan, 1981; de Grey, 2005). Rather, it is the deleterious by-products of ageing identified as diseases which require treatment (Temkin, 2010; Barazzetti, 2010; Bond, 2010). Caplan argues, however, that there are grounds for considering ageing to be a disease in view of these deleterious by-products which it entails.

Following a re-characterisation along these lines De Grey (1997, 2005) also understands ageing as a process in need of a 'cure' which can be permanently inhibited such that death need never occur. Fox (1976, p. 245) makes an argument which, if true, implies that the emergence of institutes such as SENS¹¹ may be unsurprising, despite the apparently radical changes to human norms that they advocate. She notes a tendency from mankind's increasing ability to defeat existential threats using technology that it altered how we understand our relation to death and its (apparent) inevitability, and which:

¹⁰ <http://www.cryonics.org/>

¹¹ <http://sens.org/>

'...has helped to push physicians, nurses and other medical professionals into a pugilistic tendency to combat death at any cost, and to define its occurrence as a personal and professional defeat.'

Mechanic (1973, p. 12) suggests that these distortions of the traditional ideal of medical practice continue to be driven by technological change, and hence that *'modern societies are characterised by medical conceptions that are varied and in flux'*. He goes on to claim that the rules and systems of control implemented to manage this change do not conform to any overall vision of what kinds of procedures ought or ought not to constitute a medicine of the future and have been created (Ibid. p. 13):

'...on an ad hoc basis as we went along. For example, when transplant technology confronted us with the issue of obtaining viable organs, we began to reconsider the biological meaning of death and to ponder the legal questions of organ acquisition and disposal.'

By contrast, however, arguments have been offered in support of the ad hoc nature of development and medical provision. Popper (1966, p. 213) argues that *'piecemeal'* change via responses to immediate challenges constitutes an important form of resistance to the *'utopian'* technological engineering of societies according to a vision of the *'ideal state'*. In defence of such an approach to technological change he argues that:

'...The politician who adopts this method may not have a blueprint of society before his mind...but he will be aware that perfection, if at all attainable, is far distant, and that every man...have a claim to be given all possible help, if they suffer...It is the difference between a reasonable method of improving the lot of man, and a method which, if really tried, may easily lead to an intolerable increase in human suffering.'

It is in view of these various considerations of the future of medicine and what more we may be able to achieve that the idea of human enhancement comes into view. Enhancement is, as we will see, predicated on the acquisition and development of new functional norms, rather than the restoration of existing ones.

It is thus characterised as distinct from the traditional medical enterprise and its understanding of health and normality. We will now move on to examine theories of enhancement and how they relate to the conventionally therapeutic orientation of medical practice and research.

2.5) Therapy Vs Enhancement

Human biomedical enhancement is an emerging phenomenon, and as such much of the literature is speculative in nature. In this section we examine in more detail theories relating to the therapy / enhancement distinction, as well as actual technologies which exist and enhance human capacities in relevant ways.

According to a typical reading, therapy is used to compensate for dysfunction by restoring functioning to a normal level, whereas procedures used to improve functioning above this normal level that go '*beyond therapy*' (Kass, 2003) to make one '*better than well*' (Elliott, 2004) are often described as 'enhancements'.

Although this distinction appears clear, it reveals itself to be more complex under investigation because of a) the fundamental goal of improvement shared by therapy and enhancement and b) divergence between accounts of normality (Lin & Allhoff, 2008; Bostrom & Roache, 2008; Bostrom & Savulescu, 2009).

Whether something is considered to be a therapy or an enhancement depends on where we draw the line between function and dysfunction, or between what is normal and abnormal, as defined by the limits of the 'normal range'. As we have seen, what is considered to be 'normal' or 'healthy' is subject to socio-cultural, economic, technological, and historical change. Consequently definitions of treatment and enhancement may change correspondingly (Daniels, 2000; Shickle, 2000; Stempsey, 2006), as we saw earlier in Bess's (2010, p. 647) account of enhancement as a '*moving target*' by virtue of it being '*pegged*' to the concept of health whose meaning is not static.

Other writers have also addressed this issue (Ten Have, 1995; Wildes, 2001; Hill Curth, 2003; Creuss & Creuss, 2008; Serna, 2012). Indeed Serna reminds us that medical science and technology have developed means to protect entire societies

from large scale threats to health which affected less developed societies in the past. Infectious diseases such as smallpox (Barquet & Domingo, 1997) or bubonic plague (Hinnebusch, 1997), for example, have now been largely eradicated. We may now take their eradication for granted, since when eradication occurs it becomes normal not to consider these pathogens as threats, despite that on this view the eradication of disease or development of vaccines may legitimately be viewed as ‘enhancements’ (Juengst, 1997; Lin & Allhoff, 2008).

This is clearly desirable, and as Wildes (2001) contends, given the present rate of technological development it is likely that options for ‘medical intervention’ will increase in scope and range. Leach (1975), however, interprets this trajectory of development as one in which the primary aim of medicine will change from being predominantly curative or therapeutic, to emphasising health maintenance rather than repair as overall public health improves.

A corollary of this is that, if successful, this change of focus may entail a diminution in the emergency or ‘matter of life or death’ role that medicine would have played in the past. Indeed Levine (1987) makes the related claim that increasingly effective treatment or management of disease and illness has engendered a growing emphasis on ‘quality of life’ as a goal of medical care, since many more chronic or existential challenges can be overcome. Returning briefly here to Hesslow’s theory of health, in the following passage (1993, p. 7) he underlines the goal of improvement that it shares with the apparently distinct phenomenon of enhancement is underlined:

‘...disease is so frequently associated with demand for treatment, usually because of suffering or potential suffering, that it is generally practical to use the disease label as a justification for medical intervention...but we must not let it mislead us into thinking that it is having a disease per se that is crucial rather than the potential benefits of treatment...’

The putative therapy / enhancement distinction can – apparently - be understood simply. The goals of healthcare seem unproblematic, since they aim to rectify

dysfunction. Enhancement appears distinct since it aims to boost from a state of normality. Indeed several technologies of interest are currently either only distant technological realities or significantly different from the kinds of core procedures carried out in medicine, such as the earlier examples of mind uploading (Kurzweil, 2005; Rothblatt, 2012); and the indefinite extension of the lifespan (Harris, 2004; de Grey, 2005).

There are, however, enhancements whose application bears a closer relation to standard medical practice. Cosmetic plastic surgery can be used as a form of enhancement (Sarwar & Crerand, 2003; Delinsky, 2005); Beta-blockers may be prescribed in the absence of pathology or illness, for example to musicians for dealing with the pressure of live performances (Foddy & Clayton, 2004; Schneier, 2006; Gorman & Gorman, 1987); and it has been argued that vaccinations can be reasonably characterised as enhancements (Juengst, 1997; Daniels, 2000; Holm & McNamee, 2010) insofar as they boost an already healthy immune system.

What is obviated by these examples is similar to Juengst's (1997) observation that therapy and enhancement may be inseparable to the extent that a goal of the former is served by the latter, for example in enhancing one's health to protect against the occurrence of disease. As Scripko (2009, p. 296) notes, the aims of therapy and enhancement may be continuous in many cases since '*enhancement technologies will often fulfil medicine's goal of promoting health*' (Scripko, 2012, p. 296). The clarity of the distinction is blurred further if we recall Harris' argument (2009, p. 131) that, insofar as they improve functioning, all therapies 'enhance'. Since '*an enhancement is by definition an improvement on what went before*', he concludes that because the health of most individuals receiving medical treatment is enhanced by it, so '*most of what passes for therapy is an enhancement*'.

Thus, a significant focus of the human enhancement literature is how this ambiguous and changeable distinction can be upheld when applied to specific instances in context. There is little disagreement within the literature about what the term 'human enhancement' is meant to designate. As Buchanan et al (2000, P. 110) state, the distinction is posited because it '*draws a line between...interventions*

meant to cure...and interventions that improve a condition viewed as a normal function...' What is disputed, however, is how normality can be identified correctly, and how we ought to respond to the possibility of enhancing the human. There is, therefore, at present some indeterminacy about what would constitute an ethically appropriate response. We will now turn to some of the moral issues raised by this indeterminacy.

2.6) Ethical Issues in Enhancement

Daniels (2000, p. 313) adopts a moderate ethical stance towards the benefits of human enhancement, and an epistemologically circumspect position in relation to the logical strength of its distinction from therapy. He claims that:

'...no reasonable defense of the treatment-enhancement distinction is possible if we expect too much of it.'

Daniels argues here that the main question when assessing the ethical viability of medical procedures is not 'is this a therapy or an enhancement?' but – in tacit agreement with Boorse's biostatic model of health - whether the procedure is compatible with ensuring that as many people as possible meet the natural 'baseline' of human functional range. His reason for framing the argument in such a way is that his concern is not with the theoretical or metaphysical question of what a disease or a disability 'is', but rather a practical one of distributive justice. To this end, Daniels (Ibid, p. 318) argues that we should adopt the concept of 'normal functioning' as a heuristic because:

'Despite many other sorts of comprehensive moral views, people may agree that maintaining normal functioning contributes in a reasonable and central way to protecting equality of opportunity.'

Daniels claims that since enhancements may help to even out inequalities in statistically normal functioning, the relevance of a strict demarcation between them as 'treatments' or 'enhancements' is neutralised. Furthermore Powell & Buchanan (2011, p. 10)'s observation of what they call '*the ubiquity of suboptimal*

design' reminds us that even 'normal' health may be defective relative to the achievement of certain goals.

This observation has in turn been used by Savulescu (2006), Harris (2009), and Nam (2013) in arguments which purport to show that a still more pressing case can be made to show that there is a duty to enhance. They argue in different ways that if the means to improve health and well-being are available but forbidden, then those who forbid their use must bear the responsibility for favouring the status quo and its prohibition of these benefits to health.

Endorsements of enhancement grounded in the need to provide a fair opportunity to all are advanced both by more radical pro-enhancement thinkers as well as those such as Daniels who emphasise the need for caution. Buchanan (2009), Harris (2009), Juth (2010), Temkin (2012); Sandberg & Savulescu (2011), Lin & Allhoff (2008), Bostrom & Roache (2008), Skripko (2010), Greely et al (2008) advance variations of this position. Such endorsements are grounded in the ethical legitimacy of equalising opportunity, reducing socio-biological inequalities, and increasing options for autonomous self-determination.

These difficulties permeate the treatment / enhancement debate. In particular it is important to understand how this distinction can be made in view of the difference in perceived moral status between enhancements for therapy (the tools of healthcare), and enhancements for becoming 'better than well' (deemed to fall outside the remit of healthcare, perhaps for achieving 'positional' social advantage).

The social context of enhancement has been raised as problematic, especially in relation to their use for gaining this kind of position advantage. Some believe that human enhancement technologies are likely to be corrosive to society, since if they are successful they are unlikely to be equally available to everybody, and if this is the case then they may exacerbate rather than reduce socio-economic disparities which already exist (Fukuyama, 2002; Kass, 2003).

The literature indicates that enthusiasm for enhancement is found more commonly within philosophical writing on the subject than within the social sciences. This is perhaps understandable given the historical significance attached to the influence of power structures within the sociological canon (Coser, 1977; McLellan, 2000; Giddens et al, 2012), and the historical background of eugenics which is antecedent to contemporary debates about enhancement (Adams, 1990; Raz, 2009; Bauman, 2010).

An anomalous position, however, is offered by Serna (2012), who argues that it may be possible to use enhancements in ways that benefit societies. If interventions existed which could promote *'love, care, belongingness, and solidarity'*, then these kinds of enhancements could be allowed that are *'congenial to communitarian sympathies'* (Ibid, p. 216). The invocation of these ethical concepts is significant. Since these are desirable features of human society, the suggestion that enhancements could be used to realise them underscores an important issue of contention within the debate. Advocates and critics of enhancement appeal to the moral significance of certain features of human life as reasons both for and against modifying what is given in nature. Ferrari (2008, p. 7) reminds us that:

'Both critics and supporters of NBIC convergence and enhancement appeal to the same values...: for critics, respect for human dignity implies respect for the current given physical and mental state of the human being as provided by nature; for supporters of enhancement...the present state is only a step in evolution and is quite unsatisfactory.'

Social scientific critiques frequently highlight the potentially coercive nature of biotechnological power: if what is 'given' is no longer considered adequate, the threshold of what is considered normal - and thus in no need of rectification or improvement - will raise, and individuals may feel that they must adopt these technologies in order to remain 'normal', even if they do not wish to (Conrad & Gabe, 1999; Rose, 2007). A further, related, concern has been raised by Sandel (2004) in what may be summarised as the 'arms race' argument. Used also in

various forms by other enhancement sceptics, Sandel's argument (Ibid, p. 4) deals with the possibility that access to enhancements would become increasingly competitive, leaving '*those who couldn't afford to buy their way up*' even more disadvantaged than they were before.

Parens (1995) also criticises our rejection of given 'fragility' by biomedical means as an unattainable 'desire for paradise' which is damaging both to the individual and to society. It is the concept of perfection implied here which troubles many opponents of enhancement. Of particular concern is the connection between enhancement and the eugenic ideology of the Nazi regime of the 1930s and 40s whose aim was the eradication of anything that it considered to be deviant (Reindal, 2000; Buchanan et al, 2000; Koch, 2010; Selgelid, 2013).

Nazi eugenics, however, were state-directed, population-level, coercive efforts at social engineering. By contrast advocates of human enhancement characterise it as increasing choices for individual freedom and in this respect argue that they are not synonymous with each other. Agar (2008), for example, has responded to claims of eugenicism by accepting the label, but suggesting that enhancement ought to be understood as a '*liberal eugenics*', framed in terms of individual choice, freedom, autonomy, and self-determination rather than the coercive 'negative' eugenics of the past.

Pursuing the relevance of choice a little further, Kahane (2011) has responded to the worries of Sandel and Parens that genetic enhancement in particular will create a devaluation of the 'given' or 'unbidden'. He is sceptical of the implication it is ethically corrosive for humans to direct or divert natural processes from the course that they might otherwise take, pointing out (Ibid, p. 361) that '*birth control is a form of control*'. Since parents '*can control who they reproduce with and when*', he concludes that '*natural reproduction is actually not so unpredictable*'.

This argument, however, relates specifically to reproductive choices about one's non-existent offspring. A related argument is also put forward by Bradshaw & ter Meulen (2010, p. 673) concerning decisions about self-modification. They claim

that to allow individuals to modify themselves according to a personally held vision of themselves *'as one who has his or her own ends in mind'* constitutes a defence against coercion, whether such coercion comes from others or from the limitations that nature imposes on us. They suggest only by respecting the legitimacy of such a vision does one *'recognise and respect the person as they are as a morally whole person'*. The authors (Ibid, p. 673) place significant emphasis on the importance of Isaiah Berlin's 'negative liberty rights' (1969) for withstanding the kinds of undesirable eugenic scenarios envisaged by critics of enhancement:

'Berlin is clear that no matter how obvious it might appear from the outside that certain people might do better, in some sense, if they were different, they are actually not other than they are. One has to start from the person as they present themselves. To do otherwise is to oppress.'

Advocates of human enhancement in the present day who adopt this position thus claim that their aims are laudable by distancing themselves from the antecedent background of coercive eugenics. Koch (2010, p. 696), however, argues that these aims are misguided, and that more equitable strategies for the allocation of resources could be adopted which give greater weight to accommodating biological diversity rather than the need to alter it. He suggests that if the true aim of the enhancement enthusiasts is to reduce suffering and improve potential:

'...they might endorse...those programs that improve the life of persons with cognitive, sensory, and physical differences. They do not promise readers for the blind or sign language translators for the deaf, however. They do not insist upon public access for those who travel in wheelchairs.'

Similarly Raz (2009, p. 14) argues that a distinction between 'old' and 'new' eugenics apparently grounded in autonomy is misleading, and that:

'...eugenics, viewed as dystopian and authoritarian in most of the 20th century, is in the process of being reinterpreted today as utopian and liberal.'

Bauman's (2010) critique of medical biotechnology is more general. He argues that eugenically-driven events such as the Holocaust are by-products not just of technological development, but of human ideology. He claims (Ibid, p. 113) that eugenic thinking is rooted in the Modernist assumption that man can and should exert control over nature wherever an obstacle or perceived threat presents itself:

'Modernity...is an age of artificial order and of grand societal designs, the era of planners, visionaries, and – more generally – “gardeners” who treat society as a virgin plot of land to be expertly designed and then cultivated and doctored to keep the desired form...'

Whether or not one favours human enhancement, the gravity of antecedent eugenic projects undoubtedly imbue the arguments for and against with ethical significance. Indeed Wasson (2011, p. 21) contends it is unlikely that profound ethical questions surrounding the use of new medical technologies will ever abate. She argues that they are *'here to stay'*, on the basis of *'the pace of scientific advances and the human desire to restore dysfunction and improve the human condition...'*

Pellegrino (2004, p. 2) makes a similar claim, grounded in the kinds of freedoms prized in liberal societies which people are unlikely to relinquish:

'It is likely that outright rejection of enhancement would encounter strong resistance. Satisfaction of personal desires, freedom of choice, and "quality of life" have, for many, become entitlements in a democratic society. Few will want restrictions placed on their choice of enhancement.'

De Grazia (2005), Savulescu (2006), Greely et al (2008) and Harris (2009) have defended different forms of enhancement along these lines. Assuming a) the implementation of appropriate systems of access; and b) that the use of enhancements is chosen and not enforced distribution, they argue that that the lives of persons with cognitive, sensory, and physical differences could be changed in ways that would be beneficial to them.

Defending enhancement along these lines Sandberg & Savulescu (2011, p. 105) insist that '*The best way to protect the disadvantaged...is not to prevent enhancement*', but rather that the benefits of enhancement should be harnessed in policy '*to protect the least well off and to provide everyone with a fair go*'. Similarly Allhoff (2005, p. 44) points out that it is not enhancements per se that could cause injustice, but rather that '*there would have to be an unjust distributive scheme to enable the injustice to come about*'. He concludes that assuming a just distributive scheme can be determined '*enhancement, as a good or service, can be distributed according to the principles of that scheme.*'

These responses, which locate the moral difficulty in the system of distribution and control rather than the enhancement itself lead to a further objection. This is the worry that the benefits of enhancement would accrue only to those who could afford them, thus exacerbating existing health inequalities. Allhoff et al (2009, p. 21) note that only '*the wealthy...can best afford such innovations*'. On the basis that such a situation would risk '*creating an even wider gap between the haves and the have-nots*' they thus acknowledge that within the enhancement debate '*fairness is another value to consider*'.

Again, however, responses to this objection have been advanced which argue that, properly governed, enhancement could be used to reduce inequalities rather than inevitable exacerbating them (Cooke, 2003; Kamm, 2006; Powell & Buchanan, 2011). Whilst the standard that such governance would have to meet is undoubtedly high, nevertheless it contributes to a fine balance in terms of the arguments for and against the moral acceptability of enhancement.

Along these lines Brownsword (2012, p. 345) has outlined five conditions for the ethical use and distribution of access to enhancements which would cleave its beneficial aspects from those about which we ought to be concerned. Principles 1 and 3 are as follows:

Principle 1: A should not use enhancers if this would cause harm to B (or others).

Principle 3: B should not harm A by applying improper pressure (from coercion through to inducement) for A to use enhancers.

The theoretical models of justice in access to enhancements are reasonable as far as they go. They assume, however, that the enhancements in question are safe and effective. To enhance ourselves safely, however, depends on first having properly understood the biological systems that we are attempting to modify. Despite their pro-enhancement stance, Bostrom & Sandberg (2009, p. 375) attest to the difficulties inherent to such a task in describing humans as already being ‘*a marvel of evolved complexity*’, in that:

‘Such systems can be difficult to enhance. When we manipulate complex evolved systems, which are poorly understood, our interventions often fail or backfire. It can appear as if there is a “wisdom of nature” which we ignore at our peril.’

This is of particular relevance when considering genetic modifications, since these cannot be reversed and will create permanent downstream changes in the human genetic constitution (McGleenan, 1995; Shickle, 2000; Coady, 2009), the outcomes of which may be difficult to predict or control. Fukuyama (2002, p. 82) argues that genetic enhancement represents a significant danger because the possibility of unintended consequences occurring does not provide any guarantee that it will not be attempted:

‘The history of technological development is littered with new technologies that produce long-term consequences that led to their modification or even abandonment...’

This argument is understandable because the negative consequences of misusing of powerful technologies such as genomics could be significant and far-reaching. However the opposing argument is always available. All technology, including genetic technology, carries a risk or ‘*threat of harm that cannot be conclusively ruled out*’ (Holm & Harris, 1999, p. 398). However if the presence of risk is adduced

as a reason not to engage in research then the precautionary principle at work here *'will block the development of any technology if there is the slightest theoretical possibility of harm'* (Ibid. p. 398).

If this principle were generally applied then although certain harms would be prevented it would also inhibit the reduction of others that follow from developments in medical science. Consequently such a principle is too blunt for making any more nuanced judgements between the balance of potential risks and benefits in individual technologies and products.

Even if Fukuyama's concerns are justified, Allhoff's (2005) argument implies that this is not a legitimate objection to enhancement *in principle* because it is predicated on enhancement being carried out on the basis of faulty scientific understanding. Allhoff accepts that this constitutes a practical limitation on good reasons for engaging in enhancement but in posing the question *'Once these developments are realized, what moral objections will remain?'* (Ibid, p. 44) rejects the implication that enhancement as such is ethically troublesome.

Irrespective of whether this defence is applied to permanent or reversible forms of enhancement, however, moral complexities *do* remain. Bostrom & Sandberg (2009, p. 381), for example, argue that we are now maladapted to deal with the challenges of the modern world. Although *'Evolution has fine-tuned us for life'*, since this occurred in the *'ancestral environment...as a hunter-gatherer...roaming the African savannah'*. They argue that although our environment has changed considerably, we have not evolved at a similar rate and therefore we may not be adequately adapted to deal with these changes:

'Life in contemporary society differs in many ways from life in the environment of evolutionary adaptedness. Modern conditions are too recent for our species to have fully adapted to them, which means that the tradeoffs evolution struck may no longer be optimal today.'

This appears to be a straightforward justification for why it would be acceptable to intervene in ways which alter 'normal' or 'natural' human functioning. Objections

grounded in the purported value of what is 'given' by nature made by Sandel (2004), Kass (2003), Parens (1995) and Fukuyama (2002) are relevant again here, however. Although these writers do not, as such, object to biotechnological interventions to improve health, each suggests that the more humankind beholds itself to an ideal of transcending the biological limitations that nature imposes, the less it will tolerate the 'fragility' that is distributed across the species. Parens (Ibid, p. 145) argues that:

'There is a point beyond which the reduction of our subjection to some sorts of change costs too much...I take it to be valuable for us to recognize and accept our nature, and neediness is a constituent of that nature.'

Crook (2007, p. 137) explains how this line of argument has been developed in order to characterise enhancement as an affront to nature:

'To meddle with its stability and complexity is to invite disaster, to distort the inherent meaning of things. Some would see it as subverting the inherent moral order of things.'

This is a difficult position to maintain, however, unless one can draw a clear and non-arbitrary line between the 'natural' and the 'artificial', or circumscribe what would and would not count as 'meddling' in nature.

2.7) 'Natural' Vs 'Unnatural'

Barilan & Weintraub (2001, p. 137) argue that there is nothing self-evident about adopting a view of the world in which nature is benevolent such that to 'interfere' with it would constitute an unacceptable transgression:

'The myth of Harmonia Mundi has deep roots in Western Culture and medicine as well as in many non-Western myths. However...It is also chaotic, arbitrary and not necessarily human-friendly.'

Consistent with this claim, the view that 'neediness' causes unnecessary suffering to humans has been advanced. Loftis (2005, p. 72) points out that nature can be

'*damn cruel*'. Similarly Savulescu (2006, p. 11) argues that since the natural and social distribution of abilities is uneven so it is reasonable to conclude that '*nature allots capabilities with no eye to fairness*'. Developing this line of argument, Warnock (2003) also acknowledges that the human race has limitations and frailties which can inhibit and cause suffering. She argues that on this basis it is acceptable to try to break these restrictions and alleviate suffering. It is not important, in her view, what kinds of technologies, procedures or artefacts we use to achieve these ends. Warnock's view (Ibid, p. 459) is that '*nature has an intrinsic value*', but equally that:

'...any techne can be used for good or ill...we have to decide what is for good or ill by other criteria than that of Nature itself.'

This view lends support to Chatterjee's (2007) contention that the enhancement of aspects of ourselves such as cognition will be difficult to prohibit because it is 'naturally' highly valued throughout society. This is in turn consistent with Allhoff's (2005) view that enhancement is likely to be appealing because many of the characteristics considered as typical candidates for enhancement are Rawlsian 'primary goods', i.e. goods that it would be rational for any human being to desire, given the degree of value and utility that they confer for most members of the species.

Koch (2010, p. 687), however, believes that enhancement advocates espouse a dangerous agenda in the extent of their aims to alter what has been given in nature. In focusing an agenda of enhancement specifically on the activities of medicine, he argues that enhancement bioethicists identify states such as disease, disability and infirmity as social aberrations experienced by individuals who are to '*to be simply modified or discarded in favour of the whole*'. He also argues that the way in which pro-enhancements are made implies that its advocates '*assume a mechanistic view of the individual as a machine whose elements can be manipulated*', thus doubting whether enhancement can succeed in the way that it is envisioned.

Although Koch's argument is correct in underlining the practical and ethical obstacles to enhancing successfully, it may misrepresent the pro-enhancement case. This possible misrepresentation is also found in Baylis & Roberts' claim (2004, p. 25) that enhancement is inevitable in spite of the attendant dangers because *'the essential characteristics of humanness are perfectibility and the biosocial drive to pursue perfection.'* Proponents of enhancement argue that this misrepresents their case because typically they do not cite perfection of the imperfections of nature as the goal to which enhancement should aim.

Even those who advocate very radical enhancement do not seek to 'perfect' nature, but rather to transcend the limitations that it currently imposes where possible, and where ethically permissible insofar as to do so would further the realisation of human goods (Bostrom & Roache, 2008; Harris, 2009;). One of the architects of the radically pro-enhancement transhumanist position is Max More (2013, p. 5), who does not couch his position in terms of a utopian ideal, but as *'growing in healthy directions without bound'*. He offers the following justification of why a radical transformation of natural norms of health and functioning is desirable:

'The individual element of this is expressed in the principle of self-transformation... Using technology – in the widest sense to seek physiological and neurological augmentation along with emotional and psychological refinement.' Both of these principles clearly express the implementation of transhumanism as being a continual process and not about seeking a state of perfection.'

Transhumanism is intrinsically connected to human enhancement. It is a doctrine according to which, as Bostrom (2005, p. 4) explains, current humanity is considered *'a work in progress'* and *'need not be the endpoint of evolution'*. The end goal of the transhumanist project is *'the posthuman, beings with vastly greater capacities than present human beings have'*. The concept of posthumanity ranges across many aspects of human activity, one of which is the *'application of medicine...to overcome some of our basic biological limits'*.

2.8) Posthumanism

The concept of the posthuman denotes the idea of radically transforming human nature by using technology to upgrade or transcend normal functional ability, and has numerous roots within the relevant literature. Stickers (1996, p. 65) understands man's technological drive as a response to challenges and threats that he finds in the world, and thus characterises technology as *'...an ethic of suffering, a prescription for dealing with the primordial experience of resistance.'* Ferrarin (2000, p. 290) makes the related observation that mankind's historical interest in and ability to *'take charge of his destiny'* by the development of technologies is unique since unlike the limited cognitive capacities of animals *'men are capable of rational design and thought out projects'*. Moreover he is insistent that not only is this a unique capability of mankind, but one on which it *'depends vitally'* in order to successfully develop protection *'from the infinite stimuli, threats, and provocations of nature'*.

The rational ability to plan, anticipate the future, and innovate accordingly follows from human general intelligence. Intelligence is, in turn, a defining characteristic of homo sapiens as distinct from other species (Powell, 2012). Thus we find Aristotle's account of man's 'essential' nature as consisting in the capacity for rational thought (Nichomachean Ethics 1.7):

'Life evidently he has in common even with the plants...We must exclude, therefore, the life of mere nutrition and growth. Next to this comes the life of sense; but this too he plainly shares with horses and cattle...There remains then the life whereby he acts...we must be understood to mean thereby the life that consists in the exercise of the faculties; for this seems to be more properly entitled to the name.'

Congruent with this observation, Heidegger (1950) and Jonas (1978) argue that since man qua man is rational and has historically used his rationality to develop technologies which can enable him to persist in the world, so for human beings to be a technological species is for them to realise a part of their nature. Sheets-Johnstone (2011, p. 348) make a similar claim grounded in the observation that

innovation is a product of what has been provided for humans by nature. She suggests that, rather than having transcended nature, humans have:

'...taken what is evolutionarily given and in untold instances shaped or reworked it culturally...'

The author goes on to argue that our understanding of ourselves is hindered by a tendency to make binary distinctions between aspects of our existence which by themselves have some explanatory power in respect of revealing 'what we are'. The claims that health states, for example, cannot be understood in abstraction from their context, and that their definition is thus subject to changes in this context, are central assumptions of medical anthropology. These assumptions are so central according to certain views that Wolf-Meyer & Taussig (2010, p. 114) describe them as *'banal'* and as *'an old story'*.

These authors argue it is an uncontroversial fact that innovation occurs on the margins of society and *'trickles down from technoscientific investment in the extremes'* (Ibid, p. 116) towards the centre to become normalised as their uptake increases. On the basis of the claim that *'Medicine, by its very nature, is fixated on the human'* (Ibid, p. 123) they contend that there is nothing essentially different about the kinds of interventions which are the focus of enhancement and posthumanist literature. Rather, they are simply the present day iterations of an ongoing process of innovation and normalisation which influence our categorisation and understanding of phenomena.

Similar views are found elsewhere. Pyyhtinen & Tamminen (2011) characterise the relationship between innovation and the new norms that this creates as not entailing the emergence of a radically enhanced 'posthuman' as such. The posthuman model depends upon the improvement of human capabilities by new, 'non-human' technological, chemical, and biological products which we incorporate into our lives and come to depend upon. However Pyyhtinen & Tamminen (Ibid, p. 139) argue that:

'...we are significantly dependent on the capabilities of various non-humans in our everyday existence...laptop computers, electricity, ancestors within the Indo-European language group...and we need swarms of bacteria just to keep our skin sufficiently moist.'

This account is one which is found widely across the medical anthropology and sociology of science literature when considering the role that technology and foreign artefacts play in creating who and what we are. It is a central theme within the work of writers such as Foucault (1977), Latour & Venn (2002), Haraway (1985), Rabinow & Rose (2006), and indeed Pyyhtinen & Tamminen (Ibid, p. 139) summarise Foucault's and Latour's position as follows:

'...human subjects are defined not by some autonomous essence but by the specific networks in which they participate'.

Following this characterisation, and invoking one of the antecedents to the now mainstream bioethical interest in human enhancement, Franklin (2006, p. 174) uses the '*cyborg embryo*' created in assisted conception laboratories to describe the '*co-evolution*' which characterises the relationship between humans and technology. She argues that since both the desire to have a child and the '*high-tech procedures, such as ovulation induction and cryopreservation*' necessary for the realisation of this desire are constitutive of the life finally created, so the technological and biological aspects should be understood as '*part of the same ecosystem*'.

The implication here is that human life frequently incorporates 'non-human' elements, since to the extent that our limitations determine what we must do to overcome them, these limitations and our technological responses are determinants of our nature. Framed in posthumanist terms, it follows that our ability to transgress these boundaries would change what it is that we are.

Similar observations have been made and extrapolated in both futurist philosophy and science fiction to develop the doctrine that mankind should upgrade itself technologically in order to deal with the challenges of existence in the future

(Bostrom & Sandberg, 2009; More, 2013). Hauskeller (2012, p. 4) analyses the work of Pico della Mirandola and infers a prototypic version of this doctrine from his early characterisation of man's relation to technology:

'For Pico humans were by nature free to invent themselves, and not confined by any natural boundaries...As humans we are naturally disposed to change and to progress to higher spheres. It is in our very essence to transgress boundaries, to go ever further on our way to perfection and godliness.'

Although the technological developments necessary for the emergence of the posthuman are very radical, the history of human technological innovation itself has been interpreted by some as itself intrinsically transformational. Ihde (1997, p. 73) writes:

'...there is a very mundane sense in which every technology non-neutrally transforms both the project or object towards which the technology is directed, and reflexively, the human user of that technology.'

Whether to enhance is genuinely to transcend our biological limitations or just reduce them, a less ambiguous orientation toward human enhancement may be to adopt Bostrom's (2009, p. 392) characterisation of what is given in nature as *'improvable through the use of applied science and other rational methods'*. Furthermore As Zwart (2009, pp. 161-162) suggests, given that *'since time immemorial human beings have been pushing performance boundaries'* an accurate apprehension would be to accept ourselves as already being an enhanced species:

'We have never been satisfied with ourselves, we have always kept working on ourselves, always interested in developing new tools for self-amelioration, and there is no reason to suppose that we will stop doing so in the future. The history of humankind is seen as a history of emerging practices of self improvement...'

Although the predictions of advocates of radical enhancement may one day realise the posthuman, if Zwart's interpretation is correct and attempts to enhance are inevitable and ongoing then more immediate challenges will be found in cases

where a product and its 'enhancement' use lie closer to the presently accepted boundaries of therapy. With this in mind it will be useful to keep in mind Jones' (2006, p. 81) observation that:

'...practicing scientists are not governed by enticing prospects that may or may not materialise years hence. They deal with current problems that are solvable, and on which progress can be made one small step at a time.'

Pols & Houkes (2010) also discourage making judgements about the moral acceptability of enhancements that are too general, or grounded in sensationalist visions of posthumanity. Rather they recommend the consideration of different technologies on a case-by-case basis¹², arguing that it is unhelpful to ask whether enhancement per se is morally acceptable because our lives are already technologically mediated in many ways, about which there is a plurality of opinion concerning the relative net benefits or deficits.

Jones (Ibid, p. 81) is similarly critical that *'What is lacking from so much debate in this area is a lack of consideration of what is or is not scientifically feasible'*. He therefore recommends a more incremental approach to considering the merits of enhancements, suggesting that the debate should therefore focus not on hypothetical accounts of the posthuman which have *'little relevance for the scientific work that is actually being undertaken'*, but on the ethical challenges raised by individual increments of development which may or may not lead there:

Related to this Wasson (2011, p. 22) argues that what is important – irrespective of whether something is a treatment or an enhancement – is that in assessing what can be done we continue to respect *'fundamental moral values, such as the benefit of the individual, justice and fairness'* and retain these as a guide when making decisions about the ethical status of new medical technologies. Although there are differences between the two, both Jones and Wasson emphasise the need to

¹² Given the variety of types of enhancement that fall under the umbrella term of 'enhancements' (e.g. pharmacological, genetic, bionic, prosthetic etc), the procedures that are involved and the outcomes of each, they argue that it would be wrong simply to ask whether human enhancement is or is not morally acceptable.

respect the values of individual well-being and social justice if innovation is to be directed in a way that generates ethical outcomes.

2.9) Contemporary Enhancements

In recent years enhancement has grown sufficiently in significance that it is now being subjected to scrutiny in terms of potential law and policy ¹³. Coenen et al (2011, p. 521), for example, carried out a systematic study of human enhancement technologies on behalf of the European Parliament's Science and Technology Options Assessment panel with a view to developing policy recommendations. The report was commissioned in view of the potentially wide ranging ethical implications of human enhancement:

'Though still rarely discussed outside expert circles, human enhancement issues are not merely academic: the technologies and trends involved give rise to new needs and social demands, provide opportunities for individuals and society, and present new risks. They also challenge crucial cultural notions, social concepts and views of the human condition, and may cause new forms of social pressure and social exclusion.'

The literature indicates that little data exists which investigates the acceptability of enhancement to the medical profession itself, however. Similarly little research has been carried out to understand how the therapy / enhancement distinction is understood from this perspective. To date only one major empirical study of this kind has been carried out (Hotze et al, 2011). The primary finding of the study was that, beyond the immediate concerns for the safety of their patients, the clinicians involved displayed considerable ambivalence towards a judgement of the moral status of enhancement per se.

The study generated responses and further questions (Forlini & Racine, 2011; Wasson, 2011; Drabiak-Syed, 2011; Partridge et al, 2011). Despite this, however, empirically-grounded research remains limited when compared to the

¹³ <http://bioethics.georgetown.edu/pcbe/reports/beyondtherapy/index.html/>
<http://royalsociety.org/policy/projects/human-enhancement/workshop-report/>
<http://www.nuffieldbioethics.org/neurotechnology/neurotechnology-non-medical-uses-enhancement-gaming-military>

considerable theoretical literature which has now been produced concerning the ethics of human enhancement. Furthermore as I showed in chapter one, not only has little empirical work been carried out to elicit relevant views on these matters, the technological options currently available for effective enhancement are limited at present. We will now move on to review briefly some of these technologies.

2.9.1) Aesthetic Enhancement: Cosmetic Plastic Surgery

The most widespread case of appropriation of clinical medicine for enhancement is in 'cosmetic' or 'aesthetic' plastic surgery. Having first emerged in the late 18th Century (Rogers, 1976), this is a field in which elective procedures are available for the subjective enhancement of appearance '*in the absence of disease or physical trauma*' (Grossbart & Sarwer, 1999, p. 101). It is a highly lucrative field of medicine, for example in the United States it is judged currently to be worth around \$11 billion¹⁴.

Several empirical studies of cosmetic surgery have been conducted investigating user perspectives (Pertschuk, 1998; Ishigooka et al, 1998; Gimlin, 2002; Sarwer & Crerand, 2004); professional perspectives (Dunkin et al, 2003; Kinnunen, 2010); public perceptions (Delinsky, 2005; Swami et al, 2008;); and its various relevant ethical ramifications (Davis, 2002; Davis, 2003; Atiyeh et al, 2008). These studies have not been typically carried out as studies of enhancement as such, however, relevant data exists concerning perceptions of these procedures and reasons for seeking them or providing them.

2.9.2) Cognitive Enhancement: Modafinil

A more recent product of interest within the ethical debate of enhancement is the drug Modafinil. This is a drug which promotes wakefulness, and enhances concentration and short term memory retention (Williams et al, 2008; Husain & Mehta, 2011). Initially developed for the clinical treatment of narcolepsy, there is evidence suggests that its use by students for enhancement purposes is a growing phenomenon (Williams et al, 2008; Greely et al, 2008; Tannenbaum, 2008;

¹⁴ <http://www.surgery.org/sites/default/files/ASAPS-2012-Stats.pdf>

Coveney et al, 2008; Cakic, 2009). Some clinical research has also been carried out to determine Modafinil's effectiveness as an enhancement in the healthy (Turner et al, 2003; Forlini & Racine, 2010; Aikins, 2011). Despite its relevance to the debate, however, the enhancement use of drugs such as this is a relatively recent phenomenon, and its relevant history of such use is limited.

2.9.3) Physical Enhancement: Erythropoietin (EPO)

Sport is a context in which medical performance enhancement has been highly controversial and visible. A longstanding and controversial instance of enhancement has been the use of recombinant human erythropoietin (EPO) by athletes for (illegally) gaining a competitive advantage in professional sport.

The biological aim of EPO is to raise the haemoglobin content of the blood (Jelkman, 2006). In a clinical context this is done to achieve the therapeutic goal of restoring normal functioning, and in the context of enhancement it is to confer supra-normal normal functioning by boosting exercise capacity. One important determinant of what is considered to be a 'normal' level of haemoglobin relative to a population, however, is altitude. Since the oxygen content of the air decreases with altitude, endogenous EPO production by the body increases with altitude (Eckardt et al, 1989; Savourey et al, 1996; Gunga et al, 2007; Brookhart et al, 2008). This is the reason why athletes train at altitude (legally) in order to gain a performance advantage, and it is also why the 'normal' haemoglobin content of the blood for someone living in the Andes is different from that of someone who lives in London (Gunga et al, 1996; Chapman et al, 2010).

EPO has been at the centre of several high-profile 'doping' scandals over the past 20 years (Mignon, 2003; Robinson et al, 2006; Schneider, 2007; Kayser et al, 2007; Sjoqvist, 2008;), including notable high profile cases such as those of David Millar¹⁵ and Lance Armstrong¹⁶. First person accounts attest to the 'arms race' that the

¹⁵ <http://news.bbc.co.uk/1/hi/programmes/hardtalk/9571648.stm>

¹⁶ <http://www.bbc.co.uk/news/world-europe-20026838/>
http://www.oprah.com/own_tv/onc/lance-armstrong-one.html

presence of performance enhancing substances created. For example in his autobiography (2011, p. 80) Millar recounts the following conversation:

"Hmmm." He thought for a moment. "No, it's not possible. Over three weeks you can't compete against the guys on EPO...EPO allows you to go faster for longer. I mean, you still have to train and diet and do everything else, but with more oxygen you can stay at threshold for longer and recover faster...it's just the way the sport has gone"...EPO changed everything.'

Given evidence such as this that coercion to enhance can occur, concerns raised in the literature which relate to this should be taken seriously. Despite the veracity of such concerns, however, Mignon's (2003, p. 233) history of drug use within the Tour De France offers an alternative perspective. He cites an interview given by the Pélissier brothers during the 1924 Tour in which they confessed to extensive pharmaceutical performance enhancement. The demands of the contest are reported as so arduous that, prior to the characterisation of drug use as cheating or doping, such measures were justified by the severity of the contest:

"You have no idea what the Tour de France is like", said Henri. "It's a Calvary. But Christ had only 14 stations of the cross. We have 15. We suffer from start to finish. Do you want to see what we run on? Look...That's cocaine for the eyes, that's chloroform for the gums...a cream to warm up my knees... do you want to see the pills? Look, here are the pills...In short...we run on dynamite". This scene...popularized the image of...the Tour de France riders seen as workers who have to use whatever is in their power to complete their task.'

The rapid appropriation and proliferation of EPO for enhancement attests to its success for these purposes (Gareau et al, 1996; Mayes, 2010; Fisher, 2010). It is also typically difficult to detect due to its similarity to endogenous erythropoietin, and hence had significant appeal for those seeking a clandestine performance advantage (Duntas & Popovic, 2012). The history of its enhancement use over the past 25 years indicate that certain of the worries raised in relation to issues such as justice and fairness are relevant (Mignon, 2003; Schneider, 2007), and for this

reason it is a product with a valuable combination of historical and ethical relevance to the enhancement debate.

2.10) Conclusion

In this chapter I examined concepts of health; human enhancement and its difference from therapy; and the related concept of the posthuman, across the relevant philosophical and social scientific literature. Various theoretical approaches were put forward for understanding these concepts, and a range of relevant standpoints on the ethical challenges that human enhancement technologies may pose if they are to proliferate presented themselves.

I showed that despite the abundance of theory within the field of enhancement, little empirical work exists which can ground and evaluate these theories within the context of contemporary western medicine. The identification of 'normal health' underpins the therapy / enhancement distinction, and yet the literature indicates that it is hard to identify with any degree of permanence.

This observation raises issues concerning the delineation between therapy and enhancement, and how such categorisations can be made. To the extent that the therapy / enhancement distinction has a bearing on medical decision making, it has a corresponding bearing on the ethical status of those decisions. We saw evidence that treatment norms, norms of health, disease and illness classification can and do change. We also saw arguments which can be used to show that even normal states of health can be deficient relative to a different context or an alternative set of goals.

It is important that the theoretical debate concerning the therapy / enhancement distinction is grounded empirically because of the present imbalance towards theory within the literature. Given that ambiguities emerge when we attempt a clear delineation between the concepts of therapy and enhancement, the ethical ramifications of these ambiguities require more detailed investigation that is contextually grounded. At present contextual information such as this is limited.

Since the purpose of the thesis is to understand the relationship between therapy and enhancement, any balanced and nuanced account of this relationship must discover how it is understood by the constituents of medical practice itself. At present relatively little is known about this, and the collection of more data reporting how the relationship is understood can contribute to improvements in practice and policy development if enhancement technologies continue to proliferate as has been predicted within the literature.

The proliferation of theory within the enhancement debate, whilst useful, is so divergent that the relative accuracy of these various theories in terms of the 'every day' practices of medicine and medical research is unclear (at this stage). Medicine is a social practice, and as such it cannot be fully understood from a purely theoretical perspective – attempts at understanding must take account of the perceptions of relevant actors engaged in this social practice.

2.11) Summary

In this chapter I reviewed relevant literature concerning the therapy / enhancement distinction from a range of philosophical, ethical, and social scientific perspectives. Issues covered included the distinction itself, their relation to underlying conceptions of health, and the social context of medicine and technology. I carried out a brief review of the history of enhancement and its hypothetical 'posthuman' future, as well as some examples of contemporary enhancement technologies.

The review showed that the theoretical literature is inconclusive with respect to how human enhancement should be understood and what constitutes an appropriate response to the ethical challenges that its proliferation would represent. Similarly the review indicated that the literature weighs heavily in favour of enhancement theory, and that little empirical research had been carried out which could provide insights into how enhancement is understood within its own context.

Having reviewed the literature and identified what must now be known in order to resolve the presently inconclusive theoretical debate and develop appropriate ethical responses, the need for a suitably interdisciplinary research methodology is clear. Methodological approaches will be considered in the next chapter.

Chapter Three: Philosophical Methodology

3.1) Introduction

In this chapter I will introduce Critical Realism (CR), which is the philosophical approach that I have chosen to combine the philosophical and social scientific components of the research. I will explain the relationship between philosophical theory and empirical data, and how CR can be used to integrate the two successfully towards the development of the conclusions and policy recommendations that will follow from this integration. I will provide arguments for making this methodological decision, and show how the use of critical realism in empirical bioethics improves on previous methodologies employed within the literature.

3.2) What is Critical Realism?

CR was developed primarily by the philosopher Roy Bhaskar in 'A Realist Theory of Science' (1975), and 'The Possibility of Naturalism' (1979). It was designed to 'underlabour'¹⁷ for social science (Archer, 1998; Bhaskar & Norrie, 1998; Sayer, 1997; Sayer, 2000) by providing it with a philosophical underpinning that can respond effectively to empiricist, positivist, idealist, and postmodern critiques (Bhaskar, 1998; Wight, 2012). In its reconciliation of these approaches and the fields in which they emerge CR thus supplies a justification for interdisciplinarity (Sawa, 2005; Bhaskar & Danermark, 2006).

3.2.1) World and Knowledge

CR holds that there is an objectively existent domain of reality external to and independent of the mind, which ontologically transcends our sensory experiences (Viskovatoff, 2002; Dow, 2002). This domain is mediated by our senses and interpreted against a background of subjectively held beliefs and assumptions. CR

¹⁷ *This term originates from John Locke (1690) and his conception of the role of philosophical thinking as: 'underlabourer in clearing the ground a little, and removing some of the rubbish that lies in the way to knowledge'.*

therefore argues that knowledge and reality are separate. In doing so it resists the reduction of ontology to epistemology, and thus provides conditions under which it is possible in principle for statements about the world to be non-relatively true or false, or more or less correct (Proctor, 1998; Patomaki & Wight, 2000).

The separation of ontology and epistemology entails a system in which the external world is structured in a certain way irrespective of one's view of it. One's viewpoint on the world, however, always influences one's knowledge of it. Since all viewpoints are spatio-temporally unique, knowledge claims based on the representations that these viewpoints provide are necessarily subjective and partial. It is this uniqueness which accounts for the diversity and fallibility of knowledge claims. The challenge, therefore, is to ascertain how human beings, jointly responsible for the social production of knowledge, in a state of epistemological flux, can arrive at a true apprehension of the external world that they seek to understand (Bhaskar, 1975, p. 21):

'Any adequate philosophy of science must find a way of grappling with this central paradox of science: that men in their social activity produce knowledge...which is no more independent of its production and the men who produce it than motor cars, armchairs or books...The other is that knowledge is 'of' things which are not produced by men at all: the specific gravity of mercury, the process of electrolysis, the mechanism of light propagation...If men ceased to exist sound would continue to travel and heavy bodies fall to the earth in exactly the same way, though ex-hypothesi there would be no-one to know it.'

3.2.2) Varieties of Realism

CR is, by definition, a variety of realism. Many forms of realism exist, including naive; direct; indirect; semantic; metaphysical; scientific; structural; mathematical; moral; aesthetic, all of which pertain to different questions and analyses. What they share, however, is a commitment to the mind-independence of certain phenomena (Putnam, 1975; Dummett, 1982). All forms of realism hold that some

of the things to which we refer are really 'there' in the world, not merely constructed by one's mind (Dummett, 1982, p. 55):

'The very minimum that realism can be held to involve is that statements in the given class relate to some reality that exists independently of our knowledge of it.'

It is not possible to deal with all forms of realism here. However insofar as CR is a philosophy of and for the social sciences (Bhaskar, 1979; Archer, 1998; Sayer, 2000), it is a methodology for understanding empirical phenomena, and must therefore give an account of scientific realism. Worrall (2009, p. 158) holds that scientific realism in general can be held as true on the basis of the '*staggering empirical success*' of the predictions that science can make. In relation to CR more specifically Murphy (1990, p. 296) writes that realism's legitimacy is underwritten by its explanatory power because '*only realism can account for the success of science*'.

I anticipate the objection that the social sciences are not equivalent to physical sciences, since the former deals with 'open' systems that are more variable than the 'closed' and tightly limited experiments carried out in the latter. This is an understandable objection; however, that they are not equivalent does not mean that they share no significantly relevant characteristics. For example, Bhaskar (1975, 1989) argues that human systems are constrained by the same physical laws or '*generative mechanisms*' as the rest of the physical contents of the universe. Given that the totality of physical things that exists emerged from the substratum of these laws, he concludes that we must share something ontologically fundamental with non-human aspects of the world (Bhaskar, 1975; Archer, 1998; Sayer, 2000).

Although 'closed', non-human, systems do not have agency and cannot reflect on themselves or act autonomously, the empirical success of science implies that the deep structure of the world is rationally comprehensible. Given that we have ontological continuity with the non-sentient world at this level, it must be possible to acquire knowledge that pertains both to the open systems that constitute the

social world, as well as the closed ones that are constructed in experiments in the physical sciences (Bhaskar, 1975; Proctor, 1998; Easton, 2010).

3.2.3) Empiricism and Idealism

CR accepts scientific realism. It thus commits to the scrutability of the world via both inductive (empirical) and deductive (*a priori*) means, viewing both as methodologically valuable. In this respect it attempts to reconcile opposing viewpoints which claim that one is epistemically superior to the other.

Methodological schisms following from these oppositions have emerged across philosophy and the social sciences, a salient example of which is the tension between strict forms of empiricism and idealism. Meyer (1906, p. 461) explains this tension:

'Radical scepticism flatly denies the fact that we can have a criterion of truth, yet the fundamental problem of all knowledge is this: Can we have such criteria?...On the other hand, if we deny the objective measure of value (criterion) of truth, science is no more. In its stead there will be nothing but opinion...'

CR argues that although radical forms of empiricism and idealism are incorrect, aspects of each are epistemologically useful. In order to carry out research which successfully harnesses the various benefits of both paradigms some methodological reconciliation of the dualism is therefore necessary. An example of why radical versions of these paradigms are inadequate is visible in the strong constructionist rejection of *a priori* justifications for the objective reality of the external world.

According to the strong constructionist view the knowledge required for *a priori* justification is a) practically unattainable, and b) logically incoherent, since any hypothetical 'comparison' of the world with my representations of it would involve my having to perceive the world, and this could only be done subjectively via the mediation of my senses. Von Glasersfeld (1990, p. 12) argues that any account of a reality beyond my perceptions is meaningless, since such an account would

require verification in order to be judged as true and *'to do this, we would need an access to such a world that does not involve our experiencing it'*.

This argument is problematic for two reasons, however. Firstly, it fails to give an account of what there might be in virtue of which perception could be possible. The reason why this is problematic is that the existence of a reality in which our existence is possible is a necessary pre-condition of our having the experiences that we do (Archer, 1998, p. 197):

'When we ask what needs to be the case for x to be possible, we predicate any realisation of x upon the prior materialisation of the conditions of its possibility.'

The second difficulty is that even if we are mistaken in believing that there is a reality external to us, we act as if there were. As social beings we assume that our existence is embedded in a 'real' world that would continue to exist even if we did not. Easton (2009, p. 119) characterises this assumption as *'performative'*, since *'we behave as if it was true'*. He argues that it is a reasonable position to adopt because *'in general this supposition works, especially for the physical world'*.

It is therefore possible to demur from committing to a realist account of the world, but the price to be paid for this in terms of plausibility is high, since to do so would threaten the possibility of carrying out social research that bears a sensible relation to anything beyond the representations of the researcher. It is in response to this that CR grounds its argument. All accounts of the world are undoubtedly subjective, partial, contextual, contingent, and of variable accuracy. Consequently these must be understood as revisable in light of new information. Nevertheless they are accounts *of the world* (Murphy, 1990, p. 296):

'...unlike the earlier 'naive' realists, 'critical' realists...see scientific models and theories not as literal pictures of reality but as partial, tentative representations of what there is.'

It follows from this that if we wish to carry out research in which both: a) epistemological claims are recognised as subjective, partial and fallible; and b) we

do not infer from the partiality of these the conclusion that there is nothing ontologically objective beyond experience to which epistemological claims refer, then methodological commitment to some form of transcendental realism is unavoidable.

3.3) Critical Realism and Social Constructionism

Social constructionism has antecedents in scepticism, idealism, empiricism, and anti-realism (Searle, 1995; Hacking, 1999; Wight, 2012). CR holds that there is one reality, which is objective, and includes all humans and their subjective representations of it (Bhaskar, 1975; Jeffries, 2011). This stands in contrast to strong constructionist theories which imply the existence of separate and discrete realities (Berger & Luckmann, 1966; Von Glasersfeld, 1982). CR rejects this as theoretically incoherent and hence rejects strong social constructionism. Berger and Luckman's (1966, p. 15) claim that each person's experience constitutes a separate reality can be interrogated to understand why:

'...reality is socially constructed...Sociological interest in questions of "reality" and "knowledge" is thus initially justified by the fact of their social relativity. What is "real" to a Tibetan monk may not be "real" to an American businessman. The "knowledge" of the criminal differs from the "knowledge" of the criminologist. It follows that specific agglomerations of "reality" and "knowledge" pertain to specific societal contexts'

Note that here 'reality' is referred to with quotation marks. The implication is that reality itself is a construction. In a trivial sense this is true, since the label 'reality' depends on the prior existence of a mind or minds which can generate and use it. It does not follow, however, that there is nothing objectively existent to which the concept 'reality' refers simply because these conceptualisations are made and experienced subjectively (Barkin, 2003; Jackson & Nexon, 2004).

The observation that the label 'reality' is part of a language, and language is a social phenomenon that is dependent on human minds, does not entail the conclusion that the label has no external referent beyond the subjective representations of it

that we communicate in discourse (Searle, 1995; Hacking, 1999; Bhaskar, 1998). In conflating knowledge with the world the constructionist thus commits an 'epistemic fallacy' (Bhaskar, 1975) by casting reality as our representations of it. In committing this fallacy Berger & Luckmann (1966, p. 35) make the further claim that:

'My consciousness, then, is capable of moving through different spheres of reality. Put differently, I am conscious of the world as consisting of multiple realities.'

The problem for this position is that it does not explain how the discrete 'realities' can interact with each other in such a way that the individuals inhabiting them could communicate with each other. If we are communicating as we believe ourselves to be we must inhere within a spatio-temporal realm that is prior and common to both of us. If we are not fundamentally *in the same world* then communication between us would be impossible, or some account must at least be given of how it could be done. An ontological reality external to all people is a necessary pre-condition for the possibility of engaging in social scientific investigation, because it is only in virtue of such a common reality that such an investigation could be meaningfully carried out. Fopp (2005, p. 15) explains the difficulty of adopting the strong constructionist position:

'Social constructionism has a rather uncertain or 'we cannot know for sure' (Sahlin, 2006, 179) attitude towards what we experience as objective reality. But what does an uncertain, 'we cannot know for sure' attitude mean regarding our experiences. Are we so unsure of what we experience?...How far does this agnosticism go?...If all socially regarded facts are relative to a time and place, then so is social constructionism.'

It is fair to note that Berger & Luckmann anticipate and accept the kind of criticism that I have just articulated. Despite this, however, the form of social constructionism that they defend is inadequate for interdisciplinary projects such as this (Ibid. p.1):

'...the sense in which we use these terms in the context of sociology, and that we immediately disclaim any pretension to the effect that sociology has an answer to these ancient philosophical preoccupations.'

This disclaimer is acceptable where the aim of one's work is purely sociological, since if the terms are used in a way that is internally consistent to the suppositions of the discipline then there is no problem of methodological inconsistency. As Niiniluoto (1991, p. 3) argues, however, under close analysis philosophical assumptions in need of substantiation cannot be disaggregated from the allegedly non-philosophical sociological standpoint:

'...the 'strong' programmes of the sociology of knowledge, in spite of often pretending to be non-philosophical or even anti-philosophical, are in fact heavily laden with philosophical assumptions - and also draw very strong philosophical conclusions...the often concealed philosophical prejudices of the sociologists of knowledge should be made explicit and put into scrutiny.'

Since in empirical bioethics we are attempting to combine philosophical and social scientific methods, central terms such as knowledge and reality cannot be bracketed because an understanding of their meaning must be shared by both disciplinary perspectives. The interdisciplinary nature of the research thus obviates the need for an *'immanent critique'* (Lawson, 1998, p. 156) of the kind just carried out. An immanent critique of the concepts and arguments involved enables us to assess their mutual internal consistency, and arrive at a theoretical position that successfully negotiates and integrates the competing perspectives.

The outcome of the preceding critique is that despite rejecting the claim that true knowledge of the external world is impossible, CR nevertheless accepts that all viewpoints are subjective, and it is therefore able to accommodate social constructionism on more moderate terms (Sayer, 2000; Hacking, 1999; Wight, 2012; Fopp, 2007;). An attenuated version recognises that the objective and *'persistent'* reality of the world and its contents must be assumed in order for

intersubjective discussion about it to proceed (Denzin & Lincoln, 2005). Sayer writes (1997, p. 466):

'Realists can happily accept weak social constructionism, while noting that the social character of knowledge does not mean that it cannot successfully identify real objects (including social constructions) which exist independently of the researcher. Knowledge, though situated, can, in some sense, be objective.'

3.4) Ontological Stratification

CR argues for a 'stratified' ontology (Bhaskar, 1975; Collier, 1998; Sayer, 2000) consisting of three distinct levels: the real, the actual, and the empirical. These exist in a hierarchy. The 'intransitive' domain of the real exists at the base; the first 'transitive' domain of the actual supervenes on the real; and the second 'transitive' domain of the empirical supervenes on the actual.

3.4.1) The Real

Starting with the real, CR holds that there is a way that the world is, and that more or less accurate knowledge of it must be possible. It adduces the success of science as evidence for the truth of this postulation (Bhaskar, 1975; Greene, 1990), concluding that certain physical mechanisms must exist prior to our discovery of them (Archer, 1998; Soper, 2010). According to this view *'the real is whatever exists...regardless of whether it is an empirical object for us'* (Sayer, 2000, p. 11).

Reality is therefore the totality of things that exist, containing both observable phenomena and the non-observable physical mechanisms which permit their occurrence. The domain of the real thus provides the *'generative mechanisms'* that allow human activity to occur (Bhaskar, 1975; Bhaskar, 1989). The changing contingencies of the social world are emergent from biology and chemistry, which are in turn emergent from the unchanging physical stratum beneath (Seiler, 2007; Easton, 2010).

3.4.2) The Actual

The emergence of biology and chemistry from the physical substratum constitutes the second ontological level. Observable phenomena of this kind are defined as *actualisations* of the mechanisms which make their emergence possible. Hence this level is described as the 'actual', and it is at this level that scientific and social scientific investigation is possible (Bhaskar, 1975; Bhaskar, 1989).

The difference between these two domains is that in being ontologically 'intransitive', mechanisms at the level of the real cannot be changed, whereas events occurring at the level of the actual could have been otherwise and are influenced by the contingencies of their context. Bhaskar (1997, p. 145) argues that since it is determined by human actions and beliefs, '*Social reality is...conceptually dependent*'. Given that concepts can be misunderstood CR holds that events in the social world '*can be falsely characterized – and falsely categorized*'. Occurrences at the level of the actual are thus '*dependent demi-realities*' which '*refract*' the objective reality beneath, but due to the subjectivity of human experience this reality can be misapprehended.

3.4.3) The Empirical

This leads to the third level of ontology - the empirical. The empirical supervenes on the actual, and describes the products of controlled scientific or social scientific investigation of actual events (Sayer, 2000). Its difference from the other two can be stated as follows: just because I do not experience something that is actually happening does not mean that it is not actually happening. According to this realist view, a complete understanding of the world requires more than what is empirically available to me at a given spatio-temporal location. Consequently Sayer (Ibid, p. 11) concludes that '*the world should not be conflated with our experience of it*', and hence that '*critical realism should therefore not be confused with empirical realism...which identifies the real...with what we experience*'.

Guba & Lincoln (1994) describe CR as a *postpositivist* approach. Postpositivism is characterised by its opposition to the positivist assumption that only what is

offered in experience may be accepted as a reliable basis for knowledge. If some aspects of reality remain beyond my ability to perceive them, we cannot rely on empirical data alone for an optimally accurate description of it. As I noted earlier, the postulation of unobservable entities whose existence of which is inferred from a combination of other data and the rules of logical entailment, rather than by being seen, is central to the success of science (Santayana, 1983; Hacking, 1999). That this is possible thus supports the claim that knowledge must be possible of more than simply those things which I am able to verify empirically.

Despite the limitations of empirical data, however, they perform a vitally important epistemic role, because they are nevertheless indications of the basic fundamental structures which permit their existence. Certainly empirical knowledge is far from useless, since I may have stronger reasons for believing that the relation between X and reality is Y if I have observed that it is the case. CR therefore accepts the epistemological significance of empirically derived information, and by extension the value of social science *per se* (Sayer, 2000; Easton, 2010). The combination of deductive and inductively derived knowledge seeks a best possible explanation for one's results, or an analytic generalisation that is justified by them. This form of reasoning, which is characteristic of CR, is 'abductive' and according to Jarvensivu & Toornross (2010, p. 102) is:

'...an approach to knowledge production that occupies the middle ground between induction and deduction...Unlike induction, abduction accepts existing theory, which might improve the theoretical strength of case analysis. Abduction also allows for a less theory-driven research process than deduction, thereby enabling data-driven theory generation.'

This combination of the empirical and the *a priori* can be applied to a specific instance of scientific discovery to understand the role that each plays. For example, the discovery and increasingly accurate understanding of the biological mechanism of erythropoiesis has been an 'abductive' and ongoing combination of induction, deduction, postulation, and testing (Fisher, 2010; Jelkmann, 2007; Kurtz, 2011).

On the basis of the arguments laid out so far a further move is available, as this combination can also be applied to the development and justification of ethical claims. If CR is correct then this combination of methods will yield reliable and defensible conclusions in moral discourse as well as in scientific discovery, because to the extent that they are both constituents of the same reality, they are apprehendable by a combination of the same investigative methods (Bhaskar, 1993; Bhaskar & Norrie, 1998).

CR's account of ontology shows that it cannot be reduced to epistemology: that reality is not identical with my representations of it, and that it must contain objective features which are mind-independent. One's actual individual perceptions, beliefs, and assumptions may inform one that the world is a certain way, and these beliefs may be consistent or inconsistent with the prevailing beliefs of one's actual socio-historical context. Reality, however, retains the ability to demonstrate when certain representations are fallible. In doing so it vindicates the presence of basic intransitive mechanisms that underpin the contingencies of a given social context, and inform the epistemological claims that are available to its members. As Easton observes (2010, p. 9):

'Reality kicks in at some point. We can socially construct a world in which we can fly but put it to the test and we find that we can't'

This observation highlights the need for the integrative approach found in CR. As self-reflective beings we mutually construct the structures which constitute the social world, our understanding of which is subjective and partial. Experiences of the social world give us substantive, valuable information about it. These changing, socially constructed phenomena, however, cannot escape the unchanging, mind-independent, ontologically objective physical mechanisms from which they have emerged.

Although the domain of the real lies beyond experience and its structure must be discovered abductively, the apparent success of science underlines the legitimacy of the model that CR advances. The vindication of combining inductive and

deductive approaches optimises the utility that we can derive from each, and enables us to shed light *on reality*.

3.5) Empirical Bioethics

Empirical bioethics is an interdisciplinary approach to the resolution of practical ethical issues within the biological and life sciences that integrates social scientific, empirical data with traditional philosophical analysis. It aims to achieve a balanced form of ethical deliberation that is both logically rigorous and sensitive to context (Molewijk et al, 2004; Ives & Dunn, 2010). The aim of such an approach is that it will be more able to generate normative conclusions that are tractable with the context in which the problem, challenge, or dilemma emerges.

Given that empirical bioethics incorporates both philosophical analysis and social scientific data, it is a field that is consistent with the use of CR as a research methodology. In this section I will therefore outline empirical bioethics and why it is useful. I will demonstrate CR's suitability for such projects; and provide an example of how CR can be employed in ethical analysis which involves both philosophical reasoning and social scientific data.

3.5.1) A (Very) Brief History of Bioethics

The first instances of what could be described as 'bioethical' scholarship were typically philosophical (Muller, 1994) or theological (Emmerich, 2011). This theoretical rather than empirical leaning is understandable, since insofar as it is a sub-field of ethics, bioethics is to some degree irreducibly philosophical. In the present, however, bioethics has grown and diversified into a varied interdisciplinary field which includes the social sciences; law; medicine; and policy studies (De Vries et al, 2006). This diversification has raised methodological challenges regarding the successful integration of these various disciplines.

Bioethics in its present form is a relatively modern phenomenon. Despite the perennial nature of the ethical questions that it seeks to answer the label 'bioethics' was not used until the second half of the 20th Century. As Wilson (2011)

and Martensen (2001) report, it first emerged into ethics discourse in 1970. The widespread interest now displayed in bioethics over this relatively short time span attests to the breadth of its relevance. This is visible in Reich's (1995, p. 29) analysis of the etymology of the term 'bioethics' itself:

'Noting that the word "bioethics" is a composite derived from two Greek words - bios (life; hence life sciences) and ethike (ethics), it established a broad scope for the field'

A significant factor in an increasingly explicit focus on the ethical treatment of patients - and hence of bioethics in a clinical context - were the eugenics movements of the early 20th Century (Lappe, 1991; Agar, 2008) and the subsequent atrocities carried out during WWII (Buchanan et al, 2000; Fleischhauer & Hermeren, 2006). Agreements such as the Declaration of Helsinki¹⁸ (1964) by the World Medical Association and the Council of Europe's Convention on Human Rights and Biomedicine¹⁹ (1997), have also brought the explicit consideration of bioethical issues into focus. Against this background, and in the face of the rapid advance of medical science technology in the post-war period, bioethics has become of mainstream relevance not only for scholars, but for society as a whole.

3.5.2) The Empirical Turn

Following the colonisation of bioethics by new disciplines from outside philosophy, and due to the socially embedded institutional nature of medical practice, bioethics underwent a transformation to become a diverse multidisciplinary field. Its further development into being a truly integrated, interdisciplinary, field which successfully combines these different perspectives has been complex, however.

De Wachter (1982, p. 276) writes that whilst efforts have been made towards interdisciplinarity, these have frequently fallen short of true integration, '*producing at best a 'dialogue between sciences'* without achieving a genuine reconciliation of the reasons underpinning their opposition. Consequently bioethics has been '*a field which is more likely defined de facto in terms of its issues*

¹⁸ <http://www.wma.net/en/30publications/10policies/b3/>

¹⁹ <http://www.conventions.coe.int/Treaty/en/Treaties/Html/164.htm>

than by any shared essence or scientific perspective'. He is thus uncertain whether bioethicists have given sufficiently detailed thought to 'defining the ways and methods of doing bioethics as (an) interdiscipline'.

The impact of these antecedents and critiques is that bioethics has undergone an 'empirical turn' (Borry et al, 2005; Frith, 2010; Hurst, 2010). The aim of this is to produce a means by which to produce balanced, philosophically robust but contextually informed conclusions that can be applied for the resolution of practical ethical problems.

As appealing and rational as such an aim is, however, the disciplinary schism between the tenets of (prescriptive) moral philosophical and (descriptive) social scientific analysis has caused antipathies across the field (Alvarez, 2001; Turner, 2009). These have occurred from the social sciences towards philosophy (Hedgecoe, 2004; Kleinman, 1999; Marshall, 1992); and vice versa (Herrera, 2008; Harris, 2012; Brassington, 2013). Borry et al (2005, p. 50) write:

'The field of bioethics did not attract the collaboration of many social scientists. Their methods of gathering data were unfamiliar to ethicists, and the methods of ethicists were seldom known to social scientists...there was no 'easy and consistent flow of empirical data into ethics', and bioethics had a 'simultaneously aloof and strained relationship' with the social sciences.'

Moreover, the perennial philosophical challenge of Hume's is / ought problem (1739) which holds that one cannot derive the latter (values) from the former (facts), has proved resilient within bioethics (Ives & Draper, 2009; Parker, 2009). Williams (1985, p. 237) highlights the '*genuine ethical, and ultimately metaphysical, concerns*' behind the persistent fact / value distinction and therefore the potential threat to the possibility of an 'empirical ethics' that this may pose:

'At the heart of them is an idea that our values are not "in the world"...This set of conceptions does constitute a belief in a distinction, some distinction, between fact and value.'

If the is / ought problem is correct it leaves open the possibility that the very idea of an 'empirical bioethics' may be oxymoronic, since if ethics refers categorically to how things should be rather than how they are, then the label is internally contradictory. It is therefore necessary to provide an effective counter-argument to this objection. Several attempts at doing so have been made within the literature and a range of approaches have emerged as potential appropriate methodologies for 'doing' bioethics more generally (Ashcroft, 2004; Pellegrino, 1999).

3.5.3) Previous Methodologies

Hurst (2010) argues that any philosophical scepticism concerning the value of empirical data for deriving normative conclusions is misplaced because states of affairs in the world are always taken into account in moral reasoning. Similarly Alvarez (2001) argues that the notion of doing bioethics, i.e. applied moral philosophy within the biological sciences, would be incoherent if we were to abstract the moral reasoning from the empirical context. Frith (2010) conceives ethical dilemmas as inherently '*naturalistic*' since they arise from experience and are therefore not purely conceptual problems.

Haimes (2002) points out that since social science is interested in social change, and the conceptual object of ethical analysis, namely moral progress, is predicated on the possibility of change, the two are connected intrinsically to the extent that ethics seeks to promote social goods. Hoffmaster & Hooker (2009) argue that a greater emphasis on '*constructivist accounts of reason*' will result in richer normative conclusions. De Vries (2010), Nichols (2012), and Ives & Draper (2009) ground their responses in the earlier work of Rawls' reflective equilibrium and its account of moral action (at least with respect to justice) as a balance between moral theory and empirical facts.

Widdershoven et al (2009) advocate a hermeneutic, '*dialogical*' approach between the ethics researcher and participants. Leget et al (2009) recommend a '*critical applied ethics*' and similarly Molewijk et al (2004) have developed a specific methodology entitled '*integrated empirical ethics*', all of which attempt to validate

such research by allocating equal weight to ethical theory and empirical data in the resolution of moral dilemmas.

Undoubtedly these attempts make progress in terms of offering procedures for doing empirical bioethics, and showing why it is valuable. What they lack, however, is an account of reality which makes explicit the connection between the validity of *a priori* reasoning in moral discourse, and the actual social phenomena in the world to which we are applying this reasoning. It is in its capacity to do this that CR represents an improvement on previous methods.

3.6) Critical Realism as a Methodology for Empirical Bioethics

The application of CR represents an original and valuable philosophical contribution to the field of empirical bioethics itself, and also to the wider debate concerning the validity of empirical methods in ethical analysis. I will give examples of previous applications of CR in other fields before showing in detail how it can be applied in empirical bioethics. I will demonstrate how its account of ontology and epistemology vindicates the combination of philosophical and social scientific approaches in the successful resolution of practical moral issues, and how it can produce defensibly non-relative ethical conclusions.

CR has been used in a wide variety of social research fields unrelated or only indirectly related to health, such as geography (Proctor, 1998); international studies (Wight, 2012); management studies (Easton, 2009); education research (Scott, 2005); and information systems research (Dobson, 2001). It has also been used in health-related fields including disability studies (Bhaskar & Danermark, 2006); social work (Longhofer & Floersch, 2012); family therapy (Speed, 1991); nursing (McEvoy & Richards, 2003); and pharmacy (Oltmann & Boughey, 2012). The diversity of these fields indicates CR's widespread applicability and explanatory power.

CR has only been applied explicitly as a 'lens' for bioethics on one occasion, in which it was used to overcome obstacles in combining lay and professional conceptions of health (Owens & Cribb, 2011). The authors use the theoretical

insights of CR to show how human life is a composite of objectively real, mind-independent ontological features, and subjective, socially constructed epistemological interpretations of these features. The explicit realism of the model maintains the connection between the logically scrutable objective structure of reality beyond our perceptions and the contingent and changing viewpoints which co-produce knowledge in the social world.

If CR's defence of a transcendently real ontology is correct, we are entitled to conclude that *a priori* reasoning is self-evidently compelling in the way that it appears to be. In CR the researcher is understood as a subjectively experiencing being enmeshed within and emergent from an objectively real and rationally apprehendable ontology. If this characterisation is correct then neither objective nor subjective considerations can be dispensed with if we wish to carry out applied ethics in a way that is tractable with the world, since both are aspects of it. The account that Owens & Cribb (2011, p. 10) give of health in terms of CR is illustrative:

'Ill-health...cannot be adequately explained purely in either biomedical or socially constructed, 'first hand' ways...ill-health ought to be understood as having a complex, stratified nature, existing both in the mind-independent bio-physical structures which are "out there in the world", as well as in the psychological activities of agents and politico-economic and socio-cultural roles, relationships and practices.'

Although the authors here give an account of health in terms of CR rather than using CR as an interdisciplinary methodology, the account of ontology and epistemology outlined earlier establishes the connection between the two. In the quote above health is understood as having both mind-dependent and mind-independent components, and is thus constituted by a combination of objective and subjective elements.

As I have explained, in empirical bioethics we seek to produce arguments to defend conclusions that are tractable with the world. If this aim is achievable it implies that there is a world to which such conclusions can be applied. In recognition of the

relativity of different viewpoints, however, it also accepts that this world must be subjectively understood and can be influenced by the actions and decisions that individuals make on the basis of these viewpoints. It is therefore clear that the account given by CR of the relationship between ourselves and the rest of the world is reflected in the suppositions and aims of empirical bioethics. Given this correspondence CR is ideally suited to being applied in empirical bioethics research.

3.7) Critical Realism and Moral Reasoning

The key aim of applied moral philosophy is to produce practical conclusions which have normative force. This is to say that the conclusions advanced must give compelling reasons for why they should be believed or followed, given a particular set of circumstances, and why such conclusions go beyond simple conjecture. CR's approach to resolving practical ethical dilemmas is predicated on the possibility of rationally discerning between morally acceptable and unacceptable courses of action (Bhaskar, 1989, p. 103):

'...the human sciences may be used, like any other sciences, to achieve (more or less consciously formulated and justified) ends, which may of course be equally adjudged good or bad.'

Given scepticism concerning the validity of allegedly non-relative ethical claims, it is incumbent on any philosophical methodology for applied ethics to provide a satisfactory answer to this scepticism. The demands of moral reasoning in applied ethics differ subtly from those of theoretical ethics, since applied ethics must - by definition - take explicit account of particular, discrete moral dilemmas in the world and attempt to formulate implementable solutions.

The moral analysis in these cases is therefore not concerned solely with the truth function of arguments constructed in predicate logic and abstracted from context²⁰. Rather, it seeks to strike a balance between rational argument and the

²⁰ This is not a criticism of the usefulness or insights available from tools such as predicate logic or propositional calculus. Rather my point is that there are regions of philosophical or moral analysis

contingencies of a situation which may preclude the realisation of the kind of 'ideal' solutions available in abstraction. This is expressed in CR's view of itself as a '*unity of theory and practice*' (Bhaskar & Norrie, 1998) which enables an '*enhanced reflexivity*' (Archer, 1998) between the two.

The implication of the model outlined here is that whatever arguments are given must be rational not only in the sense that they provide good reasons for accepting the conclusions to which they lead, but rational also in the sense that it would be possible to implement them in practice. As Southwood (2008, p. 13) writes, '*normative claims are or involve claims about reasons*'. If they are successful it is therefore because they have identified the best available course of action given the circumstances. He states that (Ibid. p. 13):

'...vindicating the normativity of rationality should involve trying to identify reasons for being rational...the canonical mode of defending normative claims that are in doubt is, of course, precisely to adduce independent reasons for complying with them.'

Implicit in this is the claim that morality has some existence which is not dependent on one's mind alone. If a realist ontology which vindicates the validity of deductive reasoning is defensible, it can be used as an 'anchor' for deriving normative conclusions that are rationally compelling. The reason why these conclusions must be rationally compelling is that the aim of applied ethics is moral progress. Progress is only possible if one has some static base according to which one's movement can be measured, however. If it is true that apparent instances of moral progress really are instances of progress, this can only be because of the existence of some independent standard according to which this progression can be judged.

where they are more usefully employed. Since applied work such as this seeks a negotiation between theory and data, and aims (broadly) at policy, empirical bioethics is unable to enjoy the rarified and exclusively a priori approach in which projects without such practical goals can engage. Given the necessarily 'political' nature of policy, no practical solution will be perfect, since the formation of policy recommendations involves negotiation and compromise between practical constraints and the conflicting interests of the different moral agents involved.

3.7.1) A Stepwise Illustration of Critical Realist Ethical Analysis

Sayer (1997) shows how CR provides an explicit rationalisation of the importance of empirical data for deriving normative conclusions that can enable moral progress. This rationalisation demonstrates in a stepwise fashion the connection between the two:

- i) *Identification of a problem, e.g.: unmet needs, suffering etc.*
- ii) *Identification of the source or cause of the unmet needs, suffering etc.*
- iii) *Passing to a negative judgement of the sources or causes of the problem.*
- iv) *Favouring (ceteris paribus) actions which remove those sources.*

Sayer goes on (Ibid, p. 475) to offer a full explanation of how this process can circumvent the is / ought problem:

'Bhaskar argues that transitions from (ii) to (iii) to (iv) are necessary, thus breaking "Hume's Law" – that ought cannot be derived from is. If a belief is known to be false, then, other things being equal, it makes no sense to deny that people ought not to believe it. Even if, in the case of the needs-based critique, we take the view that it does not logically follow that because a person is starving they ought to have food, it at least does not make sense, ceteris paribus, to deny that they ought to have it. The ceteris paribus clause in (iv) is intended to cover situations where there is a conflicting and overriding need which makes it unwise to remove the initial problem and its sources.'

If, following the is / ought problem, the objection to the use of empirical data in making normative claims is that the facts about a situation will not, on their own, provide any guidance about what the appropriate course of action would be, CR can provide a response. For example, if one is committed to the view that (all other things being equal) it is bad to be in certain states of need, one rejects a strict delineation between fact and value. The claim that certain needs have the property of 'being bad' implies that an ontological feature of this need is that it is something which should be otherwise. If this is correct, then in this instance a person's state of being is not value-neutral.

I anticipate the objection here that my judgement of someone's need or suffering as bad may be a relative matter, since if – for example – I were a sadist, I may derive pleasure from a person's suffering and be moved to prolong rather than stop it. One could infer from this the relativist conclusion that since normative assessments in this respect differ (i.e. I think the suffering should continue, whereas you think it should be stopped) that there is no fact of the matter about whether suffering is bad. Indeed from a detached 'Archimedean' position it may be true that suffering is a matter of indifference to the non-sentient universe.

Despite this criticism it does not change anything or help in any way once suffering is occurring, however. If, on reflection of my own experiences, I conclude that insofar as they are suffering the person in question is experiencing something intrinsically bad, I may act in order to stop it or perceive a duty to do so in view of my negative judgement of suffering. This response does not solve all fundamental problems concerning the truth of moral realism in the absence of humans or other moral agents. It does, however, provide the basis of an intersubjective justification and starting point for constructing the kind of applicable, policy-orientated heuristic conclusions sought in empirical bioethics.

If the wellbeing and views of all individuals to whom a medical decision pertains are intrinsically morally significant and should be respected, then these will inevitably have some bearing on the moral status of whatever course of action one recommends. Appeals to the naturalistic fallacy are only effective to the extent that fact and value can be shown to be properly distinct; however if it can be shown that fact and value are not entirely distinct in relevant cases, the collection and integration of empirical data within ethical analysis can be justified.

The dual benefit offered by adopting this position is that a) it helps to neutralise worries voiced over the high level of abstraction and detachment from context which characterise a 'pure' philosophical approach; whilst also b) providing a sufficiently logical defence of the central importance of empirical information to philosophically acceptable (i.e. explicitly rational) ethical analysis and decision-making.

3.8) Critical Realism and the Single Case Study

The empirical research method being used within this project is the single case study method. As we have seen, CR a) rejects the positivist claim that Humean constant empirical conjunctions necessarily provide the most reliable basis for claiming knowledge; b) shows that our collection of constant conjunctions in support of a hypothesis could never be exhaustive; and c) vindicates the crucial (although partial) and valid role that deduction has to play in epistemic justification. Consequently, CR enables us to maximise the explanatory power of interdisciplinary research involving limited data.

In giving an account of the significance of both a priori and inductive methods for moral reasoning, CR provides a means for extracting the best available account of a general phenomenon from a single instance of it. It is therefore a powerful methodology for maximising the epistemic value of tightly constrained interdisciplinary ethics research involving a single case study, and for developing tentative theoretical conclusions which may be taken forward and tested in future larger scale projects. CR can justify the analytic generalisability of results from a single case study if it has been correctly identified as a 'critical case' (Yin, 1989) of the phenomenon under investigation.

3.9) Conclusion

In upholding the equal importance of both philosophical reflection and empirical data CR vindicates the interdisciplinary aims of empirical bioethics. Previous methodologies have defended these aims; however CR gives a more thorough and explicit account of the ontological connection between data and theory, and thus a stronger justification for the possibility and value of combining them. It is therefore better equipped than previous methodologies to resist mutual criticisms between philosophers and social scientists concerning the relative validity of their methods within bioethics.

Mutual scepticism of philosophical and social scientific approaches to bioethics has been evident in the field since the 'empirical turn' of the 1990s when it became

multidisciplinary and expanded beyond its initially exclusively philosophical outlook. Social scientific critiques of philosophy have, for example, doubted the veracity of the truth claims generated by a priori argumentation, or defended a radically sceptical social constructionist position with respect to the possibility of apprehending objective truths. Similarly philosophers have been critical of the relevance of descriptive social scientific data for an enterprise such as ethics which is irreducibly philosophical and thus theoretical in nature.

CR effectively negotiates these, demonstrating both the incoherence of the strong social constructionist position, as well as giving an explicitly rational and philosophically acceptable account of the significance of empirical information for effective moral reasoning. We can conclude that in being able to successfully refute the various disciplinary criticisms that have beset empirical bioethics, CR can be successfully taken forward in this project for integrating empirical data with philosophical reasoning.

3.10) Summary

In this chapter I have introduced critical realism as the philosophical approach that I will use to combine the philosophical and social scientific components of the thesis. I have given an account of the metaphysical orientation of critical realism with respect to knowledge and the world. I have demonstrated critical realism's suitability for interdisciplinary ethics research and shown how it is able to negotiate a range of theoretical critiques from within both philosophy and the social sciences. In particular I have given an account of its refutation of strong social constructionism in order to provide a non-relative ontological basis for the data analysis that will be carried out in chapter six.

I have briefly introduced the history of bioethics in general and empirical bioethics in particular. Following this I explained how critical realism can be used as a tool for integrating philosophical and social scientific approaches to ethics in interdisciplinary research. I outlined the advantages that critical realism has over previous methodological attempts within the field. I gave an example of how

critical realist ethical analysis can successfully negotiate the is / ought challenge and thus how the approach can make a useful contribution in empirical ethics research. Finally I mentioned briefly critical realism's utility for single case study research, a fuller explanation and justification of which I will carry out in the following chapter.

Chapter Four: Empirical Research Methods

4.1) Introduction

In this chapter I will explain and justify the methods that I used in constructing and carrying out the empirical component of the project. I conceive this empirical study as being '*instrumental*' (Yin, 1989; Baxter & Jack, 2008) in its aims. Its purpose is to provide insight into how the therapy / enhancement distinction is understood within the chosen context, in order to assess the degree of congruence between these accounts and the theories found in the literature.

I have selected a single case study as a method because it is consistent with the overall aim of the project, which is to collect empirical data that will enable a deeper and clearer conceptual understanding of a larger issue. I will use a qualitative approach within the case study, as this is consistent both with the aims of the project as a whole and the philosophical methodology of critical realism that I am using to frame it.

Qualitative research seeks insights into subjective understanding, rather than the collection of 'objective' statistical data, and the interview form is more appropriate for the achievement of this than surveys or other quantitative approaches. Firstly in this chapter therefore I will explain why I have chosen a single case study method. I will then explain why I have chosen EPO as a case study. Following this I will report how the empirical study was carried out. Having done this we will be ready to understand the study findings in the next chapter.

4.2) The Single Case Study

I chose a single case study for the empirical component according to the wider aims of the project as a whole. The aim is to discover what kinds of distinctions, personal and professional views, motives, and justifications are involved in understanding the therapy / enhancement distinction from within a medical context. The study is intended primarily to contribute to conceptual depth, and focusing on one example provides a way of maximally prioritising this aim.

Also given attendant time and space constraints within the project the most effective method was to pursue one case study which could be analysed in depth, rather than several in which the analysis would have been more superficial. I judged that the aims of the project would be best delivered by selecting one 'critical case' on which a detailed analysis could be carried out. (Barzeley, 1993; Flyvbjerg, 2006)

4.3) EPO as a 'Critical Case'

I selected EPO as it constitutes what Yin (1989, p. 47) has described as a 'critical case' for the phenomenon of human enhancement. Yin's criteria for the critical case are as follows:

'When the case represents a critical test of a significant or well-formulated theory. Where such a theory exists there may be a single case that meets the conditions for testing the theory, according to its claims and propositions. This 'critical case' can then be used to determine whether these claims and propositions are correct, or whether an alternative explanation may be more accurate. Thus a critical case can be used to confirm, challenge, or extend a theory, and may help to refocus future investigations within the field.'

EPO represents a critical case for the phenomenon of biomedical enhancement because it is a medical product with a significant history of enhancement use. Furthermore the clinical criteria which determine 'acceptable' and 'unacceptable' uses of it are informed by the distinctions which underpin the biomedical model of health that is prevalent in western medicine.

The single case study method can be contentious (Stake, 1978; Yin, 1989; Stake, 2005). In particular this is because of scepticism over the extent to which any data derived from a single case study is reliable or valid in the sense of being representative of the phenomenon under investigation (Darke et al, 1998;), as it cannot be compared to data about other instances of the same phenomenon. Since the data were used as a counterpoint to theory in order that the latter may be conceptually or analytically refined, however, it was not incumbent on the choice

of method that it would yield statistical generalisability (Yin, 1989; Johansson, 2003).

My decision was informed in part by the fact that few products exist with a significant and relevant history of enhancement use, according to the parameters of the investigation. Although the broad idea of enhancing human capabilities is not new, when looking specifically at the context of biomedical enhancement on which much of the present debate focuses, relatively few case studies are available. Relatively few products exist with a significant history of appropriation for clear enhancement purposes beyond the clinical applications for which they were developed.

I explained in the literature review that cosmetic plastic surgery may be understood as an enhancement, since it is provided '*in the absence of disease or physical trauma*' (Grossbart & Sarwer, 1999, p. 101). I have excluded it, however, because studies have already been carried out to investigate perceptions of cosmetic plastic surgery from within the medical profession (Dunkin et al, 2003; Kinnunen, 2010). Moreover the categorisation of cosmetic plastic surgery as 'therapy' is contested and uncertain and thus cannot by itself provide a case with (apparently) clearly distinguishable therapeutic and enhancing applications.

Similarly Modafinil, Ritalin, and Adderall are products that are relevant to enhancement and have been the subject of qualitative studies of professional, user, and public perceptions (Forlini & Racine, 2010; Aikins, 2011; Bell et al, 2013; Vrecko, 2013; Fitz et al, 2013). Whilst a source of much contemporary interest due to their off-label use by students for the enhancement of concentration, however, they have only begun to be appropriated for this purpose relatively recently (Williams et al, 2008; Greely et al, 2008; Tannenbaum, 2008; Coveney et al, 2008; Cakic, 2009). Consequently the extent to which significant social and ethical implications are discernible and reliable is limited.

Other advanced medical products exist which may at some point have applications for enhancement purposes, but which remain therapeutic at present. One visible

example of this is the high-tech prosthetic technology used by paralympians such as Oscar Pistorius (Swartz & Watermeyer, 2008; Norman & Moola, 2011). These products may or may not confer a better than species-typical advantage over natural human legs at this stage of technological development, although if the technology continues to progress then this advantage may become less equivocal in future (Bruggeman et al, 2007; Jones & Wilson, 2009; Weyand et al, 2009; Kram et al, 2010; Burkett et al, 2011; Chockalingam et al, 2011).

The prospect of engineering 'better-than-natural' artificial limbs has attracted interest in the concept of transhuman or cyborg sport (Butryn & Masucci, 2009; Jonsson, 2010; Miah, 2010). At this point, however, there is no evidence that athletes are electing to have limbs removed and replaced by prosthetics in order to enhance their performance above the level that is already available to them via their normal physiology.

I therefore excluded advanced prosthetic limbs as a potential case study on the basis that we have not yet reached a stage where the elective replacement of regular human limbs by prostheses for enhancement purposes is a phenomenon that can be investigated. For similar reasons I also excluded the controversial issue of gene 'doping' for enhancement in sport (Unal & Unal, 2004; Rosoff, 2012; Duntas & Popovis, 2012; Fischetto & Bermon, 2013), since this is presently potential and experimental, rather than a technology whose impacts can be measured qualitatively.

EPO, by contrast, clearly exemplifies both types of relevant use, since it is a drug developed for therapeutic purposes which in recent decades has been used for enhancement purposes by professional athletes (Schneider, 2007). EPO is a copy of an endogenous hormone which maintains oxygen supply to the muscles and is a highly effective intervention for the treatment of the symptoms of renal anaemia (MacDougall et al, 1990; Fisher, 2010). It is also effective at increasing oxygen supply to the muscles of healthy individuals and hence enhancing exercise capacity from normal (Breymann et al, 1996; Gareau et al, 1996). It has been implicated in

several high profile 'doping' scandals (Mayes, 2010), for example those involving David Millar ²¹ and Lance Armstrong²².

The drug thus has over 20 years of relevant clinical and enhancement use which can be drawn on within a qualitative study. Moreover, the high public visibility of its use as an enhancement within sport provides a recognisable point of departure grounded in the real world which can be used as a route into the complex and more abstract ethical and philosophical issues at stake.

Finally, though enhancement via EPO (and indeed, sports enhancement in general) have been the subject of qualitative studies seeking the views of junior athletes (McNamee & Bloodworth, 2009; Bloodworth et al, 2012), it has not been the subject of qualitative studies which seek to elicit relevant medical professional opinion, despite its relevance for such a project.

I eliminated potential case studies which either a) were lacking in sufficient historical use; or b) had already been the subject of empirical studies related to or within the field of enhancement. Consequently I selected EPO as the single case study to be investigated, since this also satisfies the criteria for being understood as a 'critical case' for the subject under investigation.

4.4) Sampling

I sought information pertaining specifically to the clinical and off-label use of EPO via the experiences and knowledge of relevant medical professionals. I sought the views of professionals rather than users for two reasons.

Firstly, since the enhancement use of EPO is typically engaged in by athletes in a clandestine way, it is likely that gaining access to users would be prohibitively difficult. Secondly, because my aim is to gain insight into how the medical professional perceives itself and its responsibilities, and their connection to

²¹ <http://autobus.cyclingnews.com/news.php?id=news/2004/aug04/aug04news3>

²² <http://www.bbc.co.uk/sport/0/cycling/20672758>

enhancement, lay or patient perspectives on these issues will not yield useful or relevant information.

I judged that a project which collected professional perspectives on enhancement would produce more data that is relevant to understanding the phenomenon within a medical context. The construction of the specific empirical study should be guided by the aims of the issue investigated by the project as a whole (Gerring, 2004; Cresswell et al, 2007). Consequently I decided that these aims would be best served by orientating the empirical study towards obtaining a sample of professional opinion.

I chose 'purposive' sampling rather than random sampling for selecting the interview participants. This method is suitable for studies in which the researcher seeks to explore a specific issue with a group (or groups) of people who have access to key experiences and knowledge that are relevant to the topic being studied (Miles & Huberman, 1994; Robson, 2002; Corbin & Strauss, 1990). As Shaw (1999, p. 63) explains:

'While the logic of probabilistic sampling lies in "selecting" a truly random and representative sample which will permit confident generalisations from the sample to a larger population" (Patton, 1987, p. 51), the logic of purposive sampling is suited to research with different aims. Its power lies in the selection of cases "rich" in information about the substantive research problem.'

This choice of method was informed by the need to collect answers to three questions which were determined by the aims of the project:

1. How do participants conceptualise the difference between therapy and enhancement?
2. What are the participants' views on the use of biomedical technologies for human enhancement?

3. How do participants understand the limits of legitimate medical practice in relation to enhancement?

I identified two groups of relevant participants whose knowledge and experience were likely to bear relevance to the research topic and yield answers to these three broad questions. These are identified in the table below.

<p>Clinical Nephrologists</p>	<p>This group could give the perspective of medical professional dealing on a daily basis with renal anaemia patients who require EPO therapy. Participants will therefore be able to describe and explain the clinical use of EPO and comment on the differences between patients and healthy individuals using EPO, in relation to standard medical practice.</p>
<p>Renal Scientists</p>	<p>This group could provide information about EPO's past, present, and future development. Participants may be able to offer more thorough scientific explanations of the biological mechanisms at work, and thus may offer a different perspective from the clinicians, i.e. one further removed or detached from immediate circumstances of medical use.</p>

I chose my sampling method not in order to achieve a statistically representative set of medical professionals, but to elicit a range of responses and generate a 'snapshot' of the variety of views and perspectives that medical practitioners and scientists may hold in relation to the case of EPO in particular, and the concept of

human enhancement in general. This is consistent with the rationale provided by Miles & Huberman (1994, p. 29):

'Choices of informants, episodes, and interactions are being driven by a conceptual question, not by a concern for "representativeness".'

I selected two groups of participants because of their ability to speak from different professional perspectives within the context of the same case. By collecting data from these different perspectives and investigating their similarities and differences, I constructed a less partial view of the case that is more 'grounded' in reality (Corbin & Strauss, 1990).

I developed an increasingly comprehensive view by collecting new data according to what I had discovered and what information I still required. I did this by identifying which new participants would be most likely to possess the information needed. I used the 'constant comparison' method in order to determine these choices. This follows the guidance of Robson, 2002, and Corbin & Holt, 2005. Boeije (2002, p. 393) emphasises the importance of this process for carrying out qualitative research:

'Constant comparison goes hand in hand with theoretical sampling. This principle implies that the researcher decides what data will be gathered next and where to find them on the basis of provisional theoretical ideas. In this way it is possible to answer questions that have arisen from the analysis of and reflection on previous data.'

In using this method I was able to compare data from new interviews across the two groups and analyse them for similarities and differences with data previously collected (Miles & Huberman, 1984; Robson, 2002; Silverman, 2005; Vogrinc, 2008). I fed emerging themes and categories into subsequent interviews, and the coding process which followed.

4.5) Interview Method

I selected one-to-one, semi-structured interviews as the appropriate method of data collection, rather than focus groups. Interviews allow time for depth to

emerge within the data in a way that focus groups may not, since the researcher and participant are engaged in a private conversation wherein just one participant is the focus of the discussion. As DiCiccio-Bloom & Crabtree (2006, p. 40) state:

‘The individual in-depth interview allows the interviewer to delve deeply into social and personal matters, whereas the group interview allows interviewers to get a wider range of experience but, because of the public nature of the process, prevents delving as deeply into the individual.’

Within the interviews my aim was to collect data that was valid and non-arbitrary, trustworthy, credible, and relevant to my research question. This is consistent with the aims of qualitative social science research outlined by Guba & Lincoln (1981), Creswell & Miller (2000), and Whitemore et al (2001).

The one-to-one interview format allows for greater privacy than focus groups, which was important in this study. Since the use of EPO for ‘enhancement’ purposes is illegal it therefore has the potential to be a sensitive subject about which medical professionals may be less willing to speak frankly and openly if being interviewed alongside their peers. Finding out the participants’ views on off-label uses of EPO was central to this study, and thus I selected the interview format as it was likely to yield more useful data than if I had asked the equivalent questions in a focus group (Morgan, 1996).

4.6) Recruitment

Having established my target groups I identified professional bodies with likely access to relevant potential participants. These were the Renal Association (RA), British Renal Society (BRS), Royal College of Physicians (RCP), Association of Renal Technologists (ART), and EPO manufacturers Roche. I recruited 25 participants in total. The first four of these comprised the pilot study, and the remaining 21 constituted the main study. My aim was for a sample size of between 25 and 30 participants, ideally split equally between the clinician and scientist groups.

I applied to the University of Bristol Faculty for Medicine and Dentistry Committee for Ethics (FMDCE) for approval for a pilot study of four participants, which was granted. Following successful completion of the pilot study I re-applied to the FMDCE for approval for my full study. My applications to the FMDCE also included the topic guides outlining the questions to be asked in the interviews. Copies of these can be found in Appendices E and F.

No external ethics approval was required for this study by the University of Bristol in either case, since no patients, vulnerable people, or people under the age of 16 were to be included in the study. All the participants were to be qualified medical professionals, and were to be interviewed in their independent capacity as experts in the field of renal medicine or research, rather than as employees of the NHS. I contacted administrative departments at RA, BRS, RCP, ART and Roche via email with an invitation to participate in the study, and a letter attached outlining the project as a whole. In the email I requested that the invitation and letter be circulated amongst relevant members of the organisations.

Once the invitation had been circulated, potential participants contacted me directly. RCP, ART and Roche did not agree to participate, and consequently recruitment took place via RA and BRS. All of the organisations contacted represent professionals working in the private sector as well as the NHS, however only NHS employees responded to my invitation. Consequently all the participants were drawn from the NHS.

I responded to volunteers with the full project information sheet, asked them to read it and if they were interested in participating to suggest a time and location convenient to them where we could carry out the interview. Having arranged the interview I sent them the study consent form and asked them to read it in advance of the interview. I informed them that I would bring along a printed paper copy with me on the day for them to sign.

Across the 25 interviews carried out, 22 participants were male and three were female. Of these three females two were from the clinician group and one was from

the scientist group. One anomalous interviewee was conducted with a renal pharmacist. 19 interviews were carried out face-to-face at the interviewees' place of work, and six were carried out remotely by telephone or Skype. A breakdown of the professional demographic characteristics of the participants can be found in Appendix D.

4.7) Pilot Study

The pilot study group was comprised of two renal scientists, one consultant nephrologist, and one renal pharmacist who had responded to the email invitations. The renal pharmacist was the only anomaly across the two groups, being in neither the clinician nor the scientist group. I decided to carry out this interview in any case, since the participant was keen to take part in an interview, and informed me that he could provide useful information on commercial aspects of EPO procurement and usage.

I discovered during the pilot study that the first section of the interview structure proposed in the topic guide was too long, relative to the approximate total interview length of one hour. It became clear that I spent too much time pursuing interesting but only peripherally relevant 'scene-setting' discussions such as how EPO is administered, how it is manufactured, distributed, and stored. In order to maximise the discussion of the most relevant issues later in the interview I shortened the introductory section of the guide when refining the topic guides for the full study.

4.8) Full Study

Having undertaken the pilot I re-applied to the FMDCE for permission to carry out the remaining interviews. Since the pilot study was successful and generated a large amount of data, no changes to the main application were required. Once permission was granted I began recruitment. I used the same methods of recruitment as for the pilot study, sending invitations to RA and BRS. RA also placed an advertisement for participants in their newsletter. In addition I used names given to me by pilot study participants to 'snowball' for more potential

interviewees (Noy, 2008; Bryman, 2012). These two methods yielded quick results, and I was able to organise regular interviews.

Response to my initial invitation slowed, and I therefore began several rounds of recruitment in quick succession. I contacted RA and BRS again, although at this stage recruitment was more frequently secured via 'snowballing'. Due to the shortfall in interviews I targeted recruitment at regions further away from London or Bristol. By this point I was familiar with the interview format and in view of financial constraints I conducted several of these interviews via telephone or Skype.

The most challenging aspects of recruitment related to the renal scientist group. It was more difficult to recruit renal scientists, since many renal scientists work for EPO manufacturers, and my attempts to interview scientists employed by these manufacturers were unsuccessful. Secondly, many renal scientists involved in EPO research are also qualified nephrologists, and it was therefore difficult to achieve complete separation between members of the two groups, as several of the participants stated that they were able to respond in either a clinical or research capacity.

Given the crossover within clinical practice amongst the renal scientist group it was, ultimately, not possible to separate the two groups completely. In order to mitigate the effects of this as far as possible and ensure as much separation as possible I made it clear to the renal scientist participants throughout the process from recruitment onwards that I was interviewing them specifically in their research capacity. I requested them to keep this in mind when considering their answers to my questions and to provide responses that were informed specifically by their perspective as a scientist rather than as a clinician.

4.9) Interview Topic Guides

I developed two topic guides, one tailored towards each of the two groups. Some of the questions on each were the same, and some were unique to each, depending on the information being sought. For example, when discussing the details of the work

of each group I asked the scientists about the nature of their research in relation to EPO; whereas I asked the clinicians about aspects of EPO in relation to medical practice.

Where relevant, however, I also asked several of the same questions to both groups in order to compare their responses and identify similarities and differences. For example, I asked participants in both groups to explain EPO's biological action, and this question tended to produce a marked difference in responses. Participants within the scientist group tended to offer more complex, technical explanations than clinicians, who in general offered simpler accounts.

During the second half of the interviews conversation moved away from details of professional practice and became more conceptual, focusing strongly on enhancement. I therefore asked the same questions to each group more frequently so that accounts could be compared. Questions such as this focused on views about the nature of enhancement and therapy; the use of enhancements in different contexts; issues of justice in relation to access to medical resources; and comparisons between EPO and other kinds of technological enhancements.

4.10) Interview Structure and Facilitation

The interview commenced once I had received the signed consent form from the participant. For face-to-face interviews this was facilitated by asking them to give their signed consent form to me on the day, and for Skype interviews I ensured that each participant had returned an electronic copy of the consent form to me – this was in the form of either a scanned signed copy, or a digital copy with an e-signature.

Prior to starting recording I also checked that the participant had read and understood the information sheet sent in advance. At face-to-face interviews I provided the participants with a printed copy in case they had been able to read them in advance. Where this was not possible in the case of telephone interviews, I asked the participants if they had been able to read the document in advance and if they had not I sent a new copy via email whilst online.

All of the interviews were recorded on an Olympus VN-711PC 2GB Digital Voice Recorder. After each interview the recording was transferred onto an encrypted USB key via a University of Bristol computer, and deleted from the recording device. From here the recording was uploaded onto the University of Bristol's secure server, and backed up on an encrypted re-recordable DVD. Both the encrypted USB key and DVD were then stored in a locked drawer in Oakfield House, University of Bristol. Signed consent forms were also stored here securely. This procedure was carried out in accordance with University of Bristol data security regulations and the stipulations of the FMDCE.

Across both the pilot study and the main study the interviews ranged from between around 40 and 75 minutes. The shorter interviews tended to be those which had been carried out via telephone or Skype.

4.11) Coding

I coded the interview transcripts in order to systematically organise and manage the data. A wealth of information was generated, which I categorised in a way that represented an accurate conceptual representation of the research participants' views and their relative importance. As Basit (2003, p. 144) explains:

'Creating categories triggers the construction of a conceptual scheme that suits the data. This scheme helps the researcher to ask questions, to compare across data, to change or drop categories and to make a hierarchical order of them.'

I repeated the whole coding process several times, and made it an ongoing process throughout the study. The process involved both initial coding of new transcripts, and re-coding of earlier ones. The coding became decreasingly descriptive and increasingly conceptual as the process was repeated, and as the size of the data set grew. The method of coding I employed followed that recommended by Charmaz (2006, p. 42):

'Qualitative coding, the process of defining what the data are about, is our first analytic step. Coding means naming segments of data with a label that

simultaneously categorizes, summarizes, and accounts for each piece of data. Coding is the first step in moving beyond concrete statements in the data to making analytic interpretations. We aim to make an interpretative rendering that begins with coding and illuminates studied life.'

Following this method, firstly I carried out an initial coding of the whole transcript, attaching codes to the data to describe what was said. This first stage generated a large number of codes. The pilot study interviews each generated between 100 and 150 codes. The pilot study yielded so many codes partly because these were the first interviews that I carried out. At this stage I was unfamiliar with what might be said by the participants and had no prior frame of reference for this.

I carried out the initial analysis in such a way that the data was segmented as far as possible, and coded and represented neutrally, so as to resist as far as possible the influence of any judgements or biases arising from theories of human enhancement with which I was already familiar. This approach is consistent with the recommendation of Corbin & Strauss (1990, p. 13) who state that coding in this way:

'...enables investigators to break through subjectivity and bias. Fracturing the data forces preconceived notions and ideas to be examined against the data themselves. A researcher may inadvertently place data in a category where they do not analytically belong, but by means of systematic comparisons, the errors will eventually be located and the data and concepts arranged in appropriate classifications.'

After carrying out the initial coding of the pilot study data I compared the four separate lists of codes across the four transcripts. I did this in order to assess whether different participants had made similar claims or expressed similar ideas. Where this occurred I was able to amalgamate codes so that the overall number could be reduced. At this stage I also provided my supervisors with a subsample of transcripts for coding in order to compare their interpretation of the data with my own. This '*auditing*' (Seale, 1999, p. 468) of the data was '*an exercise in reflexivity*'

which enabled me to critically re-assess my own interpretation, question other possible interpretations, and enrich my understanding of the information.

Whereas in the initial coding the aim was to atomise the data as far as possible, during subsequent rounds of coding my goal was to reduce the number of codes used into a smaller, higher-order conceptual schema which accurately represented the categories at work in the participants' accounts, and moreover one which remained stable in the face of new data arising from subsequent interviews. This approach of 'data reduction' is recommended by Miles & Huberman (1983, p. 285), who explain its importance in qualitative research:

'Reduction not only allows analysis, it is analysis, in that clusters and partitions will necessarily follow the analyst's evolving sense of how the data come together and how they address the research questions s/he wishes to answer.'

The data generated grew as the main study progressed. Consequently the coding process became increasingly demanding. As the process developed in coding new interviews and re-coding earlier ones I discarded some initial codes, and grouped together certain sections of text from different interviews under newly generated codes where there was parity of meaning between them. This process enabled me to develop an attitude of 'reflexivity' towards to the data, wherein I re-examined a previous interpretation of one section of data in light of my interpretation of another.

Macbeth (2001, p.36) writes that the word 'reflexivity' has its '*etymological roots in self-reflection and critical self-reflection*', and can be understood as the process of research '*turning back on itself*'. Adopting this method enabled me to think about the data in more detail, and what the nature of conceptual connections or differences across them might be. This was crucial for maximising my open-mindedness towards the meaning of the data, and limiting the extent to which I imposed any meaning upon it. Macbeth (2001, p.37) continues:

'...reflexivity is recommended as a principal method for excavating new (anti)-foundations for the analytic and representational exercise...reflexivity begins with a

scepticism toward how indeed we have been doing these things all along. Reflexivity recommends an inquiry into the very possibilities of our unreflective knowledge and practices...'

The amount of data yielded from the pilot study onwards was considerable. The process of refinement from a large number of neutral codes to a smaller, more refined and more focused set of codes that applied across the set provided increasingly clear insight into what information was most relevant to the study participants with respect to the central issues being investigated.

The process became more complex as the study progressed, since I was dealing with an increasingly large data set. In addition the unpredictable frequency of interviews as the study progressed meant that different transcripts were undergoing initial, secondary, tertiary, and quaternary analysis simultaneously. This resulted in periods during which there was an inconsistency in the depth of analysis across the data. By the end of the study I had developed a stable coding scheme and a firm conceptual grasp of the typical concerns and viewpoints of the participants.

4.12) Saturation

As I approached 25 interviews I felt that I was achieving saturation within the data, since the amount of new, anomalous, or novel information being generated had reduced significantly. Glaser & Strauss (1967, p. 65) define saturation as the point at which:

'...no additional data are being found whereby the (researcher) can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated...when one category is saturated, nothing remains but to go on to new groups for data on other categories, and attempt to saturate these categories also.'

By the time I carried out the final interviews I was familiar with standard positions adopted by the participants and tested my hypotheses about their views by asking

questions which had been refined and focused by previous interviews. Although participants spoke from their own personal perspectives such that there was some degree of variation in terms of normative standpoints or philosophical views about the issues at stake, the range of likely viewpoints expressed had become clear. The constant comparison method outlined earlier enabled me in achieving 'saturation', wherein no new data was generated by subsequent interviews. The final four interviews generated additional data but yielded no new insights. Following Bowen (2008) I therefore concluded at this point that I could be reasonably sure of saturation.

The final four interviews were important, particularly in view of the fact that there was an imbalance between the clinician and scientist groups prior to these interviews due to difficulties in recruiting renal scientists. For the final four interviews I therefore sought scientists in order to redress this balance and test whether my more limited hypotheses about this group's views were correct.

4.13) Data Analysis

In the same way that the sampling of interview participants was purposive, so I conducted the data analysis in a similarly purpose-driven way. After completing the interviews and arriving at a stable coding scheme I moved on to the next stage of data analysis.

The process I employed in analysing the data had three stages: firstly to identify meaningful data within the transcripts according to whether it 'spoke' to the research question; secondly to code these data; and then to interpret within this content what underlying claims or positions were being defended by the interview participants. This process allowed themes to emerge, which were then fed into both subsequent interviews and tested against the sets of data which they produce. The method of interpretation I used in analysing the data is known as 'analytic induction', and is described by Robinson (1951, pp. 813) as follows:

'...the method of analytic induction begins with an explanatory hypothesis and a provisional definition of something to be explained. The hypothesis is then compared

with facts, and modifications are made in two ways: (1) The hypothesis itself is modified so that the new facts will fall under it, and/or (2) the phenomenon to be explained is re-defined to exclude the cases which defy explanation by the hypothesis.'

I chose this method because it *'gives conceptual and methodological scope for those engaging in qualitative research'* (Miller, 1982, p.285). As the researcher in this project I am driven by a philosophical interest in the therapy / enhancement distinction. As somebody who is neither a clinician nor a scientist my assumptions, presuppositions, educational background, knowledge and attitudes are therefore likely to differ significantly from the research participants.

I attempted to interpret the participants' reasoning in order to determine what rational or normative claims were being made. My goal was to inductively draw out the beliefs and assumptions were at work in informing and constructing their normative positions. If done correctly the interpretation of the testimonies of the research participants would yield explicit claims, beliefs, and assumptions that were previously hidden or unclear. Once these claims, beliefs, and assumptions were made explicit I used them as a basis for testing my interpretation of the data from one interview against the data from others.

As well as employing this iterative process within the analysis of the data from each study group, I also used it to compare the views of the clinicians and scientists across the two groups in order to seek out what differences in perspective there might be between them as a result of their different professional roles. As this process continued I was able to test, refine, improve, or reject hypotheses according to their accuracy when applied to different transcripts. This iterative process enabled me to gradually establish a firm overall conceptual interpretation of the data.

I allied this process to a procedure of 'theoretical triangulation' (Robson, 2002; Seale, 1999). Triangulation is analogous to the method of navigation used to determine one's position at sea or on a map, wherein two known points are used to locate the position of an unknown third point (Turner & Turner, 2009). Theoretical

triangulation is a method in which multiple theoretical schemas are used as different 'lenses' through which to view the information collected. In view of the various competing and currently empirically inconclusive theories as to the nature of the therapy / enhancement distinction, theoretical triangulation was the most appropriate for the purposes of this study.

Triangulation is achieved by identifying the different ways in which information might be explained, and interpreting the information accordingly (Cho & Trent, 2006). Theories that did not explain the data were discarded, and I continued the research according to these refinements such that the salient remaining issues could be pursued in greater depth in subsequent interviews (Draucker et al, 2007). I continued this process iteratively until the coding structure developed remained stable in the face of additional data collected and no new insights were being generated.

4.14) Conclusion

Given the wealth of speculative theoretical work on human enhancement compared to the scarcity of empirical research, I argue that the focus on a single or critical case with a history of enhancement as well as therapeutic use is the best way to achieve insights into professional perceptions and values from both clinical and research perspectives. Having investigated and assessed possible case studies according to the aims of the project and the philosophical methodology to be employed I conclude that EPO provides such a case study. Now that I have described the methods used in the empirical study, in the next chapter I will report the main findings which emerged from it.

4.15) Summary

In this chapter I explained the empirical study methods that were used. I explained that I chose a qualitative approach. I justified this approach according to its suitability for providing insight where conceptual clarification is being sought, as is the research aim in this case. I justified the use of the single case study method and also the choice of EPO as the case to be investigated. I explained how the single

case study method was used in conjunction with the philosophical approach of critical realism.

I reported the processes of recruitment and interview facilitation. I described how I gathered my data by way of in-depth interviews. I showed how the study methods and design represent the best way to elicit the motivations and distinctions that underpin professional decision-making amongst the study participants. I then explained the analytic processes of coding and data reduction used in identifying the key findings of relevance which are described in the following chapter.

Chapter Five: Main Findings

5.1) Introduction

This chapter introduces the main findings of relevance that emerged from the empirical study. These findings are presented thematically according to the coding and data analysis described in chapter four. The findings report information about the participants' work in renal medicine and research; appropriate boundaries of practice; clinical and research perspectives on the standard and 'off-label' use of EPO; ethical opinions of the use of other substances for enhancement purposes; concepts of naturalness and artificiality; and conceptualisations of the relationship between therapy and enhancement.

5.2) Therapy, Enhancement, and Normality

The predominant view held amongst the participants was that enhancement is a distinct phenomenon from therapy. In their accounts the distinction was grounded in the existence of real, non-trivial, statistical and qualitative differences between 'normal' health and illness or disease.

A typical expression of this view, from S3, was that *'you can very clearly distinguish between being ill and being normal...health is just being not ill.'* The difference in the case of renal anaemia patients was that prior to receiving EPO they suffered from symptoms such as *'lethargy, fatigue...breathlessness on exertion, angina...'* (C3).

When probed for a definition of 'normal' health, however, a widespread view was that a clear definition is elusive, given physio-biological variations between individuals and the relative demands of their lives. S2 gave the following example:

'... if you're an eighty year old in a nursing home who sits in a bath chair all day watching afternoon television it actually doesn't matter so much that you're haemoglobin's low and you probably won't really notice that much difference if you correct it, but if you're a twenty two year old who wants to play football, well, it'll have a massive difference, and anything in between those two extremes.'

The variation between entire social populations was adduced by C2 as a reason why 'the normal patient' eludes definition:

'...different societies - and it differs with different communities and what their expectations are - you know, what could be normal in one community may not be normal in another...there's this curve, and there's always going to be this two or two and a half percent outside...'

According to the prevailing conception of normality among my informants the needs of the ill were expressed as being greater than those of the normally healthy, such that *'being ill gives you a need but being well and just wanting to be more than well doesn't give you a need.'* This participant, S3, went on to state that *'getting better than normal isn't necessary or needed, whereas getting better from being ill is'*, and by implication that good reasons to enhance were minimal, since on this view normal health is sufficient and biomedical augmentation is not required in such a state. This characterisation was expressed by the majority of the two groups, but particularly explicitly by 15 participants.

Participants who expressed commitment to a belief in the reality of a difference between normal and ill-health tended to perceive a correspondingly real distinction between therapy and enhancement. This was grounded in the existence of relevant medical criteria, for example in C4's statement that patients *'have an indication for it and therefore it's therapy...if you're an athlete there's no indication so it's not a therapy, so it can only be an enhancement.'*

As previous quotes indicate, participants typically described their professional role and the boundaries of medical work as clearly circumscribed by the need to restore 'normality', rather than to extend functioning beyond it. This was the least equivocal finding across the study; however ambiguity was evident on several occasions. C13, for example, cited the legal prescription of beta-blockers to musicians for reducing anxiety and preventing shaking during live performances. The justification for this is that *'it's not really a medical condition but it helps them*

perform their jobs'. On probing this justification of engaging in what appears to be 'enhancement' medicine, the participant responded that:

'The problem here is definitions isn't it, which is what you term as a medical condition or not. So for a person a bit of anxiety or performance nerves is completely normal, and it's probably normal for most people, so on the basis that it's a normal reaction to a particular situation I think it'd be wrong to call it a medical condition – it's not a disease, it's not lack of health in any way, and it is performance enhancing in some way'.

Although normal functioning was the guide used by the participants as a target for their work, in relation to EPO they explained that differences between individual patients posed problems for achieving this, since appropriate dosing was unique to each individual patient. The participants typically used aggregate judgements for defining normality as 'the normal patient' could not be identified. S3 explained:

'I remember when I went to medical school and we had a conversation about what health is on some course, and they kept banging on about what health was, and health was defined – even I think in the WHO – not only as the absence of illness but a whole bunch of other stuff as well, I don't agree with any of that...no-one's ever gonna be healthy by those criteria! Not only have you gotta have no illness, but you've gotta be in full control, and fully spiritually and physically and mentally on tip top form – it's amazing!'

Eleven participants made reference to the physiology of people who live at high altitudes and who therefore naturally have a higher than average haemoglobin level. S4 suggested that individuals who live at high altitudes – whether patients, healthy people, or athletes - derive an advantage from the naturally high haemoglobin count caused by these environmental conditions:

'...if you asked them to go and exercise in Ethiopia or somewhere where hypoxia level is much higher, they can reach these target haemoglobin much easier. And there is one interesting study which shows that patients who are on dialysis who are living on high altitude, their EPO requirement is lower, because it stimulates their own EPO,

you see? And somebody looked at the survival of these patients and it was clear that the survival was better.'

Nine participants expressed concern over difficulties in normalising absolutely for equal ability, given human biological variation. S2 stated that normal genetic and physiological variation is so marked that 'we are not fundamentally equal', and that some unfairness in the distribution of ability is therefore unavoidable:

'What do you do about the 20 stone rugby forward versus the 15 stone rugby forward? What do I do about the fact that I need glasses to read anything?...there are all sorts of things like this that just aren't equal and at what point do you say "we'll normalise these ones, but we can't normalise those ones"?''

There was an indication from one participant, C2, that he perceived difficulties in clearly distinguishing between therapeutic and enhancement uses of technology on the basis that '*what could be normal in one community may not be normal in another*'. It was not clear precisely what size or type of grouping was meant by the word 'community' here; however, relative to the socio-cultural norms that prevail in such a grouping, he stated that '*I don't think you can define what normal physiology is, and I don't think you can define what enhancement is either.*'

C2's outlook was anomalous insofar as he went into detail explaining how norms change, and how this informs moral decision making. He suggested that humans are still evolving and that '*in the last 30 years probably we've evolved even quicker, mainly because of the technology*'. He stated that change is constant, and consequently perpetual re-adaption is necessary, asserting that '*we will evolve even more – we have to survive*'.

He made reference to the difference in moral norms between his father, himself, and his children, claiming that '*for progress you need enhancements*'. He concluded by identifying any technology which positively augments normal functioning as an enhancement, stating directly that '*there will be enhancements*'. He offered a condition for their moral acceptability, however, stating that '*we should do it in a*

way which is responsible and which doesn't have any adverse effects on that individual or to the society.'

In spite of various difficulties associated with the clear identification of normality it was clear that in a clinical context EPO has been dramatically successful in helping renal anaemia patients to live what is understood as 'normal' life in both objective and subjective terms. This was an outcome attested to unanimously. For example C1 described the development of EPO as '*an extraordinary achievement*'. C9 claimed that EPO's clinical success is '*spectacular...just obvious...out on a limb*', and is a rarity in that it has '*felt like a proper cure in medicine*'. This participant felt that the therapeutic benefits of EPO have been so marked that it should be considered as significant as '*syringing ears, correcting cataracts, surgically removing a cancer before it's spread, and insulin for diabetics*'.

5.3) The Moral Context of Enhancement

The predominant finding concerning views on the ethical status of enhancement was that its moral status was perceived to be strongly context-dependent, and variable according to contingent facts supervening on different scenarios. In particular what appeared to split morally acceptable uses from unacceptable ones was whether use of an enhancement would constitute an advantage that was unfair.

Where an enhancement would confer an advantage on the user that would also be denied to others its use was considered morally unacceptable, and characterised as cheating, whereas no strong moral objection was voiced in instances where the influence of the enhancement went no further than the user. This was a unanimous finding, with all participants at some point in the interview adducing 'fairness' as a principle for restricting access to enhancement. Consequently in relation to EPO a line of prima facie acceptability was drawn between its use in sport, and its hypothetical use for 'lifestyle' purposes. In the former a clear advantage would accrue to the user over the non-user, whereas in the second an enhancement user would not necessarily be exploiting non-users. This led to the typical view that:

'...whilst I've got no problem with people using a performance enhancer, I have got a problem with people cheating' (S3)

This appeared to be a distinction that was relatively straightforward to justify. Several reasons were put forward in support of the view that sports enhancement is unethical, whereas few moral objections were advanced against individual enhancing themselves in non-competitive contexts.

Objections to sports enhancement can be further divided into objections as a matter of principle alone, and those which are also pragmatic in nature. The former included appeals to the distortion of the level playing field (e.g. P1, P10), and the presence of regulative rules explicitly forbidding EPO use (C7, S2). The latter cited the irrationality of widespread enhancement use in cancelling out the net advantage to individual users (C2, S11), and unacceptable safety risks that enhancement use of EPO carries which would be legitimised if it were allowed (C6, C12). A modification of the safety objection was also advanced (S4, S7), which suggested that one way to reduce the problems related to sports enhancement would be to ensure that use is not forbidden, but properly monitored and supervised.

In the context of the 'lifestyle' use of enhancements such as EPO the only objection shared with those against sports use was driven by concerns for safety and the ethical responsibility incumbent on medical professionals to prevent unnecessary harm. Participant C12 felt that it would be 'foolish', rather than immoral, to use EPO for enhancement, but in view of the dangers would not sanction its prescription. S5 stated forcefully that *'it's not going to be an over the counter medication...that would never be allowed to happen, it would be very dangerous.'*

This issue of the professional responsibilities of the medical profession featured in every account of the moral status of enhancement, in relation to both sports and lifestyle use. An apparent tension existed between a commitment to individual liberty and self-determination which would include the freedom to enhance, and

the role that medical professionals should play in endorsing restrictions on this according to the risks of assisting with this.

A common view was that, in general, *'I don't think you can come up with a blanket principle about how [people] should and shouldn't use drugs'* (S11), however as medical professionals they nevertheless felt that beyond a certain threshold of risk it would be morally unacceptable for them to endorse the legal right to enhance. Relevant risks included personal health risks to the individual (C7, S5); risks to the integrity of the medical profession by engaging in controversial activities such as prescribing enhancements, evident for example in C7's statement that *'if all doctors were ethical people there wouldn't be very much doping'*; and in the case of sport, worries about the public message that would be conveyed if biomedical enhancement were to be seen as institutionally endorsed. S10 felt that the prevention of performance enhancement in sport is *'very important for whole society healthcare, really, and the message it sends out.'*

One common conceptualisation of the use of EPO for enhancement purposes was as being analogous with recreational use of other legal or illegal drugs. S6 established this connection as follows:

'So you're asking about the rights of the individual to do as he or she pleases....drug taking, basically'

Following this he grounded objection to the enhancement use of EPO in the statement that *'EPO has the potential to harm in supra-normal conditions'*. He argued that to the extent that illegal drugs are regulated according to safety, the same criterion is appropriate in the case of EPO. Similarly C5 defended the legal prohibition of EPO for enhancement as *'pragmatic'*. Although all participants had safety concerns over the use of medical products for enhancement, intrinsic moral objection to enhancement by medical products per se were negligible. To this extent S6's view was typical of the participants.

S3 did not typically regard the use of drugs for realising perceived subjective benefits as inherently morally problematic, and drew parallels with other

products, pointing out that *'in normal life it's not a problem...we all use drugs and different things at certain times'*. This was a surprising outcome and indicated that I had held an erroneous preconception as to participants' views on this matter. S9 expressed the view particularly clearly:

'It's a perfectly understandable aspect of human nature that if there's something about your body or your ability that you don't like and there's an opportunity to change it you might seek to do so – I don't think there's anything wrong with that'

The view expressed here was that it is relatively normal to use substances to improve or modulate performance, and was explained and justified in different ways by other participants. C11 claimed that the acceptability of the use of different interventions to alter performance is historically conditioned. In terms of comparisons to legal drugs she contrasted the legality of caffeine with the illegality of unsupervised EPO use. She suggested that the legal status of drugs is to some extent a historical accident, rather than one which is isomorphic with intrinsic moral acceptability or unacceptability:

'Look at caffeine, for example, it's a relatively new drug – it's only been around for three or four hundred years, but because it's been around before we started regulating everything there's no rules about being allowed to drink two or three cups of coffee before you go into an exam'

This participant also drew an equivalence between drinking wine for relaxation and using EPO to boost performance, claiming that it is reasonable to allow people to use potentially dangerous products because *'we can't live in a nanny state'*. Again, however, she claimed that the legality of alcohol use relative to the illegality of EPO for enhancement has been socio-historically determined, rather than determined morally a priori:

'...it's historic isn't it – wine has been around for ages, it's part of our natural psyche and culture, and erythropoietin is very new'

There were, however, a range of views about the acceptability of recreational drug use. C12 stated that *'recreational drugs are objectionable because of the crime associated with the supply chain'*. He was also concerned about the health risks to the user, but went on to say that *'I don't have an intrinsic moral objection to someone taking a drug in and of itself'*. Also in relation to recreational drug use S6 cited damage to society as grounds for objection:

'I've often heard the argument that the reason that drug taking is illegal in this country is because it affects society, that there is a societal implication...the reason why heroin is outlawed in this country is because of the problems you get for society'

References to illegal drugs frequently cited particularly dangerous substances such as heroin and cocaine as ones which there are good reasons to prohibit on grounds of individual safety and potential damage to society. In instances of products where risks are lower, however, there was again a reluctance to make generalisations about what people ought and ought not to be allowed to do in their private lives.

Once more the dangers of particular substances appeared to inform the thresholds of acceptability beyond which a legal curtailment of autonomy should be endorsed. As long as there is no risk to society, and as long as users understand the personal risks to their own health, a typical view, expressed by S6, was that *'it should be ok in that context for someone to do what they like'*. S11 made a similar claim, justified by the need to protect individual freedom where possible, stating that *'there is a degree of autonomy that people need to be allowed to make those choices.'*

5.4) Risks and Benefits

In spite of EPO's overall therapeutic success, participants were reluctant to make general statements about its net benefits, and the same was true of their views about the use of EPO for enhancement. The prevailing view was that whether EPO use does or does not in fact genuinely 'enhance' is *'multi-factorial'* (C6), since there may be many countervailing factors which could affect the net outcome.

Ambivalence was frequently displayed towards the desire to enhance, although conditions of safety and risk were expressed as factors which might reasonably be used in prohibiting access to 'off-label' enhancement. The ambivalence was grounded in a reluctance to dictate absolutely what people may and may not privately do with their bodies. The choice of whether to accept certain risks was understood to be a personal matter, irrespective of any value judgement of these decisions. In the following example from S6 the use of the words '*hubris*' and '*vanity*' imply criticism of certain decisions, but the quote suggests he does not believe that criticism alone is a strong enough reason to justify the curtailment of liberties:

'There's no medical need, it's for the aesthetic pleasure of the individual or whatever you want to call it – their hubris or their vanity. It has no societal impact, it gives income to someone, someone's willing to pay for it and the individual has to weigh up the risk and benefit. So as long as they can pay for it privately and it's not on the NHS then, you know, no one seems to have a problem with it'

Correspondingly, where safe 'off-label' use could be ensured, S3 argued that there would be little reason to object. He indicated a connection between public demand and the safety of medical products, wherein new trajectories of use for medical products may occur where use can safely be extended for non-medical purposes:

'...we have some medicines that are on sale to the public...you can go along and buy Piriton, that does sometimes have non-medical usage as if you give it to kids they sleep well, they get a good night's sleep, and I'm sure some people use it in non-medical ways, but it doesn't do a great deal of harm so that's a medicine that we don't regulate'

Three participants anticipated a further question concerning the balance between the need to protect the public from unnecessary health risks whilst also protecting individual liberty. C1 identified a recent historical change according to which medicine has undergone a degree of institutional re-orientation such that greater autonomy in decision making is transferred to the patient, wherein '*people have*

much more of a say, are kind of stakeholders in medicine and responsible for their own health' such that 'people make their own decisions'. This point was also noted by ten other participants.

The consensus in these cases, expressed clearly by C1, was that it is *'clearly for the better'* that this attitude prevails and that the profession has *'moved away from a sort of patriarchal "doctor knows best" kind of thing'*. In spite of favouring this transferral of autonomy, however, these participants were happy, on balance, to weigh in favour of current regulation of EPO in view of the risks associated with its use. A typical justification for this related to the *'shared decision making'* model defended by C12. According to this model equal weight is given to patient autonomy and professional judgement in order to arrive at a decision that balances a respect for self-determination with the obligation of medical professionals to prevent harm.

All participants noted that individual goals and values differ, and that some people may therefore be motivated to take EPO in the achievement of those goals. They explained that judgements about benefits relative to risks must take a range of subjective factors into account, including the patient's own health and personal experience of the disease, their age, goals, lifestyle, and typical range of activities. Members of the clinician group in particular, however, viewed themselves as gatekeepers to medical technologies, and since EPO is a medicine with potentially dangerous side-effects, they viewed it as too risky to use without guidance. They claimed that whether or not an individual has a medical need for EPO, a physician has a responsibility to ensure that those who receive medical assistance are not exposed to unnecessary risks, as C2 indicates:

'I can tell my patient "you're anaemic and we should try and get your haemoglobin a bit better because it improves your concentration, your exercise capacity, you reduce the cardiovascular risk" - it shouldn't be too high, it shouldn't be too low. But how would I advise an 18 year old boy who would like to compete, saying "you should take EPO, the benefit might be that you might win the race, but there's a 10% chance that you could have a stroke"'

Implicit in this statement is the view mentioned earlier that there is no need for the healthy to take EPO. This was expressed by seven participants, all of whom suggested that enhancement use of EPO is simply irrational, rather than morally wrong. In view of the net lifestyle benefits for already healthy individuals, C7, for example, stated that simply being able *'to get to work two minutes quicker'* was *'pointless'* and not a reasonable claim on EPO for enhancement purposes, when balanced against the risks of doing so.

This participant in particular was reluctant to identify the enhancement use of EPO as generating a simple net benefit just because it improves exercise capacity and endurance. For example, he claimed that there is a difference between altitude training and using EPO, since exercise at altitude both increases actual fitness and raises haemoglobin. On the other hand he asked *'can you then get the same effect by simply putting your haemoglobin up with EPO and not training at altitude? Probably not'*.

Divergence from this view by other participants, however, indicated how professionals working within the same field can conceptualise enhancement differently. For example, although C10 considered the question of whether enhancements should be legally accessible as being *'a grey area'*, she took a relatively straightforward line in respect of whether benefits to performance should count as enhancements:

'...how far do you go to say people need this and your life will be better or your life will be really improved by having this done to you?...it's not gonna completely make someone an amazing athlete just having EPO, but having that extra stamina meaning that someone can train longer and train harder...'

The commitment of the participants to generating beneficial outcomes and increasingly effective iterations of EPO motivated discussions about pharmaceutical research and development; legal and illegal markets in pharmaceuticals; the commercial pressures which come to bear on access to EPO; and issues of justice relating to appropriate regulations controlling access.

5.5) EPO and Other Enhancements

Bearing a similarity to views about the ambiguous moral status of EPO use for different purposes, the majority of participants expressed a belief that the moral and philosophical status of different technologies is also influenced by contingent social facts.

Consistent with the widespread finding that the participants tended to perceive real differences between therapy and enhancement, they also tended to commit to differences between EPO and other technologies for enhancing abilities. S1 stated, however, that *'to actually articulate that is rather more difficult'*, in spite of the fact that *'...one feels subjectively that there is something profoundly differently between giving yourself a recombinant hormone to perform better than buying the latest crampons to go and climb Mount Snowdon'*.

Although all participants identified difficulties in making a priori logical distinctions, they rationally grounded distinctions between EPO and other technologies which produce the same physiological effect qualitatively and empirically, and included socio-cultural influences on how differences might be understood. For example S1 pointed out that *'using telephones is regarded as fairly unavoidable...whereas EPO, there is an element of dishonesty associated with it'*. Given the element of dishonesty present in sports use, he stated clearly that *'one difference is simply just how socially acceptable it is'*.

The question of honesty arose whenever the issue of EPO's illegality was discussed, and S6 in particular took a trenchant view about the difference between hypoxic training and EPO use, suggesting that methods of raising haemoglobin such as the former that are not prohibited should be understood as *'legal cheating.'*

A further justification of a difference between the use of EPO and other products was grounded in the contingencies associated with being a medical professional and the values that one is expected to uphold in this role. C5, for example, suggested that there was some degree of similarity since all successful methods of enhancement will provide supra-normal capabilities, but nevertheless upheld a

distinction between them on the basis that, *'it's not part of medicine's remit to do that, so we just sort of duck out of that one...we've got to operate within boundaries'*. Similarly C7 claimed that the difference between therapeutic and enhancing applications of medical products was informed by the taxonomy of classification used:

'...there is a sort of nomenclature for this which is that there are quite a few substances which are naturally occurring substances and you can either take them in replacement doses which mimic what you should have naturally, or you can take them in pharmaceutical doses, which are doses that then have effect over and beyond just replacement'

On six occasions cosmetic plastic surgery was discussed in the context of enhancement and compared with EPO, and it may represent a boundary case dividing views on the ontological and ethical status of human enhancement more generally. Opinion diverged in several respects. For example, participant C8 felt that the two were analogous and was critical of cosmetic plastic surgery, particularly towards those medical professionals who engage in it. His opinion was that *'a lot of plastic surgeons are preying on weak and vulnerable people'*.

He adopted the same stance in relation to the hypothetical legal availability of EPO for enhancement on grounds of justice, stating that *'I philosophically don't like the idea of there being better access to any sort of healthcare dependent on ability to pay'*. Conversely, S6 viewed EPO and cosmetic surgery as analogous, but displayed ambivalence towards the desire to enhance oneself. He asserted a difference between very clear medical abnormalities which require treatment, and more subjective *'nuanced abnormalities'* which may not require treatment but for which it would be legitimate to alter in principle if desired. He thus foregrounded autonomy over one's body as the primary factor of moral relevance, assuming that other conditions of safety and justice could be satisfied.

In instances such as these the difference in legality between cosmetic surgery and EPO for enhancement was viewed as a historical accident. S6, for example, stated

that he did not know why one is legal and the other is not. The fact that these two cases were on several occasions viewed as analogous, however, did not appear to represent a good enough reason for sanctioning the enhancement use of EPO, and thus eliminated the importance of any legal inconsistency between them.

Participant S9 offered an alternative perspective, and whilst not endorsing EPO use for enhancement because of the attendant risks, took a broadly positive stance on cosmetic surgery, grounded in the legitimacy of the desire to alter one's body if one is not satisfied with it:

'...my wife is an orthodontist and some of her patients have teeth that they don't like, they're transformed by having orthodontic treatment, it changes their whole approach to life, it changes their whole character and undoubtedly improves their quality of life, so that's a cosmetic practice for which there are real and genuine physical and mental health gains'

The findings on views of cosmetic plastic surgery were relevant in terms of enhancement, since it is a field of medicine which is accessible in the absence of illness or pathology, or rather, in the absence of the kind of diagnosis which would ordinarily legitimate treatment in other cases. For this reason it may, alongside its standard therapeutic purposes in facial reconstruction and the treatment of burns and so forth, be construed as a field of medicine which is legally available for both therapeutic and enhancement purposes. The divergence of views on both its moral status and the extent to which it is analogous to EPO revealed the ethical and ontological complexity of human enhancement as it relates to the institution of medicine.

5.6) Justice in Access

Ensuring justice in access to EPO relative to need was a key concern across all of the participants. The unanimous view was that access should be determined and dictated by medical need. Correspondingly, whilst principled objections to the use of EPO or other products for enhancement per se were limited, it was clear that ensuring the supply of drugs to the healthy simply because they may be desired

was not a motivating factor in their work. This reinforced the emergent prevailing view of medicine as institutionally owing a duty to the sick that it does not bear to the healthy.

Of greatest concern was ensuring that those suffering from illness have access to treatments, and that legal mechanisms are put in place to ensure their just distribution on this basis. In relation to the mechanism by which this is achieved in the UK, C4 offered unambiguous support of NICE as the appropriate arbiter of regulation:

'I support the general idea behind NICE that any drug that wants to be able to market itself needs to have evidence to support it, so I think that should be done at a national level to avoid postcode lotteries and it should be done on the basis of evidence and not pressure from interested parties'

The corollary of this was that they viewed it as unjust to fail to provide resources when a medical need is present. C7 referred to severe EPO rationing in the early 1990s that caused situations in which '10 people got EPO and if you were the eleventh you had to wait for someone to be transplanted or die before you could have it'. He described this as '*tangibly an unfair situation*'.

On discussing this issue further the participants expressed views on justice relating to the permission or denial of access to EPO or other products medicines for enhancement by the healthy. There was little disagreement between opinions on the goals of medicine and whether non-clinical, off-label uses of medical products can be described as consistent with them.

In expressing a view about this that was typical across the study, C2 interrogated the purpose of enhancement, given that medicine typically aims to rectify statistically abnormal functioning in individuals who '*fall outside the norm*' when compared to '*95% of the population*'. Statistically normal functioning was not considered to generate a need, and hence C2 claimed that instances of EPO use by the healthy raised the question '*what's the goal you're trying to achieve?*'

The prevailing view was that the achievement of justice in medicine is coupled to the allocation of resources according to need, rather than the desires of the healthy to improve themselves. The participants discussed the difficulties of ensuring distributive justice in terms of the appropriate channelling of benefits to patients, when balanced against economic factors which come to bear on securing pharmaceutical products at the lowest price. Participant C6 believed that financial resources are being wasted by buying too much EPO, relative to the symptomatic benefit that this represents:

'If we quickly aligned our targets to the evidence base so we use less we would spend a lot less...in order to feel 80% better we only need to give you a haemoglobin of nine and that costs the state £1,000. Now if we want to give you a haemoglobin of 11 you'll feel a bit better, but that costs you as an individual £2,000'

Two participants offered trenchant views relating to the importance of prioritising the interest of patients at all times, and resisting the preferences of the market as far as possible. For example C7 claimed that medicine derives a moral value from treating the sick, and that this moral value is best realised via the state provision of healthcare, as this kind of provision helps to limit any deleterious effects of market pressures affecting patients:

'I get paid exactly the same as if I spend five grand investigating them and 10 grand treating them... people are always subject to conflicts of interest. Being a salaried doctor I still have lots of conflicts of interest, but whenever I'm seeing a patient the effect on my income is not a conflict of interest'

5.7) Commerce and Research

The commercial aspect of pharmaceutical production was widely perceived to have an impact on the moral status of outcomes relating to the use of medical products for standard and 'off-label' purposes. In particular the profit motive inherent to pharmaceutical trade and manufacture was viewed as capable of exerting a pernicious influence on the scale of use of medical products. When allied to the prevailing view of the healthy as having 'no need' to enhance themselves, the

widespread opinion was that unnecessary enhancement should not be encouraged, since this may increase the profits for manufacturers by selling products to people who are capable of living healthy lives without them.

This view was summarised by C7, who claimed that off-label access to products such as EPO is unjustifiable as its safety cannot be ensured because *'unscrupulous drug companies won't be too bothered about who they sell it to'*. He expressed concern over the existence of a large unregulated market in EPO, since such markets are by definition hard to control:

'You can go to China and you can just buy it straight from the factory or you can get it off the internet. There'd be people working at the factory that could have a pallet of it or people on the delivery lorries. There'd be all sorts of ways of doing it'

Three participants gave personal insights to this, citing examples of where kidney patients have been suspected of or discovered to be selling EPO as a performance enhancer on the black market after it became clear that, as C3 observed, *'some of them are ordering much more often than they should be if they're using the drugs at the prescribed rate'*. C3 also posed the question *'where is the EPO coming from?'*. On the basis of an incident involving a Chinese patient he said that *'it just struck me that one of them was a Chinese chap who's frequently heading back to China, and what's to say he's not selling half of his drugs on the internet or back in China?'*

The possibility of coercion by the market in EPO for enhancement was thus considered to be a serious risk with the potential to distort just outcomes in its use and distribution. Nine participants were concerned that loosening regulations and widening legal access privately or over-the-counter would inevitably increase the marketing options available to the manufacturers, and could cause political difficulties in ensuring distributive justice according to need. C8's statement was representative of this:

'...if you ended up with a situation where it was considered acceptable for there to be a cohort of drugs that are prescribed on an as needed basis as they are now, but

there's lots of supplementary drugs that people could buy, I guess the temptation for the exchequer would be to move more medicines into pot B and have fewer in pot A'

C8 was also concerned about increases in the scale of risks resulting from medically unnecessary use, since these would *'allow for more vulnerable people to be preyed upon by marketers'*. The concern was that whilst *'in a medicines framework there's really strict regulations'* such that he *'couldn't prescribe something for you without a good reason'*, that this would be absent in deregulation. His objection was that *'with this more loose concept of enhancement that isn't there, so I'd worry about protection that's available to people'*.

Concern over the impact of increasingly easy availability of EPO was expressed in different ways. Two participants implied that EPO is already sometimes clinically used *'beyond therapy'* as a function of market pressures. In the case of the UK, P1 suspected some over-prescription of EPO which goes beyond medical need because *'now it's more freely available and it's cheaper'*. He asked *'can we ethically push the boundaries out for patients to enable them to do more active things?'*, and reported worries that patients are being over-treated in suggesting that *'we're getting to the point now perhaps where because it's so cheap we are using it a bit too freely in some areas'*. In addition it appeared that EPO's controversial enhancements uses necessitate extra caution in prescribing *'because EPO is a drug that's abused'*.

C7 cited evidence from the USA in which EPO is prescribed under a model of private healthcare, and where a more immediate financial incentive is present for doctors. He suggested that EPO is already being clinically over-used as there are financial incentives for clinicians to prescribe it, since under a healthcare insurance system *'the more EPO you prescribe the more money you make, so unscrupulous doctors gave people EPO that didn't need it'*. By contrast as an NHS employee receiving a centrally controlled salary, he pointed out that *'there's no financial incentive for me to give people things they don't need'*. C5 summarised the prevailing view outlined here more succinctly, claiming simply that *'no-one's clean in this business'*.

Following this, several references were made to the fact that pharmaceutical manufacturers will only invest in research and development of a product if profit margins are sufficiently large. EPO is highly cost effective because so many people are affected by kidney disease, and consequently continued EPO research was claimed to be inevitable. Forthcoming non-injectable preparations will, as a result of being cheaper to produce and store, generate a larger profit margin, as well as potentially constituting an improvement on its present therapeutic application by being less invasive. Opinion was divided as to whether EPO specifically is a product whose enhancement or lifestyle use might increase once cheaper, pill, patch, or spray- based preparations come to market. C3, for example, believed that enhancement use would grow:

'I could see it in America very easily, the advertisements on the television – "are you thirty something, have you got young children, are you exhausted, would you like more energy? Ask your doctor about such and such"'

Whereas others, such as C6, were more sceptical:

'For some people very, very small margins are important. For most people it's the big stuff that's important - can I get out of bed in the morning? Can I get the kids ready for school? Can I go to work? Simply being able to complete their tasks at work a minute quicker over the course of an eight hour day isn't really that relevant'

Given what is still not understood about how EPO works and the risks entailed by these gaps in knowledge, all participants believed that more research is necessary, even though the drug is safe when properly administered. The depth of the current gap in understanding appeared to be considerable, as in relation to the mechanisms by which it works as a sports enhancer S1 stated that he stated that *'I've asked some world experts on EPO physiology and they've not really been able to explain it'*.

5.8) Differences Between Clinicians and Scientists

There were some discernible differences between the attitudes of the clinicians and the researchers, although they were subtle and the differences were not dramatic. As the study progressed it became clear that the views held across the two groups were more homogenous than I had anticipated when I began. This was particularly true of their ethical views, where little divergence was evident across the study. Where differences were noticeable these related to technical biological and scientific knowledge, rather than moral viewpoints.

Clinical nephrology has a long and well established basic science research tradition. Many clinical nephrologists carry out scientific research as well as their clinical work, or have done so at some point in their career. All of the renal scientists that I interviewed and who have worked in EPO research are also qualified doctors. Although I interviewed them in their scientific research capacity rather than their clinical capacity, it may be that it is difficult for them to separate the two roles entirely, and similarly difficult for me as the researcher to disaggregate the two groups completely.

Nevertheless one distinctly noticeable difference between the groups was in their explanations of the biological functioning of EPO. Clinicians tend to offer relatively simple explanations, whereas scientists' explanations were much more complex. Participant C3 in fact prefixed his account by saying it was a *'perhaps simple understanding of it'*, and on being asked whether he could explain EPO's biological action, C8 answered as follows:

'Well, not in great detail! But it works in the bone marrow and basically stimulates the production of red blood cells'

By contrast participants in the scientist group offered more detailed accounts. S1, for example, explained how the amino acid chain which constitutes the EPO molecule must be folded. He also outlined the mechanism by which the molecule itself becomes active, and used precise biological terms such as *'endoplasmic reticulum'*. He described the modification of the *'alpha chain of the transcription*

factor, along with an explanation of *'a so-called activated protein called B3000 or a CPP'* and its impact on the *'downstream gene'*. Description at this level of detail did not feature in the clinicians' accounts.

The second noticeable difference was that the scientists expressed greater certainty that new derivatives and iterations of EPO would come to market. S1 claimed *'it's inevitable'* that new derivations of EPO will be developed, and S4 indicated it was highly likely that new forms of EPO will appear given its current research trajectory:

'...it has been actually the trajectory for research for a long time, because people actually use it and extrapolate that into other directions'

Although some differences were discernible across the clinician and scientist groups, it is hard to generalise about any clear divergence of opinion with respect to therapy and enhancement, how they can be distinguished, and what should be done about the use of medicine for enhancement purposes. There was evidence that participants in both groups were equally engaged in the questions, and equally perceptive about the issues at stake. S3, for example, voluntarily extended the discussion to thinking about the potential role of EPO within work or leisure:

'...supposing you did a very hard job, a very tough physical job, and you had no choice but to do that job, and EPO would make you better at doing that job, make your daily grind a bit more tolerable, then I don't see why you wouldn't use it'

S2 also voluntarily broadened out the conversation beyond standard clinical medicine. He explained his view on enhancement by drawing an analogy with the use of antibiotics. Antibiotics for treating disease in humans are also employed as growth enhancers in agriculture. They enhance growth by destroying bacteria living in ostensibly healthy farm animals. This, he claims:

'...implies that there's something about the microbial flora in an apparently healthy farm animal that is slightly deleterious to it, and that by giving a drug that we would

use as a treatment in medicine you can actually get an advantage even when you haven't got the illness there'

He concluded by explaining how this might be analogous to the use of EPO for enhancement, arguing that:

'if the erythropoietin allows people to do things they couldn't do without it then that may be an advantage if it's really important that they do those things'

It should be noted that the caveat imposed by S2 here concerning the importance of enhancing oneself provided the criterion according to which assistance is justifiable. Despite not registering any objection to enhancement as such, he defended a 'titration' of resources relative to need on the basis that *'...we're in a cash limited system, so we can't provide everything that might be of tangible theoretical benefit'*.

These broader views were not exclusively offered only by the scientists. In one case C2, a clinician who does not carry out any scientific research, pre-empted a question about the continuity between EPO as a means of enhancement, and every day technologies which could be said to 'enhance' in some way, such as telephones. In anticipating a later question he suggested that anything which positively augments normal human functioning can be considered as an enhancement:

'I can't remember everything, so I put lots of things on my smartphone to remind that at 9 o'clock I should ring Mr. Andrews, at 10 o'clock I should be in this meeting, 3 o'clock I've got an appointment with you...so this is an enhancement isn't it?'

This claim in particular led to a discussion about the concepts of natural and artificial, and the relationship between evolution and technology, about which other participants also expressed views.

5.9) Naturalness and Artificiality

The concept of the 'natural' was revealed to be ambiguous. Discussion on this matter was raised by a question relating to the difference between using EPO to

raise haemoglobin for performance enhancement, and undergoing hypoxic training to do so. The lack of correspondence between optimum haemoglobin replacement levels via EPO use, and the species-typical or 'normal' haemoglobin content of the blood prior to the onset of anaemia was also relevant in motivating conversations about the moral value of the natural and the non-natural.

A view held by 12 participants, or around half of the group, was that hypoxic training is '*more natural*' in some way than EPO use, since EPO is '*a manufactured product, it's a pharmaceutical*', whereas '*going up to altitude is just something that humans do*'. The distinction appeared to be grounded in what is '*achievable in nature*'. This participant, C4, made some acknowledgement that the distinction may be arbitrary, however, on reflecting that '*I suppose I'm drawing an artificial line in the sand somewhere*'. Nevertheless, he adhered to his distinction overall:

'... sure enough you might need to get a plane somewhere, but it's pretty much achievable in nature to go up to altitude and train there, whereas giving yourself Aranesp for one month, bought from a dodgy doctor, is not achievable in nature'

Contrastingly, the other half of the participants judged the two methods as relevantly similar, since the outcome of both EPO use and altitude training is the same, namely a higher haemoglobin content.

There were similarities here with views concerning the difference between therapy and enhancement. Differences between the natural and the unnatural were apparent to the participants, but these categories were informed empirically rather than logically *a priori*. Participant C12, for example, began an explanation with an appeal to human nature and its technological alteration, but concluded that this line of argument was not ultimately successful:

'There's something about changing nature as well here isn't there, there's something about what is the intrinsic nature of people, and you might argue that the difference is that using external means of assistance like a drug , a car, a CD player or whatever it might be is not about changing yourself physically, whereas using EPO is. But then

we exercise in order to look different as well as to maintain fitness...it's difficult to see why there should be a specific moral objection to enhancement in that sense'

S9 identified the consideration of these concepts as something which goes on within medical practice, stating that *'we have this philosophical argument in medicine...there are people who think that we shouldn't reinvent nature, so doctors get accused of playing God or somehow interfering with natural processes'*. He went on to explain that this accusation is problematic, since all medical interventions can be construed as artificially interfering in natural processes.

He characterised therapy and enhancement as *'different aspects of the same thing'*, and pointed out that the logical end of an argument against medicine on the basis that it interferes with nature would be never to treat, that *'you wouldn't take someone's appendix out, you'd let them die, and that's not good healthcare practice'*. C9 suggested that it was not the 'artificiality' of an intervention which constitutes its moral status, nor its classification as a therapy or an enhancement. According to this view, 'artificiality' as such was not considered to be a centrally relevant moral concept.

Of key relevance to the therapy / enhancement distinction and its moral implications, however, was the issue of what constitutes an optimum level of haemoglobin, and thus how much exogenous, 'artificial', EPO should be used to treat patients. Therapeutic benefit was defined primarily in terms of the extent to which it *'makes people symptomatically better'* and restores normal functioning, irrespective of whether this corresponded to a statistically normal level of haemoglobin, since the former can be achieved without the latter.

A haemoglobin replacement level slightly below the bottom of the normal range is typically sufficient for this, and is also associated with a lower risk of stroke than when haemoglobin is within the normal range. Hence a typical response, expressed by S1, was that *'we don't replace haemoglobin to the level that you or I might have a haemoglobin in health but we bring it up to the 10 to 12 grams per decilitre range'*. Importantly S1 pointed out that despite the replacement level being beneath the

level of statistical normality, this was sufficient for achieving the therapeutic goal since *'the reality is we will have stopped them becoming ill'*.

In all interviews there were discussions about optimum haemoglobin replacement targets and how these relate both to species-typical levels and the supra-normal levels sought by athletes using EPO. There is currently no entirely settled view on why the optimum replacement target is below the 'natural', species-typical level. An hypothesis put forward by S2 was that it may be due to modern humans having a haemoglobin level that was *'set by evolutionary pressure'* at a much higher level than is now required, given dramatic changes in human living conditions since the emergence of homo sapiens which mean that *'we're now living in a time of plenty'*.

S2 went on to suggest that because of the absence of prior evolutionary pressures we may be now maladapted with respect to the species-typical level of haemoglobin *'because now very few people in our society are encountering sabre-tooth tigers that maul them, cause them to lose a pint and a half of blood but then still leave them with enough energy to run away'*. He also offered a second possible explanation, in pointing out that women now die only relatively infrequently through blood loss during childbirth, whereas in the past this otherwise *'would be a heavy evolutionary pressure without any resuscitation available, at least in the western world'*.

Whatever the reason for the species-atypicality of optimum haemoglobin replacement, the prevalent view across the participants was that it is only peripherally relevant to their work. Similarly the epistemic gap concerning the mismatch between species-typical and optimal replacement haemoglobin levels had little bearing on how the participants understood the appropriate limits of clinical practice.

5.10) Semantic Vagueness and the Boundaries of Medicine

Study participants often recognised philosophical grey areas resulting from the semantic vagueness involved in attempting to articulate the difference between therapy and enhancement, and by extension the boundaries of medicine. On two

occasions participants directed these complexities back towards me, the researcher, suggesting that it is my role as a philosopher, rather than theirs as a clinician or scientist, to think about what the differences might be:

'Is there an answer to these questions?!' (S1)

'It's not easy...otherwise you wouldn't be doing a PhD on it!' (C3)

Participant S6 went into greater detail in interrogating the basis on which conclusions are arrived at and decisions are made in philosophical analysis:

'You see, philosophy I understand as using logic and reason to try and dissect a problem to get to an answer – I don't know, does philosophy allow for one's instinct to play a role in decision-making?'

I inferred from comments such as these that whilst the participants recognised the presence of philosophical ambiguities and complexities, they viewed them as only tangentially rather than directly relevant to their work. This suggests that although they are aware of potentially unresolved questions concerning the boundaries of medicine, it does not prevent them from understanding the central aspects of their work and obligations in a straightforward and robust way, grounded in socio-cultural expectations of what it is that medicine and healthcare ought to do. C9 claimed that these expectations are in flux, however, and that *'society evolves a choice'*. This state of flux may in turn be responsible for C1's statement that:

'...there is an arbitrary component to it – I mean I'd say that medicine operates within society and so to a substantial degree what we do as doctors or healthcare professionals is influenced by what society deems to be acceptable and appropriate, and the way that doctors have behaved has changed in the past few decades.'

S11 made a different but related point, suggesting that what is and is not considered legitimately 'medical' by the medical profession itself is to some degree ad hoc. In relation to guidelines and indications for EPO use he stated that *'I don't think there's any overriding principle being applied'*, but rather that the conditions for legitimate use are *'to do with professional perceptions of the indications for*

particular drugs', and that pragmatically it would be risky to prescribe outside whatever the guidelines happen to be since 'they'd be leaving themselves open to a charge of professional misconduct.'

When discussing enhancement's relation to medicine he stated that *'none of these things are based on a set of overriding principles'*. He too claimed that *'the whole thing has evolved'*, suggesting that *'it's all historical'* on being asked why the boundaries of 'legitimate' medical practice are as they are.

C12 made a similar point relating to historical changes in definitions of illness and disease. Offering a 'common sense' interpretation of therapy and enhancement he stated that *'the cut off in most people's minds would be that if you are not treating a pathology then you're talking about enhancement'*. He went on, however, to point out that the concepts of illness and disease are not fixed, stating that the standard therapy / enhancement distinction *'doesn't take account of the fact that the idea of what is and is not pathological is very fluid'*.

S6, whilst not offering a condemnation of biomedical enhancement, offered a tentative solution, suggesting that decisions about who can access medicine 'off-label' is one which should be made by a different set of trained professionals than doctors, since a doctor's aim is to heal the sick:

'Your question of enhancement in the normal population or in someone that wants to do it for the fun of it, that really shouldn't be up to us because we're doctors, we're physicians, we treat people that are ill, so that's our concern. People who are well, maybe there should be another group of people who deal with those, because ethically we're not trained for that'

5.11) Closing Remarks in Interviews

Although the question of enhancement was often one which was of only peripheral interest or relevance to the work of the participants, they were invariably interested in the issues and happy to discuss them at length. Towards the end of

the interviews participants offered closing comments such as these from C6, S2, and S11:

'...it's not what I expected. I expected really to be talking about just renal patients, the literature. So to get on to the ethics of things has been really quite an interesting conversation... to start talking about use in non-renal patients, misuse etc, the ethics of doing things for enhancement, has been more interesting'

'I think it's been thought provoking and interesting and it's probably apparent from my more hesitant answers to the later questions that you've raised issues I've only partially thought through, whereas the straight facts on erythropoietin don't require fresh thought'

'It's been an interesting reflection on autonomy and choice in a way that I hadn't perceived before we started the conversation, and EPO has just been the centre of that discussion'

These remarks were in themselves instructive. In showing me that the issues we discussed are not ones that they think about in detail from day to day it was clear that the complex conceptual and ethical questions at stake, while intellectually diverting and ethically problematic, are not ones about which they are required to be concerned professionally. For example, towards the end of one interview, when asked her view about how decisions should be made concerning the balance between medical products provided by the state and within the private sector, and what uses should and should be licensed for, S8 exclaimed simply:

'I don't really have an answer to that to be honest – it's not my job to decide!'

Although in several cases participants identified problematic challenges – for example in relation to justice issues such as the balance between 'paternalistic' regulation of medicine for the benefit of the public against the need to also protect individual liberty – they tended to see these as existing only on the fringes of their actual work. The majority of people for whom the participants provide a service are ill, where the term 'illness' denotes dysfunction that is objectively and

subjectively real. Any philosophical and moral difficulties about medical dilemmas that exist outside of these boundaries tended to be thought of as being ones to which they do not need to provide answers.

5.12) Conclusion

It became clear during the study that the kinds of reasoning engaged in by me as a philosopher, and by these medical professionals as research participants, were frequently different. What we share, however, is an interest in what constitutes moral behaviour in medicine. From the study it was evident that there is some convergence in our aims, despite our differences in perspective and approach. What is different about these approaches is that a pure philosophical analysis of ethical questions is relatively detached, tightly defined, and logically abstract, whereas as professionals the research participants must think more widely about what constitutes ethical decision making in practice.

In engaging with the subject matter of enhancement within the interviews, these medical professionals found themselves having to make reconciliations. On one hand there was a relative normative clarity both to their motivations and the professional expectation that they help the sick. On the other hand, they often appreciated the logical and ethical ambiguities which emerge from a philosophical analysis of the therapy / enhancement distinction. They were keen to discuss these issues and the reasons why they challenge the premises of their professional motivations and expectations.

On several occasions participants referred to renal medicine as a particularly 'cerebral' or 'intellectual' field, and that this characteristic was one of the factors which attracted them to it. This is not to suggest that professionals in other fields of medicine would not necessarily be interested in the philosophical aspects of medicine, however an inclination towards intellectualising medical practice may be one of the reasons why they were prepared to consider these philosophical difficulties in depth.

Ultimately the participants were able to leave worries about enhancement to one side by virtue of the pressing need to help the sick, however their reflections regularly indicated that they understand the source of a philosophical interest in the therapy / enhancement distinction, namely the identification of the boundaries of medicine as ones whose precise location may be reasonably called into question.

During the study I formed the view that the high profile and well-documented nature of EPO use for off-label purposes helped in opening up the discussion of the potentially more abstract conceptual aspects of human enhancement in general, and making the broader discussion of this comprehensible. The history of EPO use was clearly of interest to many of the participants since it is a product which is central to both clinical and research aspects of renal medicine. On several occasions participants said that for this reason they had followed high profile cases of EPO use such as Lance Armstrong and David Millar.

These kinds of high profile cases can be understood as very distant from the normal concerns of day-to-day clinical and research practice, since professional sport is a marginal activity in which most people are unable to engage, whereas renal anaemia affects many thousands of people and compromises their ability to achieve even the basic tasks of daily living. The use of EPO is explicitly forbidden by the World Anti-Doping Agency in order to protect the 'level playing field' central to the ethos of sport, and hence it is easy to appeal to this rule as a reason why athletes should not use it in competition. Thus sports enhancement use and standard clinical use represent two poles which are understood as respectively ethically problematic and unproblematic.

Many of the insights which emerged from the study arose from discussions of the more ethically ambiguous region between these two poles, for example the hypothetical use of EPO for enhancement but not in overtly competitive environments. These more ambiguous reasons call into play a different balance of ethical priorities, since if the competitive element is removed, for example, then issues of justice and fairness can be less easily adduced as reasons why people ought not to engage in EPO use for off-label purposes. Consequently it was the

discussion between the two poles which indicated most clearly the priorities of the research participants in relation to enhancement.

As gatekeepers to potentially dangerous medical products, the endorsement of any liberalisation of access to these products was clearly dependent on whether safety could be reasonably ensured. In respect of enhancement the need to protect the public from health risks and injustice was the cardinal ethical principle underpinning the dominant position towards the moral acceptability of enhancement. If safety and justice could be reasonably ensured, however, then a countervailing commitment to respecting personal autonomy and self-determination became a key determinant of their decision-making.

This detailed negotiation between personal ethical commitments and the expectations of responsible medical practice that emerged from the data gave an important insight. This insight shows how balanced ethical decisions can be made and justified in relation to a contentious ethical question, such as enhancement, which challenges the already ambiguous boundaries of acceptable and unacceptable professional practice.

5.13) Summary

In this chapter I outlined the main findings which emerged from the empirical study. The data showed what was of ethical importance to the study participants in terms of the acceptability of human enhancement; the data also provided insight into how the participants conceptualise enhancement and the nature of its difference from therapy; finally it also highlighted the different approaches to rationality employed by them as medical professionals, and me as a researcher approaching from a predominantly philosophical standpoint.

The research participants tended to adopt an ambivalent position in relation to the liberty to enhance per se, with other contingent considerations supervening on biomedical enhancement being those which informed how they constructed a defence of 'acceptable' or 'unacceptable' use. The key normative considerations in assessing acceptability of access to medical products, for therapeutic or

enhancement purposes, were safety, fairness, and justice. Principled objections to enhancement beyond this were limited.

The predominantly held view was that enhancement is connected to medicine but in a peripheral, rather than central, way. As such, in clear-cut cases such as sports enhancement it was perceived to be non-trivially different from therapy. The deductive reasoning employed in interrogating the therapy / enhancement distinction from a philosophical perspective revealed itself as a different approach to the resolution of dilemmas from the empirically informed reasoning used by clinicians and scientists in their work. Whilst both forms of reasoning were mutually comprehensible, conceptions of the distinction were informed from different starting points and assumptions.

Chapter Six: Philosophical Analysis

6.1) Introduction

In this chapter I will analyse the study data in terms of relevant theories concerning the relationship between therapy and enhancement. I will therefore bring together the conclusions from chapter five and the literature reviewed in chapter two. I will compare the issues of relevance within the data with corresponding theories and aspects thereof, and carry out a philosophical analysis of these in order to improve our understanding of the therapy / enhancement distinction.

The steps to be taken in this chapter are as follows. Firstly, I will re-state the initial problem and summarise what needs to be known in order to resolve it. Secondly, I will give an overview of the study data. Thirdly I will address the conclusions arrived at in the previous chapter concerning the data that can help to clarify the therapy / enhancement distinction and shed light on the main issues of ethical concern to the study participants. I will provide an example of theory / data integration and analysis, and subsequently apply the same procedure throughout all of the data being analysed. The data will be compared with theory in order to illuminate those areas which are presently ambiguous. Finally, I will draw conclusions from these analyses which will be summarised to be taken forward into chapter seven.

Consistent with the philosophical approach of this project, the analysis that I will carry out in this chapter will be done from a critical realist perspective. In the analysis I will proceed on the basis that critical realism has given an accurate account of knowledge and the world, the nature of their difference and their relationship to each other. The postulations of an objective ontology combined with a subjective epistemology, and the ability of both empirical data and a priori reasoning to yield partial truths about reality will be the assumed basis for analysis. This follows the reason and justification for accepting these postulations explained in chapter three.

6.2) Stating the Problem

The literature review showed that there is disagreement and epistemological uncertainty with respect to the correct interpretation of the contested therapy / enhancement distinction. It is not obvious whose reasoning we should follow: is it that deductive philosophical arguments which highlight the logical weakness of the distinction have identified inconsistencies within the institutional status quo and its nominal exclusion of enhancement? Or despite the claimed significance of the logical continuity between therapy and enhancement, should we favour the status quo and its current orientation? As changeable and historically contingent as it may be, perhaps we should follow the medical professional view in order to ensure that assistance remains prioritised for the sick rather than the healthy. Do the empirical data compromise the theoretical integrity of the pro-enhancement arguments made within the enhancement literature? Or do these theories indicate that the study participants have erred with respect to the normative judgements of enhancement that they offer?

Given this challenge my aim is twofold. Firstly, to show that philosophical theory requires social scientific data to impose important normative limits on the counter-intuitive conclusions at which it can arrive. Secondly, to show that medical practice requires philosophical analysis to make it clear where errors in reasoning have been made, and to attempt to weigh conflicting arguments as objectively and non-relatively as possible.

6.3) Overview of Data

My central observation of the data is that there was no absolute congruence between the empirical data as a whole, and any single theoretical account of enhancement. Certain views partially echoed positions found within the literature, although the data pointed in several different directions. Although *some* views validated *some* theoretical accounts to *some* extent, the data did not comprehensively refute the various deficiencies inherent to the conflicting accounts found across the literature.

To the extent that the data do not resolve all the theoretical complexities of the therapy / enhancement distinction, the distinction remains ambiguous. Since my aim is to improve on previous theoretical accounts and clarify what would be, overall, the best application of theory in practice, a net balance between the two must be negotiated.

Fortunately, despite the theoretical ambiguities still present, certain themes of ethical importance were discernible within the data in terms of the relationship between enhancement and medicine. These areas of consensus and agreement will therefore be used as the basis for developing conclusions and recommendations that are presented in the final chapter of the thesis.

6.4) Health as 'Adaptedness'

Areas of partial congruence between theory and data are evident. I will therefore examine one instance of partial congruence between theory and data and analyse the implications that follow from this relationship. For this example we will use Pörn's (1993) theoretical characterisation of health as a state of 'adaptedness' relative to one's goals. This is relevant because a corresponding view was voiced several times within the study, in particular by S2 and C6. S2, for example, compared the needs and 'adaptedness' of patients and sportsmen using EPO in the attainment of their goals:

'...if you're an eighty year old in a nursing home who sits in a bath chair all day watching afternoon television it actually doesn't matter so much that you're haemoglobin's low and you probably won't really notice that much difference if you correct it, but if you're a twenty two year old who wants to play football, well, it'll have a massive difference, and anything in between those two extremes'

EPO has a dramatically positive impact upon anaemia patients' ability to meet the demands of everyday life (MacDougall et al, 1990; MacDougall, 2001). For athletes the margin of performance enhancement available is smaller, since they are already at or close to peak physical fitness. In elite sport, however, these small margins are valuable since they may make the difference between winning and

losing (Holm & McNamee, 2010; Savulescu & Foddy, 2010). In the case of EPO for enhancement by the averagely healthy person, however, C6 stated that the performance margins offered are unimportant, since:

'...simply being able to complete their tasks at work a minute quicker over the course of an eight hour day isn't really that relevant'

Consistent with Pörn's account and in view of the above, one could argue that health should be cast as an agreement between capabilities and goals. Given that EPO use would make little difference to most healthy people's ability to achieve their everyday goals, 'health' could reasonably be understood as being naturally 'adapted' sufficiently well relative to those goals. Importantly, however, the comments of S2 and C6 also underline deficiencies in Pörn's account, as well as endorsing it in other respects.

A professional cyclist will be in a state of exceptional physical fitness and (probably²³) exceptionally good health even if, for example, he is unable to win the Tour de France without the use of performance enhancing drugs. Yet Pörn's theory implies that the natural inability to reach this goal means that we should identify the cyclist's health as deficient, because his unassisted physical condition precludes him from meeting it: he is not sufficiently well 'adapted' to the task without assistance. Similarly, just because there is an 'agreement' between the 80 year old person's low haemoglobin count and limited physical goals, it does not mean we should conclude that this individual is healthy.

If health is reduced simply to adaptedness in this way, the therapy / enhancement distinction dissolves. Any state may be considered 'deficient', depending on the correspondence between the person's physical health and their goals. The example thus reveals a tension. We can infer from this that the 'adaptedness' account has some degree of utility in explaining the relationship between therapy and enhancement. However, insofar as it also produces inconsistencies when

²³ Leaving aside for the time being that high level sport can in some cases be deleterious to health in the long run, for example if we bear in mind potential long-term damage to the body through exceptional exertion in the first half of life, and the threats to immunity that can be caused by constant exertion at the margins of human ability.

compared to views expressed within the data, it does not fully capture the therapy / enhancement distinction as perceived from within the context of medical practice.

I conclude that Pörn's theory has weaknesses in view of the fact that it is not able to fully explain enhancement when considered in context. Therefore, any contextually successful account of enhancement should utilise those aspects of the 'adaptedness' theory which have explanatory power, and reject those which limit it. Doing this will point towards what else is required in constructing a full account, and thus help to identify what features of this account are still missing.

Having seen an example of how theory and data can be mutually analysed I will apply the same process to the other relevant data from the study. To begin forming the basis for some consensus or resolution of conflicting views and theories of the relationship between therapy and enhancement I will examine issues of moral relevance about which there was widespread agreement across the data.

Irrespective of divergence in views concerning the logical coherence of the therapy / enhancement distinction, the empirical study indicated three salient issues of ethical importance to all participants: Professionalism and Safety; Risks and Benefits; and Justice. In addition the data yielded a range of views concerning the reality and integrity of the philosophical distinction. An issue of importance to both the philosophical and ethical aspects of the debate which also arose in the study related to the concepts of naturalness and artificiality.

Even though aspects of the therapy / enhancement distinction remain unclear, the three issues of moral relevance mentioned indicate what was of primary ethical importance to the participants from a clinical and research perspective. This is important because what they consider important may be different from what seems significant from a detached philosophical view. Taking into account what is ethically relevant for these professionals will help to frame preliminary hypotheses as to what conditions (if any) would have to obtain for enhancement to be an acceptable use of medical resources from their point of view.

6.5) Safety and Professionalism

The two interconnected issues of safety and professionalism relate to norms of practice, since the socio-cultural norms and technological possibilities that prevail influence what is or is not expected of the medical profession within a given context (Benedict, 1934; Fabrega, 1991; Kleinman, 1997; Stempsey, 2006; Franklin, 2006). These norms are not static, and hence the content of one's expectations of medical assistance may change over time according to the actual procedures available. As Fleischauer & Hermeren (2006, p. 10) explain, however, the contents will be expected to correspond to more fundamental goals that are broader and less transitive:

'Caring, curing, helping, and preventing...constitute the ends or internal goals of medicine...Under each of these overarching classical goals numerous specific operational goals can be discerned. These more specific goals are dependent on the state of scientific knowledge, technical achievements, and experience as well as on changing philosophical views and ideologies which in the course of history have resulted in different conceptions of disease.'

Arguments can be made both for and against enhancement in terms of how it may or may not serve these 'classical' goals. Strong pro-enhancement positions were not evident within the study. Irrespective of a spread of views being advanced concerning the logical coherence of the therapy / enhancement distinction, the need for a safe and beneficial balancing of concerns imposed a strong moral condition on appropriate accessibility in all cases. This condition was also adopted in pro-enhancement arguments within the literature (Allhoff, 2005; Greely et al, 2008; Harris, 2009; Sandberg & Savulescu, 2011). Despite that in all of these cases the writers endorse the use of enhancements, they do so only on the condition that the risks associated with doing so are outweighed by the benefits.

A conception of the responsibilities of the medical profession based in the four goals outlined was reflected widely within the data. EPO does not reverse renal anaemia, and in this respect it is not a cure for the condition itself. However, it does

safely 'cure' the symptoms of the illness when used carefully and results in dramatic improvements to life. For example S1 and C9 offered an account of the clinical use of EPO which show that it clearly assists in the realisation of the classical goals outlined:

'...they were disabled by their anaemia – they were tired, breathless, low exercise tolerance, unable to do normal things...you give them EPO all of a sudden all of those physical symptoms are alleviated...it is amazing really...It's an extraordinary achievement'

'...the effects on quality of life were considered just obvious – if you saw people walking around with a haemoglobin of six and then had a haemoglobin of nine to 10 the effects were dramatic...And there were lots of studies done...that showed that moving people from six or eight or whatever it was to nearer to 10 was associated with a major advantage'

If the kind of balance between safety and benefit outlined here are properly representative of key normative features of therapeutic medical practice, we may ask whether the same balance could be applied to instances of enhancement as well. The balance between the commitments to safety and beneficence in terms of the conditions of acceptability that they would impose on access to enhancements was summarised by C10:

'It's a grey area - if you look at plastic surgery and things, it's not something people need, so if there was a market for doctors to help people with performance enhancing drugs in a safe way then maybe there could be an area where you could be prescribed EPO. There are other things in medicine that are done for purely superficial reasons'

Beyond a certain threshold of risk it was unanimously deemed unacceptable for the medical profession to allow access to certain interventions, irrespective of whether the interventions would be understood as therapeutic or enhancing. This is congruent with the Hippocratic Oath's insistence that a doctor must not harm his or her patients (Markel, 2004; Antoniou et al, 2010). Basic intransitive moral commitments of this kind are also canonical within scholarly work on the

principles of medical ethics (Beauchamp & Childress, 1976; Gillon, 1994; Gillon, 2003; Pellegrino, 2005).

Four articulations of this view were particularly relevant. C2 stated that the 10% risk of a stroke to a healthy 18 year old using EPO for performance enhancement was too high to permit access; C8 offered an analogy of non-medical EPO use with cosmetic plastic surgery, claiming that individuals seeking enhancement would be 'preyed upon' by a sector of the profession for the financial gains available. S5 claimed that EPO is simply too dangerous to de-regulate. S3 made use of the example of Piriton – a hayfever medication sometimes used 'off-label' to enable children to sleep more easily – as an instance of a drug which is safe enough to de-regulate for such purposes. He then contrasted it with EPO and made a justification for the difference in legal status of the two:

'I don't have a moral objection to anybody using a medical product for a non-medical purpose, I think there's a very clear philosophical and mental distinction in my mind between the two acts...but I can see there's also a need to regulate medicines...some medicines that are on sale to the public...you can go along and buy Piriton, that does sometimes have non-medical usage as if you give it to kids they sleep well... it doesn't do a great deal of harm so that's a medicine that we don't regulate, other medicines we do regulate for fairly good reasons because they're dangerous or because they're addictive, because they have more potential to do harm than good, because we don't want them sold directly to the public, we don't want a market created in them, and what EPO should fall into is probably that category'

In each case an important factor in determining the boundaries of ethical practice was the level of risk conferred by the different relevant factors that come to bear on the situation. This is a separate theoretical issue from whether or not it is in principle morally acceptable to use medicine for enhancement purposes. Positions such as this were advanced in the literature. Allhoff (2005), Cakic (2009), Bostrom & Sandberg (2009), Sandberg & Savulescu (2011) all argue that safety is a rational guiding principle for decisions about accessibility to medical interventions, whatever those interventions might be.

A corollary of this is that access to enhancements ought to be less ethically problematic if conditions of safety can be satisfied. Cakic (2009) also notes, however, that the foregrounding of safety can be construed as excessively paternalistic. He argues that whether or not a decision is considered to be excessively paternalistic depends on the threshold of personal risk about which the medical profession deems it acceptable for patients to make a judgement.

6.5.1) *Autonomy Vs Paternalism*

The tension here is one that has been institutionally visible in recent decades. The medical system – at least in places such as the UK (Stevenson & Scambler, 2005) and the USA (Kon, 2010) – has attempted to become less paternalistic, and to strike a balance of ‘shared decision making’ between professional advice and patient autonomy. This reorientation was echoed in C1’s statement that currently ‘*people have much more of a say, are kind of stakeholders in medicine*’.

The driving ethical principle here is the autonomy of the patient. Assuming that we live in a liberal society wherein the protection of personal freedom is considered to have intrinsic ethical importance, it is a principle which should also be upheld within healthcare (Cohen, 2000). Juth (2010) claims that the degree of weight awarded to patient autonomy within medicine is proportionate to the value placed on it more generally within society. Since personal autonomy is highly valued in liberal societies (Gauthier, 1993; Etzioni, 2011; Juth, 2010), he argues that the same principles influence decision making in healthcare, thus changing what is perceived as an appropriate balance between the desires of the patient and the views of the doctor.

This reorientation therefore invites fresh debate over the appropriate moral balance between the autonomous desires of those seeking medical assistance on one hand, and the responsibilities endowed upon those providing it on the other (Schwartz, 1992; Graber & Tansey, 2004). This is pertinent in respect of enhancement. For example a doctor may believe, if an individual desires a medical intervention which is not medically necessary and may damage health, that there

is a strong justification for refusing assistance irrespective of the fact that this may thwart the autonomous desire of the person seeking it. In the case of EPO the study participants frequently adduced the dangers of extra-therapeutic uses of the drug as a scenario in which this would be justifiable. C5 offered the following justification in relation to the salient issue of EPO for enhancement in sports:

'If the rules were just 'allow athletes to use EPO' harm would come - athletes would overdo it, and make their blood count too thick, and then get strokes and thromboses and things and that would be very bad, so there is a sort of pragmatic reason why we wouldn't just open the floodgates'

Given certain conditions, therefore, a justification for medical paternalism may be evident, since if patients were permitted to make decisions that would harm them this would be an abrogation of the doctor's duty to care. Following Loewy (2005) in extending this argument, if a medical decision were sanctioned that does turn out to be harmful this may threaten the patient's autonomy in the long run. Recognition of the tension between autonomy and paternalism emerged within the study. A typical reaction to this, from C12, advocated seeking some balance between the two according to a model of what Entwistle (2010) have also called 'shared decision making':

'Autonomy is not, cannot be the cardinal value or the be-all-and-end-all. It cannot be... if you give someone a kind of consumerist kind of autonomy you leave them high and dry, you give them information but you don't give them support, and you also can't deliver on that if they choose to do things you don't want to do or can't afford...to what I would have in the middle, which is what I'd call...shared decision model, where you combine the patient's expertise in their existence, if you like, with the clinical expertise in disease management...'

Given EPO's risk profile at supra-normal haemoglobin levels, for example, no participant fully endorsed its deregulation for enhancement purposes. When abstracted from the EPO case, however, there was some degree of recognition in principle for a more liberal view. S6 stated that, assuming the use of a medical

product for enhancement would have no negative societal impact and was paid for by the user rather than the state, no moral objection would remain in principle.

According to his view *'the individual has to weigh up the risk and benefit'*, rather than the doctor. In these circumstances C11 suggested that the medical profession should not police all aspects of behaviour which may be personally harmful to individuals, and that *'we can't live in a nanny state'*. S3 also defended in principle the right to enhance using a product such as EPO if one's personal circumstances necessitated it:

'...supposing you did a very hard job, a very tough physical job, and you had no choice but to do that job, and EPO would make you better at doing that job, make your daily grind a bit more tolerable, then I don't see why you wouldn't use it'

The position adopted here by S3 is of central relevance to the ethical debate about enhancement. Central to this view is the recognition that someone may be healthy but nevertheless have a legitimate need relative to their circumstances that could be met via medical assistance. This is the basis on which Daniels (2000), Savulescu (2006), Bostrom & Roache (2008), Harris (2009), and Sandberg & Savulescu (2011) have constructed their arguments in favour of allowing access to enhancements. It does not follow from the professional judgement that someone is healthy according to present criteria of illness or disease that their needs could not be met using medical means.

S3's statement is consistent with the position advanced by the authors listed above that someone may be healthy but nevertheless be deficient relative to their circumstances. This is a conception of needs that is vindicated by a critical realist approach, as in its commitment to a mind-independent ontology it holds that the world will impose constraints on us that cannot be removed simply by epistemologically reconceptualising our account of it (Bhaskar, 1975; Sayer, 2000; Easton, 2010). Whether or not the needs of the person in S3's example are considered 'medical' has no effect by itself on the fact that the person is physically limited relative to his circumstances without assistance.

S3 suggested that it would in principle be reasonable for the person in his example to seek and receive medical assistance. This position adopts a balance between autonomy and paternalism that does not stop with a decision not to assist following a clinical judgement that no 'medical need' is present. Rather it accepts that there may be cases in which an autonomous desire to enhance can be perceived as reasonable and acceptable in principle from a medical professional perspective.

6.6) Risks and Benefits

Irrespective of the degree of theoretical sympathy displayed towards enhancement in general, in the case of EPO a widely held view was that the risks associated with its use for enhancement is too great for its use sanctioned for these purposes. Thus some degree of paternalism was favoured in employing the 'doctor knows best' model described earlier by C1. This implies the view that the moral acceptability of enhancement is not uniform, and is dependent on relevant factors related to risk which pertain on a case-by-case basis.

6.6.1) Contextual Determinants

A balancing of contingent risks and benefits in individual cases was a significant determinant of moral status. Quotes from C1 and C2 provide examples of this attitude:

'...just because you can buy Viagra on the internet does that mean we should just sell Viagra in Boots? The answer is no, because some people would harm themselves with it...there are there are examples where relaxing prescribing restrictions might be good...for instance something like the morning after pill is probably a good example of that. Is it a good thing to make the morning after pill more accessible? I would say if it reduces unwanted pregnancies in teenage girls yes it probably is...'

'I think you have to take a case by case basis and the scenario of the individual and the society - what's the impact, what's the short term and what's the long term...?'

Consistent with this approach S11 rejected ‘*a blanket principle about how [people] should and shouldn’t use drugs*’, and that, with respect to certain unspecified health choices ‘*there is a degree of autonomy that people need to be allowed to make those choices*’. S3 implied that the use of enhancements is in fact to some degree normal, stating that ‘*in normal life it’s not a problem...we all use drugs and different things at certain times*’. S9 acknowledged as acceptable and ‘*perfectly understandable*’ that individuals may wish to alter aspects of themselves with which they are unhappy and if it is possible to do so, even if they have no clear medical need to do so.

Each example here endorses the views of Caplan & McHugh (2004), Kamm (2006), and Kahane (2011) that the moral status of enhancement in general should not be assumed before taking into account the context of specific instances of it. Hence they recommend that judgements must be balanced, and achieve some level of rational equilibrium. S11 implied that since each case will be different, so the appropriate response will differ correspondingly, and that personal autonomy must be adopted as a consideration within any judgement. S3 suggested that some attempt at consistency must be made between medical decision making and the freedoms that we are able to enjoy outside of a medical context. S9 recognised that clinical judgements must take account of the fact that certain desires for self-modification or improvement in those who are not necessarily considered to be ill are reasonable and comprehensible.

6.6.2) Limits of Practice

We can pursue the implications of S3 and S11’s position concerning the ‘normality’ of the desire for improvement by examining related claims made by C2, C5, S6, and S8. In relation to what falls inside and outside of the ‘*medical gaze*’ (Foucault, 1963), these four suggested in different ways that whether someone should or should not be permitted to access enhancements is a question which currently falls outside the remit of most medical professionals.

C2 argued that, institutionally speaking, medicine typically aims to rectify statistically abnormal functioning in individuals who ‘*fall outside the norm*’ when

compared to '95% of the population'. Since, by contrast, statistically normal functioning was not considered to generate a need, a corollary of this is that decisions concerning the prescription of enhancements would on a current view of its responsibilities be external to the medical professional. Developing this S6 offered the following suggestion:

'Your question of enhancement in the normal population or in someone that wants to do it for the fun of it, that really shouldn't be up to us because we're doctors, we're physicians, we treat people that are ill, so that's our concern. People who are well, maybe there should be another group of people who deal with those, because ethically we're not trained for that'

This implies a belief that it is intrinsic to the profession of medicine that it treats deficiency. The claim here is that, whilst it is incumbent on the medical profession to provide benefits for people who fall within certain agreed parameters of need, they are not responsible for making decisions about assistance that fall outside of these parameters, irrespective of the potential benefits. C6's suggested response to this challenge in the form of a parallel service providing enhancements has been considered within the literature (Chaterjee, 2004; Pellegrino, 2004; Goffete, 2006) as a possible outcome of a proliferation in enhancement technologies.

The suggestion being made by S6 is understandable and defensible as far as it goes. It is nevertheless vulnerable to critiques which show that no absolute line can be established between cases which it would and would not be incumbent on the medical profession to consider. The reason for this is that it presupposes already having come to a settled conclusion about what counts as the difference between health and illness, and therefore by extension, the difference between therapy and enhancement. As we have seen in Bess' (2010) '*moving target*' account, however, it is not clear how this can be done with any degree of permanence.

It is legitimate for medical practitioners to reject the consideration of a moral dilemma on the basis that it is too distantly connected to current medical practice to be relevant at present. However, since the norms which sanction these practices

may not remain static, there is no guarantee that the boundaries of practice can be insulated from having to adopt these new norms indefinitely (Mechanic, 1973; Hesslow, 1993; Stempsey, 2006; Serna, 2012)

6.6.3) Ambivalence

I showed in the literature review that a study by Hotze et al (2011) is to date the only major empirical study on attitudes of physicians towards the prescription of enhancements. The study found that around two thirds of the participants were ambivalent towards the use of enhancements in principle (Ibid. p. 8), assuming that they are safe to use and equally accessible to all. Significantly, just over half of the participants believed that most medical interventions could themselves be construed *as enhancements* (Ibid. p. 8). The first of these findings, namely ambivalence with respect to enhancement in principle, was reflected unanimously within the EPO study. Moreover, similar conditions of risks and benefits were adduced as countervailing reasons that would influence the moral status of a decision to provide or allow enhancement.

The presence of ambivalence amongst medical professionals has two implications. Firstly, despite the institutional parameters which circumscribe practice, the identification of a strong distinction between therapy and enhancement is shown to present a challenge. This challenge is not restricted only to philosophers concerned explicitly with logical classifications of this kind, but to those engaged in medical practice as well. I qualify this observation, however, in stating that it was only a challenge to the participants in conceptual terms when they reflected on the issue theoretically. The theoretical challenge did not affect their work in practical terms.

Secondly, Wasson (Ibid, p. 22), in her response to Hotze et al, argues that in view of the difficulty in clearly separating therapy from enhancement, questions concerning the medical legitimacy of enhancements '*will not go away*'. Wasson argues that the therapy / enhancement ambiguity will continue to exert pressure on the institutional boundaries of medicine and the extent to which they do or not

serve a sufficiently broad range of ends, because the kinds of developments that enhancement appears to offer are likely to be desirable to many.

A similar view concerning their desirability is also advanced elsewhere (Chatterjee, 2004; Pellegrino, 2004). If Wasson's analysis with respect to autonomy is correct, we see the relevance of society's expectations of medicine to its institutional character. Participants C1, C9, and S11 made reference to this in different ways. C9 stated that '*society evolves a choice*' about what it wants from healthcare; S11 similarly stated that '*the whole thing has evolved...it's all historical*'; and C1 claimed that:

'...medicine operates within society and...what we do as doctors or healthcare professionals is influenced by what society deems to be acceptable and appropriate, and the way that doctors have behaved has changed in the past few decades'

Implicit here is the claim that the institutional character of medicine is partially determined by an agreement between: the kinds of services society wants, expects, or desires; the kinds of services and benefits the medical infrastructure is willing to provide; and the temporality of medical technological developments which determine what is possible. To the extent that this agreement plays a role in defining what institutional form medicine *ought* to take, society's expectation of healthcare must play a role in determining what medicine institutionally does and does not sanction, and those states of relative health for which it is considered reasonable to receive assistance. It is clear that norms of health are not static, and that these are connected closely to changes in social norms. Thus, these changes must play a role in the practices that constitute what is and is not medically available given a particular context.

6.7) Justice

6.7.1) Private and Public Access to Enhancements

Vos & Willems (2000) claim that what one may reasonably expect is causally connected to what is technologically possible and available. In turn what is

available is influenced by a range of factors, one of which is market pressure. The pressure that this exerts is ethically contentious since it may have a bearing on the just allocation of resources according to need, as Shickle (2000), Koch (2010), Fukuyama (2002) and others argue. Pellegrino (2004) has argued that widening subsidisation to include enhancements would threaten the ethical integrity of medicine, since the extra pressure exerted on limited resources may warp their just allocation.

One alternative might be to allow only private access to enhancements, so as not to divert public resources away from those with more severe needs. Indeed it is improbable that all enhancements could ever be state-subsidised, so were enhancements to be legalised some stratum of private provision seems inevitable. A persistent objection to the private availability of enhancement technologies within the literature is that the benefits would accrue to those who could afford them, and limited medical resources may be diverted away from those who need them the most (Fukuyama, 2002; Pellegrino, 2004; Koch, 2010). This worry was reflected in the study. Examples from C1 and S2 illustrate this:

'...if you want to make it freely available you would then see the diversion of resources into something that was of little demonstrable benefit, and away from areas of healthcare perhaps where we could say this is clearly a good thing'

'What do I think about people buying something that we wouldn't normally offer them on the National Health Service? Well that depends on the fundamental reason why we wouldn't normally offer them – is it because we think it is of no benefit to them, or is it because we think the benefit is not one that the National Health Service can afford? If we genuinely think that the thing might be deleterious or of no benefit then I think people who might be persuaded by less scrupulous to spend their money on acquiring those things need to be educated that there really is no point...I would like some system in which somebody else who couldn't afford that would also benefit in turn...'

This criticism was voiced within the study by C1, C5, C8, C13, and S2. Given that some enhancements would inevitably be available only privately, this model is likely to obtain if enhancement were to proliferate. This entails a system in which availability of enhancements is split between the public (state-subsidised) and private sectors. If such a system were implemented, in which the focus of resource allocation is the improvement of conditions for the worst off rather than restricting the liberty of the better off, it would imply a prioritarian model of distribution (Parfit, 1997; Brown, 2007; Arneson, 2000).

6.7.2) Enhancement and Prioritarianism

The principle guiding prioritarianism is that benefits to the less well off are more important than to those who are better off, and must therefore *take priority* (Parfit, 1997; Brown, 2007). Rather than attempting to achieve this by curtailing the freedoms of the better-off, the primary aim therefore would be the provision of enhancements for people with the greatest need. Thereafter a secondary aim would be the realisation of conditions under which everyone else could become better off (Savulescu, 2006) and enhance themselves if they wished. Both pro and anti-enhancement positions can be advanced in response to this.

One way to understand this is to start at the observation that treatment thresholds for EPO have changed. P1 reported that a constant reduction in the price of the drug has meant that '*over the past ten years we have seen a massive transformation from it being very restricted to it being freely available*'. This reduction in turn means that it has become possible to treat more patients at a lower threshold of severity, and consequently it can be administered before patients develop symptoms that make them feel unwell. As S1 explained:

'...we have a whole anaemia service...they have huge block contracts with manufacturers...nowadays we don't allow anyone to become anaemic. We will introduce the EPO before they start to feel unwell, before the haemoglobin gets too low...they'll never come to us and say "wow that's great stuff, you really made me feel better"...we will have stopped them becoming ill and they'll never be aware of that'

This demonstrates the causal influence of market forces upon the generation of new norms. The new norm has brought the initial treatment threshold closer to the point at which an intervention would be considered 'enhancing' rather than 'therapeutic'. This observation lends support the arguments made by Lin & Allhoff (2008) and Scripko (2009) that enhancement is an unavoidable concomitant of advances in therapy, since in seeking to reduce or eliminate causes of ill-health these advances, when successful, necessarily bring about new norms in terms of what one can reasonably expect when receiving medical assistance. The new norm in this case has increased overall access to EPO for people with anaemia, thus reducing prioritarian injustices in cases where a decision must be made between two people with anaemia of differing severity. As C7 observed regarding allocation of EPO shortly after its introduction:

'10 people got EPO and if you were the eleventh you had to wait for someone to be transplanted or die before you could have it...tangibly an unfair situation'

If maximising the benefit to all those in need is a legitimate goal of justice, it follows from C7's statement that the cost reduction in EPO has contributed to its realisation. For example, if we were to consider these kinds of decisions about enhancements from a Rawlsian perspective (Allhoff, 2005) behind the 'veil of ignorance' (Rawls, 1971), it would be rational to prefer to be in a system in which the cost of an enhancement was sufficiently low that as many people who could benefit were able to do so. Following this, a prioritarian approach may suggest some conditions under which the inclusion of enhancements within the medical framework could be justified (Parfit, 1997, p. 214):

'...if I am worse off than you, benefits to me matter more. Is this because I am worse off than you? In one sense, yes. But this has nothing to do with my relation to you...benefits to the worse off matter more, but that is only because these people are at a lower absolute level. It is irrelevant that these people are worse off than others. Benefits to them would matter just as much even if there were no others who were better off'

Imagine the following scenario. Person A has serious renal anaemia and needs EPO to meet the normal tasks of daily living. Person B does not have renal anaemia and can meet most of the normal tasks of daily living, but has a physically arduous job and would derive a valuable performance benefit from using EPO. If there are sufficient resources to supply EPO to both, no injustice would accrue to A simply because, having received it, he would be unable to engage in the same kind of employment as B.

Consequently situations can be conceived in which a drug could justly be administered for both therapeutic and enhancement purposes, were sufficient resources available. Both A and B would benefit from being enhanced from and to different physiological baselines, and yet A, whose functioning remains weaker, does not suffer any injustice. This is because the benefit that he receives is absolutely valuable, rather than being merely instrumentally valuable because it confers a positional advantage over someone else.

It is relevant here to recall S3's justification for the enhancement use of EPO in certain circumstances, that if someone had a job that was especially physically arduous '*and EPO would make you better at doing that job...then I don't see why you wouldn't use it*'. Although justifications for the enhancement use of EPO were limited and conditional, the conditions stipulated by S3 under which it may be acceptable are consistent with a prioritarian approach to their use.

6.7.3) Calibrating the Market and Limiting Injustice

Earlier I reported the criticisms made of the market by P1, C3, C4, C6 and C7 in relation to its effect on justice. For example C7 claimed that '*if all doctors were ethical people there wouldn't be very much doping*'. C5 asserted that '*no-one's clean in this business*'. If their criticisms are reasonable we may have grounds to believe the warnings of Parens (1995), Fukuyama (2002), Kass (2003), and Sandel (2004) that a private market in enhancements could be corrosive to distributive justice. In particular Parens' '*schmocters*' (1998) are a concern. These are medical professionals providing private enhancement medicine services according to

ability to pay, rather than according to severity of need. These practitioners are analogous to private cosmetic surgeons, however worries about their practices would be proportionally greater if the enhancements that they provide confer on the recipient an advantage that could be used for gaining a positional advantage over other people.

The pro-enhancement prioritarian case advanced is predicated on successfully being able to harness the market in such a way that it produces just distributive ends, irrespective of whether '*schmocters*' would take advantage of the legalisation of enhancement products. The case to the contrary, however, remains sceptical of the possibility of achieving this in practice. In relation to EPO specifically C10 was sceptical as to the wisdom of extending legal access to include enhancement uses:

'People use drugs used for ADD for concentration but they get them on the black market, so maybe there's a market for them to be sold by private doctors – it could be something like that, like EPO...there could be a market for it but...there would need to be a lot of regulation, and there could be problems with it as well'

In relation to enhancement more generally, C8's earlier remark is pertinent again here concerning the risks to fair allocation, were access to enhancements permitted. His objection is understandable, since medical resources are always limited, and as Nordenfelt (2001) points out, there will only ever be so much that any system of subsidised medical care can provide. This is particularly true of countries such as the UK with universal, state-funded, healthcare. Given finite resources there will always have to be a titration of those resources according to need.

What is problematic, however is that, as C2 explained, '*there's always going to be this two or two and a half percent outside*' the range of normal statistical distribution. Consequently, wherever the treatment threshold lies, it is arguable that some injustice will always accrue to that percentage of individuals who are denied assistance. If this is true then it would not be possible to eliminate the possibility that an analogously '*tangibly unfair situation*' such as C7 described in

relation to historic EPO rationing could occur, however much the boundaries of assistance were to be extended. It follows from the finitude of resources that some people will always be considered ineligible for help.

Bess (2000) demonstrates this in a thought experiment involving two boys of equal height but of short stature, both of whom are seeking treatment with growth hormone. One boy's shortness is the result of a hormone deficiency caused by a prior brain tumour, the other is 'naturally' short. The doctor agrees to treat the boy with the hormone deficiency, since his shortness has been caused by disease, but refuses to treat the other because the cause of his short stature is non-pathological.

In our society it is advantageous for men that they are tall. Increased height is associated with greater mating potential, higher social status, and higher earnings (Bostrom & Roache, 2008). If it is important that opportunity is distributed as equally across members of a society as possible, and if height is advantageous for men, then there is a *prima facie* justification for allowing both members of the pair to increase their height to closer to the norm, since this ought to provide them with at least an average opportunity in respect of the advantages of height. Daniels (2000, p. 312) points out how such cases are problematic:

'Does the concept of disease underlying the treatment-enhancement distinction force us to treat relatively similar cases in dissimilar ways? Are we violating the old Aristotelian requirement that justice requires treating like cases similarly? Is dissimilar treatment unfair or unjust?'

I will feed this analysis into the present example. If one were to deny a healthy person access to EPO or some other product that could assist them in normal life, one could argue that this would count as discrimination of the same kind as the doctor who refuses to assist the non-pathologically short boy. In doing so the risk would be a failure to respect the demands placed on him and the environment in which he finds himself. Even though it might be possible to enhance his functioning, he would be prohibited from doing so because it is not deemed medically necessary, not because of an absence of need *as such*. As I have stated,

unconditional endorsement of the enhancement use of EPO was not evident within the study. However, there were instances which indicated some degree of recognition for the principle being explored by Daniels. S2 expressed this as follows:

'...each of those are technologies that allow people to do things that they couldn't do without technology, and if the erythropoietin allows people to do things they couldn't do without it then that may be an advantage if it's really important that they do those things...'

In this example the ethical acceptability of assisting is not cast as dependent upon whether it is an 'enhancement' or a 'therapy', but upon the question of whether some wider equilibrium between risks, benefits, and justice obtains. A further relevant perspective on the kind of argument that Daniels makes was also offered by C11:

'...if the bulk of the population can run up one flight of stairs, and somebody's anaemic and can barely crawl up one flight of stairs then it's reasonable to give them medication that will enable them to at least walk up the stairs, even if maybe they can't run up them'

C11's quote does not pertain specifically to enhancement uses of EPO, but nevertheless it is analogous to Daniels' argument. Here the justification for providing assistance is grounded in the observation that even if to do so would not enable the recipient to perform at the highest possible level, it would at least reduce the disparity in their ability relative to the majority of society. If this justification is reasonable, there are grounds for accepting Daniels' conclusion that the cause of the boy's limited stature is irrelevant. Insofar as to increase his height closer to the mean would improve his life there is a prima facie reason for assisting, whether or not his height would entail this assistance to be classified as 'therapeutic' or 'enhancing'.

6.7.4) Biological Inequalities

Sandberg & Savulescu (2011) offer a sustained defence of enhancement that is congruent with this aspect of the debate. They ground their defence in the observation that the natural distribution of capabilities is uneven. An observation of this kind was made by S2 in his straightforward claim that *'we are not fundamentally equal'*.

However, the argument being discussed here stands in contrast to the 'arms race' position of Sandel (2004), Koch (2010), and Fukuyama (2002). Their interpretation is that the liberty to enhance would exacerbate, rather than reduce, existing inequalities since the benefits would accrue to the rich. Proponents of this line of argument also hold that if enhancement were sufficiently widespread it would result in a devaluation of given ability, since individuals would feel coerced to enhance themselves in order to 'keep up' (Chandler, 2012).

There is indeed evidence in the case of strictly rule-governed activities such as competitive sport that worries of this kind are legitimate (Mignon, 2003; Schneider, 2006;). Objections consistent with this were articulated in the study. S2 expressed concern that the introduction of enhancements to sport is likely to exert coercive pressure on athletes to do so, and that this *'creates a downward spiral in terms of behaviour'*. Similarly C4 offered an argument grounded more explicitly in the ethical problems associated with economic disparities in access to enhancements:

'...if you're using it for competitive purposes, the chances are your income is related to your success, and your income is inversely related to your payment...you're cheating your competitors out of their income...'

In relation to this concern over justice in access C8's earlier statement concerning their widespread private availability of enhancements is relevant once again in stating that *'I philosophically don't like the idea of there being better access to any sort of healthcare dependent on ability to pay'*. This kind of economically-grounded objection can be responded to, however, by pointing out that such a worry

concerns the system of distribution for enhancements, rather than the enhancements themselves. Allhoff (2005, p. 44) has made this argument in relation to genetic enhancements and the differences between libertarian and Rawlsian models of distribution:

'...the obvious point is that genetic enhancement procedures alone will not lead to unjust results...If we can determine what constitutes a just distributive scheme, then genetic enhancement...can be distributed according to the principles of that scheme'

EPO is one of few products with a relevant history of enhancement use. This history has been ethically troublesome, since it has only been used for cheating by those athletes with the means to access it. It does not follow from this, however, that biomedical enhancement as such is ethically contrary to justice. This can be seen if we consider the following statement from S2 in relation to the conditions under which one should or should not be permitted access to biomedical enhancements:

'...what do you do about the 20 stone rugby forward versus the 15 stone rugby forward? What do I do about the fact that I need glasses to read anything?...there are all sorts of things like this that just aren't equal and at what point do you say "we'll normalise these ones, but we can't normalise those ones"?''

In both examples inequality exists, and normalisation is construed as eliminating the inequality between the individuals by enhancing each relatively deficient individual. Whilst it is uncontroversial to receive a prescription for glasses to correct sub-normal vision, it is not clear that medical assistance would be available for the 15 stone rugby player wishing to increase muscle mass, despite the fact that he may be at a relative disadvantage.

Two ways to adjudicate present themselves. The first is by appeal to the existing criteria for medical treatment, and yet these are, as we have seen, contingently defined. Given the vulnerability of accounts of normal functioning to change, the criteria provide no *a priori* justification for weighing only in favour of assistance for eyesight enhancement, only a conventional one, despite the presence of a

relative need in both cases. Consequently, assuming it were possible to implement the mechanisms for ensuring access to enhancements to those who would derive the greatest benefit from them, the ends of justice may be served by being open rather than closed to the possibility of allowing the use of certain enhancements.

A second way to adjudicate would be by reference to the contextual difference between the two. In the case of the rugby player, to intervene may enhance the lighter player's chance of success in the match. It may, therefore, potentially make the difference between winning and losing. In the case of poor eyesight no single issue of victory is at stake in the same way. To have one's eyesight enhanced may no doubt confer an advantage, but it is not obvious that the advantage is gained at someone else's expense. This insight is redolent of the thought experiments of Daniels (2000) and Bess (2010) concerning the two short boys, as well as the assumptions of prioritarianism (Parfit, 1997, Brown, 2007).

6.7.5) Enhancement, Competition, and Variable Moral Status

This observation relates to an important ethical issue which arose in both the literature and the study – namely, that of justice with respect to competition. Whether or not an enhancement is or is not morally permissible may depend in part on the nature of the activity being engaged in, and whether or not its use has been explicitly forbidden. The use of biomedical enhancements in sport is objected to on the basis that it confers an unfair advantage over the non-user, and that insofar as it does so it constitutes cheating, which is morally objectionable. As Greely et al claim (2008, p. 703):

'In the context of sports, pharmacological performance enhancement is indeed cheating. But, of course, it is cheating because it is against the rules'

The use of EPO, for example, by cyclists in cases such as that of Lance Armstrong²⁴ and David Millar²⁵ has been widely condemned on this basis. This condemnation is

²⁴ http://www.nytimes.com/2013/01/18/sports/cycling/lance-armstrong-confesses-to-using-drugs-butwithout-details.html?_r=0

²⁵ <http://news.bbc.co.uk/1/hi/programmes/hardtalk/9571648.stm>

based on the existence in sport of 'regulative rules'. Schermer (2008) holds that it is only the presence or absence of a regulative rule which affects the ethical status of enhancement in sport. She argues that since not all conceivable means of maximising or enhancing performance are forbidden, it can only be considered ethically problematic to engage in those that are. To explicitly forbid EPO in sport makes its clandestine use morally unacceptable, since (typically) athletes compete voluntarily, and in doing so tacitly agree not to break those rules. According to this argument, it is cheating in the sense of breaking a rule which is unethical, not enhancement as such.

A widespread condemnation of enhancement in sport was evident across the study for reasons consistent with Schermer's argument. This condemnation was typically unequivocal. S9, for example stated that:

'I don't approve of breaking the law, so when there's a law against using drugs in sport I think the law should be obeyed'

C7 offered an equally unambiguous criticism:

'...you're a professional sportsman and that is the rules of your professional sport and if you don't stick to them it's cheating and therefore it's bad'

A distinction was frequently drawn, however, between the use of enhancements in 'competitive' and 'non-competitive' scenarios. The most common reference made was to the notion of a 'level playing field' in sport, and the moral importance of protecting it (C1, C4, C5, C7, S1, S2, S5). Thus, one way to distinguish between acceptable and unacceptable use of enhancements may be by reference to the context. In rule-governed scenarios such as sport where one person's success entails another person's loss, if the use of a product is explicitly forbidden, then there is a prima facie reason to state that a doctor should not provide it and the sportsperson should not use it, since the advantage that this confers will be unfair. This is the kind of justification adduced in the two examples just given.

If, by contrast, the circumstances are such that a performance enhancement advantage can be achieved without any apparent corresponding loss to someone else, a principled objection to the prescription and use of an enhancement is more difficult to defend. This line of argument has been made within the literature by Allhoff (2005) and Harris (2009) who argue that enhancement could only be ethically unacceptable to the extent that it causes harm or produces injustices. A view of this kind was advanced in particular by C10, C12, S2, S3, and S6 to the effect that, all other things being equal, if the use of enhancement will not result in an unfair advantage leading to an injustice, it is not obvious that its use would be morally unacceptable. C12, for example, stated that:

'I don't have an intrinsic moral objection to someone taking a drug in and of itself, the moral objections come if they're taking the drug to gain an advantage over other people unfairly'

Similarly, C11 drew a distinction between competitive and non-competitive uses:

'...if you have three glasses of wine and you feel more relaxed at the end of that it's not that different to taking some EPO and giving yourself a bit of a boost...you could have the argument that some people really want to have the stimulation and the buzz and they understand the risks and they're prepared to do it and pay for it, but it shouldn't be part of competitive sport'

A contrast is evident here when reconsidering the earlier examples of beta-blockers for reducing nervousness in professional musicians in the absence of an anxiety disorder (S11); and the hypothetical use of EPO by a healthy individual with a very arduous job (S3). In both cases an enhancement would be used by professionals to gain an advantage in their work, and would be justified on this basis. However, one can argue that maintaining one's employment is inherently competitive (Capp, 2011; Temkin, 2012; Chandler, 2012). If this is true it underlines a nuance present in the conditions that constitute ethically acceptable use. Sahakian & Morein-Zamir (2010, p. 200) make the following claim concerning competitive circumstances. The claim relates specifically to cognitive

enhancement, however in addressing competitive circumstances it is more widely relevant:

'Another concern is that the use of cognitive enhancers may be considered cheating, allocating an unfair advantage over others in particular circumstances such as in competitive situations or test taking'

This claim is problematic because it assumes that competitive environments are homogeneous, and it does not allow for differences between scenarios that might alter the moral status of the use of an enhancement. Many normal circumstances in life are competitive to some extent, but the use of enhancement is not ethically uniform across them. The examples relating to work given by S11 and S3 are cases in point. In these examples it is not obvious that the provision of an enhancement is necessarily ethically unacceptable, because the fact that it could assist these individuals in meeting the demands of their job is an adequate justification for providing it. In this respect the fact that keeping one's job may be competitive does not, by itself, count against the ethical acceptability of prescribing or using an enhancement to help in doing so.

One might object that this conclusion is too general because the jobs themselves are clearly different, and thus heterogeneous not just with the work of the professional athlete, but with each other. S3's labourer would use EPO simply to boost his or her endurance in a physically intensive manual job, whereas S11's musician is being assisted in what he or she has been highly trained to do. The difficulty with this view, however, is that despite the jobs being different, to appeal to the level of skill required for doing the job as a reason to provide an enhancement in only one of the two cases would be discriminatory. This would arbitrarily favour one of the pair whilst penalising the other on the basis of the physical capabilities or skills that they do or do not happen to have.

Equally the two may appear disanalogous because clear beneficiaries are present in the S11's musician case that are absent in the case of S3's labourer. If using beta-blockers improved the musician's performance by enhancing his or her ability to

deal with the pressure of the situation this would presumably increase the audience's enjoyment. Again, it is not clear why the labourer should be denied assistance and discriminated against. In this instance he or she is being penalised arbitrarily for having a job with an insufficient number of obvious and immediate beneficiaries. Discrimination of this kind would be still more unjust if it turned out that the labourer had dependents. If this were the case then more-or-less immediate beneficiaries would be present and it would be irrelevant here that the kind of benefits that they receive would be socio-economic rather than the aesthetic benefits experienced by the audience.

Despite the differences between these two cases, a competitive element is present in each. If the analysis of these cases is correct it therefore highlights a nuance in the relationship between competition and the moral status of enhancement that should be made clear. For example 'work' is a heterogeneous category, because forms of work are diverse. It is reasonably straightforward to judge, as C11 does, that it is wrong for a professional cyclist to use EPO in the competitive circumstances of his or her work because it is explicitly forbidden in an activity that is entered voluntarily. Judgements are less obvious in relation to S11's musician seeking performance enhancement via beta-blockers or S3's labourer seeking it via EPO.

Although the context of professional employment supplies some element of competition, it is not obvious why it would be wrong for either the musician or the labourer to enhance themselves. It is also unclear, despite this similarity, whether the other factors supervening on the two competitive scenarios affect the moral acceptability of allowing or denying enhancement in each case. The most that we can conclude, therefore, is that if it is acceptable to enhance oneself in some competitive environments, then the presence of competitive circumstances as such cannot be adduced as a reason why allowing access to enhancements might be unjust in the way that Sahakian & Morein-Zamir suggest.

6.8) Naturalness and Artificiality

The concept of 'the natural' is ineffective on its own for distinguishing between morally acceptable and unacceptable uses of medical technology, since as Savulescu (2006, p. 11) notes, '*nature allots capabilities with no eye to fairness*'. S9 made a similar observation in relation to '*people who think that we shouldn't reinvent nature*', demonstrating that if this approach is adhered to strictly, '*you wouldn't take someone's appendix out, you'd let them die*'. Consequently, objections to enhancement that appeal too strongly to interference with nature are inadequate.

Objections arose within the study which appealed to concepts of naturalness and artificiality as a reason why the use of enhancements would be morally problematic. Although objections made on this basis were relatively rare, assumptions about nature follow from a conception of normality, and thus implicitly underlie much of relevance within the enhancement debate. I will therefore show here how 'the natural' alone cannot be successfully adduced as a reason not to allow enhancements.

Certain ethical positions found within the data were defended by reference to categories of 'natural' and 'artificial' that, whilst being treated as objective and mind-independent, in fact reveal themselves to be epistemological categories that have been subjectively imposed on the world. These examples are clear instances of the '*epistemic fallacy*' that critical realism highlights as false. In mistaking claims about one's perceptions of the world for claims about the world itself, ontology and epistemology are conflated. Once it has become clear how this conflation occurs in appeals to nature, we can show how it is that certain judgements are rationally more defensible than others. We can then recast an account of the moral status of enhancement in a more balanced and coherent way.

6.8.1) Appeals to Nature

The weakness of appeals to nature has been recognised even by nominal opponents of human enhancement. Parens (1995), for example, adopts a nominally

sceptical position towards enhancement but is aware of the vulnerability of the concept of 'nature'. It is possible to imagine theological arguments that object to certain biotechnological modifications as unacceptable interference with God's will, but a degree of equivocation is displayed even in analyses of this kind (Hanson, 1999; Al-Hayani, 2007; Hefner, 2007).

In recognition of the problems of appeals to nature, it is important not to use the 'unnaturalness' argument as a straw man, since enhancement poses ethical challenges irrespective of the vulnerability of the appeal to naturalness. Moreover, several interviewees recognised that since all medicine may be construed as interference with nature, objections to enhancement on this basis alone will be inadequate. The failure of this objection is neatly summarised in the earlier quote from S9 concerning the interference with nature required in removing someone's appendix to prevent them from dying.

Nevertheless, several trenchant critiques of enhancement have been made on this basis, and insofar as there are uniting themes running through these, one of the most frequent is the intuition that certain applications of biotechnology in some morally important sense 'go too far' (Parens, 1995; Kass, 2003; McKibben, 2003; Sandel, 2004; Kamm, 2006; Koch, 2010).

The most salient example of a confused appeal to 'nature' or 'the natural' among my interviewees related to athletic enhancement and the purported difference between (illegal) EPO use and other (legal) methods of hypoxic training. High altitude training (Levine, 2006) and the use of low oxygen chambers (Spriggs, 2005) in sport are legal, whilst EPO use is forbidden²⁶, even though all share the goal of increasing the oxygen carrying capacity of the blood (Joyner, 2003). In two instances it was argued that that the key distinction justifying the difference in legal status was determined by relative 'naturalness'. C4 claimed that:

'...the EPO that we give is not a natural product...it's a pharmaceutical, that's what I mean by unnatural, compared to just going up to altitude is just something that

²⁶ http://www.wada-ama.org/Documents/World_Anti-Doping_Program/WADP-Prohibited-list/2013/WADA-Prohibited-List-2013-EN.pdf

humans do...you can just climb a hill...sure enough you might need to get a plane somewhere, but it's pretty much achievable in nature to go up to altitude and train there, whereas giving yourself Aranesp for one month, bought from a dodgy doctor, is not achievable in nature'

C3 claimed that the difference was constituted by the artificiality of exogenous EPO when compared to taking advantage of the low oxygen content of high altitude environments in order to achieve the desired performance enhancement:

'...there's a difference between drug products that have been manufactured, a chemical that you take, versus something that is more natural. A bike is a human creation...I see all of those things like lifestyle modifiable things, like exercise, taking exercise, changing the way you eat, riding a bike...it's mechanical but it's human being powered'

Dealing with C3's quote first, he accepts that both a bicycle and synthetic EPO are manufactured, but suggests that the difference between the two is that the bike must be powered by human effort alone, rather than with 'artificial' assistance. The implied claim here is that, were the cyclist to use EPO, power would be supplied by other, 'artificial', means beyond that which the unenhanced cyclist could apply, and that this would be morally suspect.

The claim is vulnerable, however. For example it is not the case that a cyclist is going to win the Tour de France *simply* by using EPO – it is still going to make a difference how hard he trains (which may include legal methods of hypoxic training) in combination with EPO use; how naturally gifted he is; how mentally committed he is to achieving victory, and so on (Savulescu et al, 2004; Miah, 2006; Savluescu & Foddy, 2010). All means used to enhance performance will contribute to how effectively *he* can power the bike. To illustrate this further we can take a longer perspective and connect it with C4's argument.

6.8.2) Broad and Narrow Conceptions of the 'Natural'

Bacon (1620), Barilan & Weintraub (2001), Warnock (2003), and Soper (2010) give accounts in which nature is explicitly understood as being prior to humans, and as providing the conditions for their existence. According to these accounts nothing happens which nature does not permit. Another way of expressing this is to say that everything which occurs obeys nature. Warnock (Ibid, p. 450) writes:

'...the natural world long predates humanity, but, as we have learned to understand, its laws are discoverable and gradual in their operation. We did not make them.'

If we apply this to the present example we can say that once we discover the laws underpinning the systems that we wish to manipulate we may then take advantage of these discoveries. Variations in the oxygen concentration of the air are prior to the invention of exogenous EPO. However they are also prior to the technological means for travelling easily to places where we could derive a benefit from training at altitude, the use of which is apparently morally unproblematic according to C4. In this respect it is misleading to distinguish one route to successful enhancement as being obviously more or less 'natural' than another.

The ability to overcome the limitations of unassisted human ability - whether this is the aeroplane required for flying to the Andes, or the knowledge of amino acid chains required for being able to engineer new ones – depends on first correctly apprehending the system that we wish to manipulate or control. If we misunderstand gravity the plane will not fly; if we misunderstand how the kidney works then man-made erythropoietin will not successfully raise haemoglobin. On this view none of the modes of travel listed above are distinctly more or less 'natural' than the creation of synthetic EPO. There are immovable physical constraints which determine what may and may not be done, as Bacon (1620, bk. 1, aph. 3) states:

'Human knowledge and human power meet in one; for where the cause is not known the effect cannot be produced. Nature to be commanded must be obeyed; and that which in contemplation is as the cause is in operation as the rule.'

Perhaps the problem can be resolved by further clarification. It would after all be possible to forgo aeroplanes, boats, cars and so on in the pursuit of altitude training – it is for convenience that athletes choose to use vehicles to reach these altitudes, rather than ‘naturally’ going on foot. It could therefore be argued that we can *in principle* go and train at altitude without technological assistance, whereas access to an exogenous boost of erythropoietin will always depend on the prior existence of the technological means required to produce it. This objection is vulnerable, however, because – again - it sets the boundary between ‘natural’ and ‘unnatural’ at an arbitrary point.

In C4 notes that one ‘*might need a plane*’. A plane is, presumably, an ‘artificial’ creation, and yet its artificiality is considered irrelevant to the perceived moral difference between altitude training and EPO use. This inconsistency underlines a difficulty in C4’s claim concerning ‘availability’ in nature. We might ask where, if not in nature, do Aranesp²⁷ (a widely used EPO product) and the raw materials for its invention and production reside? If nature is the source of availability for the raw materials of both EPO and aeroplanes, it is not obvious why one should be considered more or less natural than the other.

One objection to this line of argument would be to point out that modes of transport are not categorically equivalent to medical enhancement technologies such as EPO with respect to their relation to ‘nature’. EPO is literally incorporated into the body, whereas the other technologies referred to are not, and in virtue of this obvious difference it may appear that they are too different to bear comparison.

The criticism is descriptively accurate insofar as it reminds us that one technology is external to the body and the other is internal. However, even if one accepts the observation, it is not obvious what is significant about this difference unless the term ‘enhancement’ can only be used to describe one intervention and not the other. To the extent that both are technological innovations which extend ‘given’ human ability in useful or valuable ways, they enhance. Moreover despite the fact

²⁷ <http://www.aranesp.com/>

that EPO is medical in nature and an aeroplane is not, it is hard to see why this difference in particular has any bearing on the relative 'naturalness' of their use.

The account of nature implied in these cases therefore cannot withstand too much scrutiny. To the extent that nothing physical can exist which contravenes the laws of nature, everything physical must be *constituents of nature*. On this view the relatively narrow conception of nature implied by C3 and C4 collapses into a wider one. Here a boundary between the 'natural' and 'unnatural' has been identified according to the perceptions of particular socially embedded individuals with contextually bound views and values. Whilst we must concede that our own perceptions are also subjective and thus remain critical of them, we must nevertheless be aware that distinctions of the kind outlined have been *imposed* rather than *discovered*.

It is possible to achieve greater logical consistency if all medical interventions are understood as having a shared aim of modulating 'given' functioning in some way. This interpretation was suggested by S2 and S9. Of particular relevance, again, is S9's argument concerning the ruptured appendix that all medical interventions are in some way artificial. If it would constitute poor medical practice not to remove the appendix because it would result in a preventable death, S9's position highlights how inconsistent accounts of the difference between biomedical interventions according to their relative 'naturalness' are not helpful on their own as justifications for certain interventions but not others.

6.9) A Critical Realist Analysis of Appeals to Nature

I will now return to critical realism as a method of analysis, and lay out some initial thoughts to be developed further in the conclusion. What will become clear is that a critical realist analysis demonstrates why arguments such as those of C3 and C4 are misleading. Claims about the moral unacceptability of performance enhancement via EPO use when compared to 'acceptable' methods of achieving the same end such as altitude training appeal to what these individuals perceive to be a substantive difference in the 'naturalness' of the two methods.

This difference is grounded on more foundational assumptions or beliefs about what is entailed by the concept of 'nature'. In doing so they posit an ontological difference between altitude training and using EPO – to do the former is 'natural', whilst to use the latter is 'unnatural'. It is this postulated ontological difference which lays the ground for the further claim that it is morally acceptable to do the former but not the latter, and the (nebulous) implication that 'natural' methods are 'good', whilst 'unnatural' methods are 'bad'.

According to C3 and C4 an ontological difference appears to be clear. Under analysis the difference dissolves, however. In its account of epistemic subjectivity critical realism holds that the statements of C3 and C4, and the perceived ontological differences that they identify, are informed by a backdrop of personal beliefs, values, and norms which are relative to each. That a claim is made about the world, however, does not mean that the claim is correct. It is in virtue of this observation that the elision between ontology and epistemology highlighted by critical realism is visible. If we apply this insight to the therapy / enhancement distinction, the elision will be visible again.

Whether interventions are carried out in the name of therapy or enhancement they aim to improve health and / or functioning in some way. Whether the intervention is understood as a therapy or an enhancement, is an epistemologically relative matter which may depend on any number of contingencies. By contrast we can make the non-relative ontological realist observation that functioning exists along a spectrum, irrespective of these categorisations. Thus, a critical realist analysis highlights the division between the shared ontologically objective aspect of therapy and enhancement (i.e. the improvement of health and / or functioning) from the way in which the two are subjectively categorised. In doing so the conflation made between these discrete ontological and epistemological aspects is brought to the surface. A quote from C7 will help to develop this further:

'...there is a sort of nomenclature for this which is that there are quite a few substances which are naturally occurring substances and you can either take them in replacement doses which mimic what you should have naturally, or you can take

them in pharmaceutical doses, which are doses that then have effect over and beyond just replacement'

Medical nomenclature is an institutional construction. What the nomenclature captures or does not capture is not fixed, since it is subject to change and reclassification. The reference to '*...what you should have naturally...*' is also revealing. The term '*should*' is normative because it makes a claim about what *ought* to be the case. When coupled to the concept of haemoglobin replacement it implies a positive evaluation of species-typical or 'normal' functioning. This is congruent with the analysis of Toulmin (1975), Lennox (1995), and Nordenfelt (2006) that value judgements are cloaked in assessments of health which otherwise have the appearance of being merely descriptive and value-free.

Following this we can see that *transitive* (moveable, flexible, value-laden, socially contingent) epistemological categories determining who may or may not receive medical assistance supervene on the underlying ontologically objective and intransitive category of improvement, or enhancement *per se*. Given these transitive epistemological and intransitive ontological features, a critical realist analysis is thus helpful in understanding the contested therapy / enhancement distinction and its correspondence to more basic ontological facts about human functioning.

6.10) The Therapy / Enhancement Distinction

A range of viewpoints was put forward concerning the reality of the distinction and the ways in which it can and cannot be defended. As with the ethical analysis, I will consider these in light of theoretical positions on the distinction found within the literature.

6.10.1) As Ambiguous and Unstable

On several occasions enhancement was distinguished from therapy by reference to norms of different kinds. C4, S2, and S3 gave accounts grounded in the kinds of biostatic norms defended by Boorse (1975); Lennox (1995); and Wakefield (1995).

S1 and S11, by contrast, justified their accounts by reference to socio-cultural norms as characterised by Benedict (1934); Lewis (1954), and McKeown & Lowe (1974). In some cases participants used both kinds of norms as a justification for upholding the distinction, for example in the accounts of C2 and C12.

However, as we saw in the literature review, judgements may change concerning whether a state is or is not considered to be normal (Vos & Willems, 2000; Wiseman, 2004; Stempsey, 2006). To the extent that the distinction is grounded in judgements about normality which may change, any account that appeals to a norm risks relativity and so will not provide a static foundation for constructing an account of the distinction that is firmly anchored in reality. A more fundamental or objective account is available via an analysis that can successfully negotiate these contingencies without relying on them for its definition.

When discussed in purely theoretical terms C2, C5, C9, C11, C12, S2, S4, S7, S9, and S11 indicated that the therapy / enhancement distinction is difficult to substantiate as a matter of logic alone. For example C2 contended:

'I don't think you can define what normal physiology is, and I don't think you can define what enhancement is either'

This difficulty was compounded by instances in which medical classification and nomenclature are themselves ambiguous, for example in C12's statement that:

'We do have good objective measures, but we have a definition of health that is woolly, that is not easy to pin down...there's bound to be a grey area between what is enhancement and what is treatment...the cut off in most people's minds would be that if you are not treating a pathology then you're talking about enhancement, but that doesn't take account of the fact that the idea of what is and is not pathological is very fluid'

These cases tacitly correspond to scepticism concerning the logical validity or relevance of the distinction voiced by Savulescu (2006) and Harris (2009). According to the view that they adopt, therapy must be understood as a relative

category which is supervenient on the more basic and intransitive underlying concept of enhancement. Savulescu writes (2006, p. 304):

'Enhancement is, indeed, a wide concept. In the broadest sense, it means "increase" or "improvement." For example, a doctor may enhance his patient's chance of survival by giving the patient a drug.'

The claim here is that insofar as it is synonymous with the general concept of health improvement, enhancement *per se* necessarily includes the central aim of therapy. On this view enhancement is such a 'wide concept' that it logically subsumes the category of therapy. If this argument is correct then no complete account of therapy can be disaggregated and understood entirely on its own terms. This is because any such account would unavoidably entail the goal of improving health, and thus by extension 'enhancing' it, irrespective of the state of health from which this is done.

Support for this view was evident from C2, C5, C9, C11, C12, S2, S4, S7, S9, and S11. Each of these participants suggested that under close examination a clear logical difference between therapy and enhancement dissolves. S9 used the example of cosmetic dentistry, which is administered under the auspices of standard clinical practice but has been the subject of debate concerning its status as a therapy or an enhancement (Morley, 1999; Gordjin & Chadwick, 2008), as an analogy to describe how it is that the distinction can become unclear:

'...my wife is an orthodontist and some of her patients have teeth that they don't like, they're transformed by having orthodontic treatment, it changes their whole approach to life, it changes their whole character and undoubtedly improves their quality of life, so that's a cosmetic practice for which there are real and genuine physical and mental health gains'

Similarly, C3 and S11 used beta-blockers as an analogy. These are often legally prescribed by doctors to healthy people in certain professions, for example music or acting (Foddy & Clayton, 2004; Schneier, 2006; Gorman & Gorman, 1987), in order that they can respond effectively to nervousness caused by public

performances associated with their work. Despite that the seeking and receiving of beta-blockers is a standardly 'medical' encounter, S11 reported that the granting of assistance by prescribing them does not require the identification of any anxiety disorder:

'The problem here is definitions...So for a person a bit of anxiety or performance nerves is completely normal, and it's probably normal for most people, so on the basis that it's a normal reaction to a particular situation I think it'd be wrong to call it a medical condition – it's not a disease, it's not lack of health in any way, and it is performance enhancing in some way'

This ambiguity in differentiation was also recognised elsewhere in the study, for example in C12's statement that the notion of what is considered pathological is 'fluid' in nature. This corresponds both to evaluative philosophical models of health such as those put forward by Agich (1983), Engelhardt (1986), and Nordenfelt (1993), as well as constructionist accounts (Blaxter, 1978; Jordanova, 1995; Rose, 2010). Thus the kind of justification for the inclusion of an 'enhancement' procedure under the normal auspices of medicine offered by C13 and S11 in relation to beta-blockers tacitly appealed not to statistically informed criteria of the difference between normality and abnormality, but the subjective criteria of patients or the kinds of interventions that it is considered socially acceptable for doctors to provide.

6.10.2) As Clear and Defensible

In contrast to these accounts C1, C4, C8, S3, and S6 adhered strongly to the basic reality of the therapy / enhancement distinction. This was most clearly demonstrated in instances such as S3's statement that '*health is just being not ill...getting better than normal isn't necessary or needed*'; C3's reference to the clearly debilitating symptoms of anaemia which justify clinical assistance from EPO such as '*lethargy, fatigue...breathlessness on exertion, angina...*'; and S6's simple assertion that in cases of enhancement '*there's no medical need*'. Participants grounded this adherence by an appeal to normal functioning and its validity for

discerning between those who do and do not require medical assistance. C4, for example, offered the following account:

'...you have an indication for it and therefore it's therapy...if you're an athlete there's no indication so it's not a therapy, so it can only be an enhancement'

This was reinforced by S3:

'...you can very clearly distinguish between being ill and being normal...getting better than normal isn't necessary or needed, whereas getting better from being ill is'

S6 extended this characterisation by making a distinction between procedures carried out for the remediation of an objective need, and those sought just for their subjective desirability:

'There's no medical need, it's for the aesthetic pleasure of the individual or whatever you want to call it'

Again, this view finds theoretical support, for example in the biostatic accounts of health of Boorse (1975) and Wakefield (1995), as well as in the critiques of enhancement offered by Fukuyama (2002) and Sandel (2004). This view can be broadly summarised by S3's claim that *'health is just being not ill'*.

A related issue of consistency across the group was that medicine's primary commitment should be to the reality of differences in severity of need, such that resources can be directed according to those needs, even if a strict delineation between therapy and enhancement is logically unstable. This position was defended at some point by all the participants, irrespective of the diversity of their individual views about the a priori validity of the therapy / enhancement distinction. Quotes from C5 and S6 summarise this position:

'it's not part of medicine's remit to do that, so we just sort of duck out of that one...we've got to operate within boundaries'

'...we're doctors, we're physicians, we treat people that are ill, so that's our concern...'

The prioritisation of needs in a hierarchy represented the way in which these participants understood the boundaries of their practice. Recognition of a scale of real needs of varying severity was perceived to be necessary in order that resources can be titrated appropriately. For example S2 gave the following defence of such a hierarchy:

'...we're in a cash limited system, so we can't provide everything that might be of tangible theoretical benefit...I'd like people who really need something to have access to it, and then there would be a titration downwards in which people who didn't really need it should have less and less access to it to a point where if it was of no discernible benefit they shouldn't have any access to it at all'

C4 stated that with respect to the difference between therapy and enhancements he was *'drawing an artificial line in the sand'*. Despite this, however, he ultimately defended medical need as an objective way of distinguishing between whether an intervention would be therapeutic or enhancing:

'...you have an indication for it and therefore it's therapy...if you're an athlete there's no indication so it's not a therapy, so it can only be an enhancement'

This position finds support within the literature (Daniels, 2000; Buchanan, 2000; Buchanan et al, 2000). In these cases attempts have been made to reconcile the practical ethical need to ensure distributive justice with the logical vulnerability of the therapy / enhancement distinction which may threaten it. The widespread defence of the reality of medical needs offered within the study is no doubt useful for developing normative recommendations concerning the governance of any access to enhancements.

Despite its practical utility, however, this standard does not sever the intrinsic connection between therapy and enhancement which follows from their shared goal of improvement. Nor do demands of justice of themselves do anything to strengthen or refute the a priori weakness of the distinction. I stated that Bess (2010) characterises enhancement as a *'moving target'* because it is *'pegged'* to a shifting definition of normality. Similarly Harris (2009) contends that since the aim

of all therapies is to enhance, it is not rational to appeal to the distinction as the final arbiter of decisions to treat.

Moreover despite the primary ethical responsibility to allocate resources according to need, the presence of this responsibility does not of itself resolve the question concerning the logical validity of the distinction. Although it allows for the ranking of a hierarchy of needs, it does not give any indication as to where in the hierarchy the line can be drawn between normality and abnormality.

6.11) A Priori Vs Empirical Justification

A tension exists between purely *a priori* and purely conventional justifications for or against the therapy / enhancement distinction, neither of which is fully satisfactory on its own. Furthermore a dogmatic adherence to one is likely to relegate the importance of certain features of the other. This is undesirable, as both kinds of justification contribute to the ethical integrity of medicine as an institution. What is required is an understanding of practice which reflects a balance between theoretical and institutional values. Indeed this demand summarises the normative rationale which has driven the empirical turn in bioethics (Molewijk et al, 2004; Borry et al, 2005; Ives & Dunn, 2010), and for this reason both should be incorporated when seeking to understand ethics in practice.

The conventional criteria used to justify medical assistance do not refute its logical continuity with therapy. Rather, they delimit those services which medicine will or will not provide under its auspices, according to a balance between i) prevailing norms of health; ii) the amount of resources available relative to medical needs; iii) what is technologically possible and available; and iv) the balance of risks and benefits which pertain to providing assistance. These factors are contingencies, and in this respect interventions are sanctioned according to a set of criteria that are always vulnerable to change. Consequently, decisions about the appropriate boundaries of practice must be substantiated by more than an assumption that therapy and enhancement are discontinuous simply because they are conventionally treated that way in practice.

One response to this may be to suggest that the logical weakness of the therapy / enhancement distinction need not be *terminally* problematic, even though it causes problems for the *a priori* delineation of one concept from another. The data indicate good, defensible, practical justifications for appealing to these contingent criteria as reasons for allowing or denying access to medical products. These criteria are examined in more detail later in this chapter, although an example of how clear justifications were made is found in the following quote from S6. The quote expresses the importance of safety when intervening medically, irrespective of whether the intervention is therapeutic or enhancing:

'From a research clinical point of view we know clearly that EPO has the potential to harm in supra-normal conditions, so I don't think from a physical point of view it's a good thing to stress the body by taking drugs which take one outside the bounds of normality'

S6 thus separates the intrinsic moral acceptability of enhancement per se from practical considerations of safety which would count against prescribing a specific product for enhancement purposes. In this respect S9's reflection on the relationship between therapeutic and enhancing applications of technology also yields a valuable insight:

'It is a philosophical question...I suppose they're different aspects of the same thing as they are capitalising on technology to be able to make you do something better, and I suppose there's nothing wrong in theory with that, and there are then the safety aspects and the practicality of injecting yourself with needles carries risk in different ways...so I think there are some practical difficulties. In principle I suppose there's no particular difference'

These views justify the granting or denial of assistance according to the level of risk involved, rather than whether the assistance would count as therapy or enhancement. This justification is anchored in a central responsibility of medical practice, namely that the physician does no harm. In this respect justifications such as this have the ethical advantage that they circumvent the question of whether it

would be acceptable for them to prescribe enhancements, because beyond a certain threshold the risk of harm over-rides any countervailing considerations.

6.12) Changing Norms

This issue of contingencies is important. In particular its relevance derives from historical changes in norms of health. As we saw earlier, what is *considered socially normal*, and what is *statistically normal* are neither necessarily static nor congruent (Rayner et al, 2010; Moravcsik, 1976; Amundson, 2000), and are frequently technologically, economically, culturally, and socially mediated. Given that the therapy / enhancement distinction is nominally underpinned by a norm of health, and norms of health are vulnerable to change, this compromises the integrity of distinctions made on this basis once a particular historical scenario and its contingencies no longer obtains. C11 made the following observation:

'Look at caffeine...it's a relatively new drug – it's only been around for three or four hundred years, but because it's been around before we started regulating everything there's no rules about being allowed to drink two or three cups of coffee before you go into an exam...it's historic isn't it – wine has been around for ages, it's part of our natural psyche and culture, and erythropoietin is very new'

Similarly S2 observed that the characteristics of a system such as erythropoiesis, which determines the haemoglobin content of the blood, were set during a historical epoch in which norms of human life were very different. Although certain environmental threats to health and life that were present during this epoch have since receded, our erythropoietic system has not altered in correspondence with this. He suggested that the normal haemoglobin content of the blood is now higher than necessary, given the less immediately dangerous and more sedentary nature of modern human life. S2 stated that haemoglobin content has been:

'...set by evolutionary pressure...we're now living in a time of plenty...now very people in our society are encountering sabre-tooth tigers that maul them, cause them to lose a pint and a half of blood but then still leave them with enough energy to run

away...would be a heavy evolutionary pressure without any resuscitation available, at least in the western world'

Haemoglobin content is correlated with the risk of thrombosis, and this risk increases with proximity to restoration at a species-typical level. The ideal therapeutic target when balanced against this risk is slightly lower than statistically normal. (Smith et al, 2003; Ehrenreich et al, 2004; Strippoli, 2004; Drueke et al, 2006; Remuzzi & Ingelfinger, 2006; Miskowiak et al, 2008; Sargin et al, 2010). When asked about why this is the case, a typical response was that the reasons are not yet fully understood (C2, C3, C5, C6, S2, S4, S9). C6 suggested that the reasons may be '*multi-factorial*':

'...there's various things at play...in an adult male a normal haemoglobin should be around 13...people who have a normal haemoglobin delivered by EPO have worse outcomes, whether that be mortality outcomes or increased events such as stroke. Also it's less clear that we see symptomatic improvement. So going from six to nine brings about significant symptomatic and functional improvement. Going from 11 to 13, there's much less good evidence that you actually improve anything. Certain individuals yes, but actually at that point we're probably increasing the risk without improving any benefits'

This view lends support to Koch's argument (2010) which foregrounds the need for caution when attempting enhancement. Despite the rapidity with which biological knowledge advances, he contends that our understanding of biological systems may not always be detailed enough for us to intervene safely. This also lends tentative support to Bostrom & Sandberg's (2009) argument that health cannot necessarily be inferred from species-norms, since these norms may not always represent an ideal balance of risks and benefits throughout time. If they are correct, then given fluidity in norms of health, what may be considered therapeutic from one perspective may appear to be 'enhancing' from another. An example of this can be seen in C2's observation of changing socio-historical norms:

'...in the last 30 years probably we've evolved even quicker, mainly because of the technology...we will evolve even more – we have to survive...for progress you need enhancements...there will be enhancements'

Similarly, and consistent with the findings of Gunga et al (2007), Brookhart et al (2008), and Chapman et al (2010), S4 explained that since haemoglobin content is partially controlled by the oxygen content of the air relative to altitude, so norms of health are also geographically mediated:

'...if you asked them to go and exercise in Ethiopia or somewhere where hypoxia level is much higher, they can reach these target haemoglobin much easier. And there is one interesting study which shows that patients who are on dialysis who are living on high altitude, their EPO requirement is lower, because it stimulates their own EPO, you see? And somebody looked at the survival of these patients and it was clear that the survival was better'

The challenge, then, is to understand whether or not the therapy / enhancement distinction can be substantiated on a more solid basis, beyond varied and changing norms which define it contingently and empirically. We need not necessarily assume that any one kind of justification is 'better' than the other, rather, a comprehensive account of the therapy / enhancement would take account of both a priori and inductively derived knowledge. Although it may be that good justifications for the reality of the distinction can only be made empirically, this is only a problem if we believe that *a priori*, deductive, knowledge is superior in some way to empirical or inductive knowledge.

A possible consequence of awarding too much weight to the deductive weakness of the distinction would be a correlative weakening of the justification for allocating resources according to significant and empirically verifiable threats to health. For example C9 claimed that the development of EPO therapy for renal anaemia is '*out on a limb*', and is a rarity in that it has '*felt like a proper cure in medicine*' alongside '*syringing ears, correcting cataracts, surgically removing a cancer before it's spread, and insulin for diabetics*'. It would be an ethical weakness of any attempt to dissolve

completely the difference between therapy and enhancement, because the conclusion of a total dissolution would be to hold that no single health need is intrinsically more serious than any other.

One of the logical weaknesses of the therapy / enhancement distinction is its reliance on the concept of normal health, which is ambiguous under analysis. The price we may pay for not attaching sufficient weight to empirically identifiable aspects of ill-health on the basis that the concepts involved are logically ambiguous may be a high one, however. If the logical vagueness of the term 'normality' is appealed to as a reason why the therapy / enhancement distinction should be discarded completely, there is a risk of sanctioning injustices to people whose functioning quite clearly deviates from a prevailing norm in a way that threatens their health, functioning, or wellbeing. As S6 notes:

'...you know we all have two legs so if you've got one leg then that would clearly be an abnormality. There are obvious abnormalities, and there are nuanced abnormalities...you've got clear obvious abnormalities like patients who had two kidneys and now has no kidneys functioning and wants therapies to enhance their life and their life span'

This quote demonstrates clearly that views from within the medical profession which defend the reality of the therapy / enhancement distinction on the basis of empirical rather than *a priori* evidence are strong, persuasive, clearly defensible, and should be taken seriously. Thus what is of interest here is that the primary means of justification advanced in favour of the therapy / enhancement distinction in the study are different to the kinds of arguments and justifications employed in philosophical argument.

S6's reflection on the way in which he distinguishes between those needs which require assistance, and those which do not, illustrates this. He suggested that intuition has an important role to play in medical decision making which may be relegated in importance within philosophical analysis:

'You see, philosophy I understand as using logic and reason to try and dissect a problem to get to an answer – I don't know, does philosophy allow for one's instinct to play a role in decision-making?'

Pursuing this difference between inductive and deductive bases of judgement, the claim that there is no essential difference between therapy and enhancement just because they are irreducibly logically connected is counter-intuitive. Indeed, the difference between health and illness does appear to be real and non-trivial. Returning briefly to a critical realist approach to this problem, if one adopts the critical position view that the world beyond the mind is ontologically objective (Bhaskar, 1975; Archer, 1998; Sayer, 2010; Easton, 2010), one can commit to the view that certain physio-biological states are genuinely physically limiting to different degrees. This view is accurate irrespective of whatever judgement of relative health is made about them (Bhaskar & Danermark, 2006; Owens & Cribb, 2011). S1's account of treatment before and after the introduction of EPO offers a clear justification for adopting this position:

'...going back twenty years patients with renal failure would often be very anaemic, they'd be pale, they'd be tired and breathless, they couldn't exercise...when EPO came along all of a sudden really their lives were transformed'

Observations such as this present a challenge for pro-enhancement positions that appeal strongly to the logical continuity between therapy and enhancement. Empirical features of ill-health used in medical decision making must, it seems, be awarded weight. If they are not then it is incumbent on the pro-enhancement case to show how erosion of a legitimate hierarchy of needs can be resisted in an analysis which foregrounds the logical connection between therapy and enhancement. Despite the distinction's logical weakness, to collapse the distinction entirely on this basis may risk worsening the situation of those people whose medical needs are already significantly limiting. The problem we face is how to reconcile the two forms of justification for and against the reality of the therapy / enhancement distinction.

6.13) Enhancement's Place in Medicine

If we conclude that enhancement has no legitimate place in medicine, we would need to reassess borderline cases of enhancement which are already available. One example of this is the legal prescription of beta-blockers in the absence of a diagnosis of an anxiety disorder mentioned earlier and raised in my study by C3 and S11. The prescription of beta-blockers in the absence of a disorder was considered acceptable by these participants.

Similarly, in drawing an analogy between the use of beta-blockers in work and the hypothetical 'lifestyle' use of EPO in sport, C3 claimed that relaxing regulation to legalise enhancement use is not necessarily ethically problematic in principle. He suggested that moral unacceptability would be caused by other circumstantial factors, rather than simply whether one can or cannot legally use a drug for enhancement:

'...so if there was someone who was an amateur who wasn't competing but just wanted to optimise his performance just for playing tennis in his local club, and he was competitive and he just wanted to function in life optimally, I don't really have a problem with him, that's not very much different from me taking beta blockers to stay calm giving a presentation to an international congress, so I don't have a problem that way. Whereas once it becomes about competition and international recognition as you as an athlete then I guess everybody has to have equal access to those drugs or nobody has access to those drugs'

On the other hand it is possible to give too much weight to the conclusion that the distinction between therapy and enhancement is illusory simply because a logical analysis demonstrates that 'enhancement' of health is the aim in both cases. Problems will arise if we reject the need to commit to prevailing diagnostic norms simply because they may change.

If it were considered equally reasonable to seek assistance for *any* biomedically improvable 'need', injustices may accrue to those with more severe health problems, as some of those resources would need to be directed to assisting people

who, according to current diagnostic criteria, have no need for them. A worry of this kind was voiced by C8 in considering the consequences of widening the criteria of access to drugs to include enhancement use:

'...if you ended up with a situation where it was considered acceptable for there to be a cohort of drugs that are prescribed on an as needed basis as they are now, but there's lots of supplementary drugs that people could buy, I guess the temptation for the exchequer would be to move more medicines into pot B and have fewer in pot A.' 'allow for more vulnerable people to be preyed upon by marketers'

Both interpretations of the distinction thus entail difficulties. In the first case there is an inconsistency between the relative legal status of beta-blockers and EPO for certain enhancement purposes. Notwithstanding the safety issues associated with EPO use, it is legitimate to ask what the principle being applied here is that leads to this difference in legal status.

The difficulty in the second case is related to the first. If legal access to drugs such as EPO were widened to include certain enhancement uses on the basis that its legal status is presently inconsistent with that governing the use of beta-blockers, this would have implications for the fair allocation of finite resources. Market pressures may come to bear on policy decisions concerning the appropriate subsidisation of medical products that could threaten to divert resources away from those who are in greatest need. We are therefore caught on the horns of a dilemma. If progress is to be made, some negotiation or reconciliation of these difficulties is required.

6.14) Conclusion

From the preceding analysis of theory and data we can draw some conclusions that can be taken forward and developed in the final chapter of the thesis. The therapy / enhancement distinction was shown to be logically insubstantial under scrutiny. To this end I conclude that it cannot serve as a final guide for discerning between acceptable and unacceptable forms of medical assistance. Despite this, however, the unanimous commitment amongst the study participants to the principle of

allocating resources according to need indicates that any revision of the therapy / enhancement distinction that is to be tractable with medical practice must retain this commitment.

In the following chapter I will show how these two positions can be integrated into a more accurate philosophical account of the relationship between therapy and enhancement. Despite underlining the weakness of the distinction between the two, this account also recognises a hierarchy in the severity of health needs in virtue of which resources should be 'titrated' accordingly. I also conclude on the basis of the analysis that whilst it is not possible to completely dismiss conceptions of 'normal' health, and by extension some idea of the difference between 'therapy' and 'enhancement', these categories cannot be the only arbiters of medical decision making.

On the basis of the above I draw the further conclusion that resource allocation should be governed more explicitly by (ontological) need relative to goals, resources, and countervailing factors of safety and justice, with correspondingly less weight awarded to (epistemological) categorisations of normality, health, illness, disease, and whether an intervention is a 'therapy' or an 'enhancement'.

6.15) Summary

In this chapter I analysed the empirical data in terms of relevant theories concerning the relationship between therapy and enhancement. I did this for two reasons: firstly, to examine whether the data provide any insight into the relative accuracy of competing theories; secondly, to investigate how the various theories help us to understand the practices and values that determine how the therapy / enhancement distinction is understood contextually from within the medical profession. I examined the various issues of ethical significance expressed by the study participants, as well as views concerning the logical validity of the therapy / enhancement distinction. I showed how a critical realist approach can be applied to the analysis of these issues, and used this to generate insights that I will take forward and use as a basis for conclusions in the final chapter.

Chapter Seven: Conclusions

7.1) Introduction

In this chapter I will draw some ethical conclusions that arose from the analysis in chapter six, and make policy recommendations regarding the legal control of human enhancement technologies. I will do this in order to satisfy a twofold aim of the thesis as a whole: firstly to refine and advance our understanding of the philosophically complex therapy / enhancement distinction; secondly, to develop practical ethical responses to the phenomenon of human enhancement in ways that will be tractable with clinical and research practices in future.

First I will address ontological and epistemological issues concerning the nature of the relationship between therapy and enhancement, and how an account of this relationship can be justified. The second part addresses ethical aspects of human enhancement with respect to achieving justice in medicine and healthcare allocation. I used the theoretical approach of critical realism in analysing the theory and the data in chapter six, and I will use it here in developing the final conclusions.

I will situate the conclusions, recommendations, and the revised account of therapy and enhancement within the existing literature and provide some orientation in terms of their relation to existing theory. The contribution of the empirical data in assisting in this orientation will also be explained. Towards the end of the chapter we will consider the limitations of the research and potential sources of error, and avenues for future research of ethical significance which arose from the project. Prior to developing the conclusions, however, firstly I will summarise what I have done over the course of the thesis.

7.2) Thesis Summary

In chapter one I introduced the therapy / enhancement distinction and explained why it is logically problematic. I outlined why the logical weakness of the distinction has ethical implications for medical practice in terms of ensuring a fair

allocation of resources. I examined the implications of a rapid proliferation of human enhancement technologies in future. I explained that ethical policy responses would be needed to ensure an appropriate balance between the need to protect the prioritisation of medical need according to severity on one hand, and the liberty to enhance on the other.

Having introduced these issues I explained the need for an interdisciplinary approach to clarifying our understanding of human enhancement in view of the theoretical inconclusiveness of the literature and the relative absence of empirical data. I briefly outlined the history, present, and future of enhancement; the nature of medical responsibility. Finally I introduced the philosophical approach of critical realism as the research methodology to be used in the thesis.

In chapter two I reviewed the literature of greatest relevance for answering the central research questions, namely: how should we understand the relationship between therapy and enhancement? And what would be an appropriate policy response to the practical ethical challenges that a growth in human enhancement technologies might have on medical practice and research?

These questions informed the selection of the literature to be examined and consequently the review focused on: concepts of health, disease, and illness; the therapy / enhancement distinction; ethical issues in enhancement; and the history, present, and future of enhancement. Since the research was to be interdisciplinary, combining philosophical analysis with social scientific data, I included literature from across these disciplinary perspectives within the review.

In chapter three I introduced the philosophy of critical realism as the methodology to be used for framing the research. This approach is designed to 'underlabour' for practices in social science. Its argument for a realist ontology combined with a relativist epistemology provides a way of maximising the compatibility of diverse or apparently opposed disciplinary perspectives. For this reason it is well equipped as an approach for interdisciplinary ethics in which empirical data is used as the basis for normative philosophical analysis.

I explained and justified the choice of methodology, and gave examples of how it can successfully negotiate the epistemological scepticism critiques such as strong social constructionism and the naturalistic fallacy. I provided a detailed account of how critical realist theory can be used to integrate normative and descriptive elements in a way that balances the insights of each and produces rational and compelling ethical arguments.

In chapter four I explained the research methods used in the empirical component of the thesis. I gave reasons for using a single case study, rather than several. I then offered a brief review of possible enhancement technologies which could be used for the empirical study, and I justified the selection of synthetic recombinant erythropoietin (EPO) as a critical case' for enhancement.

Within this chapter I also explained and justified: the selection of one-to-one in depth interviews rather than focus groups; the decision to interview both clinicians and scientists in order to achieve insight into contextually-informed views about enhancement; and the identification of an appropriate size for the study.

Finally within this chapter I described the construction of the pilot study prior to the main study; reported the recruitment process for interviewees, and described the interviews; accounted for developments in questioning according to the emergence of themes throughout the process; explained the processes of coding and data analysis; justified the decision to finish the study after 25 interviews once data saturation had been reached.

In chapter five I reported the main findings that emerged from the empirical study and which assisted in answering the central research question of the project. I reported the themes of greatest ethical importance to the study participants both in relation to enhancement in general, and EPO in particular. I found ambivalence towards enhancement to be widely evident, however the professional responsibility for ensuring safety and justice were considered to be non-negotiable

conditions that would determine the ultimate moral status of a decision to allow or refuse access to an enhancement.

As well as the key ethical findings, I gave an account of views expressed concerning the philosophical and logical underpinning of the therapy / enhancement distinction. Frequent references to naturalness, artificiality, and their relation to normality were also reported in view of their relevance to the research. I cited the difficulty in separating completely the clinician and research groups which emerged throughout the study as a possible limitation on the clear identification of significant differences between the two.

Having reported the main findings, in chapter six I carried out a philosophical analysis of the data. This connected relevant theory from the literature review of chapter two with the empirical information provided by the study. After briefly restating the research problem, I reported the lack of absolute congruence between the data and any one particular theoretical model of enhancement was reported. Throughout the chapter I examined and analysed in detail areas of partial congruence between the two.

I analysed the main themes of ethical and philosophical relevance from the study in light of competing theoretical perspectives on enhancement. Consequently safety, justice, naturalness, normality, and the therapy / enhancement distinction itself were discussed in detail. I gave an example of critical realist analysis in order to show how it successfully combines philosophical and social scientific approaches in preparation for the final chapter in which I will use this to frame the conclusions of the thesis.

7.3) The Therapy / Enhancement Distinction: Good and Bad Arguments For and Against

The investigation was motivated by an ambiguity concerning the logical delineation of therapy from enhancement. One response to this ambiguity is to conclude that if the distinction cannot be logically substantiated or upheld then we should dispense with it, following Harris' (2009, p. 143) critique:

'It does not draw either a morally significant or an explanatorily significant distinction and so fails utterly to be useful.'

On the other hand, if practical ethical justifications exist for adhering to the distinction or certain aspects of it, then these would weigh in favour of its retention, although perhaps in a partial or attenuated form. If arguments both for and against are valuable in different respects, then a rational strategy is to negotiate a defensible and balanced '*symbiosis*' (Frith, 2010) of the two.

Irrespective of the logical weakness of the therapy / enhancement distinction, the study participants unanimously viewed their primary role as to help people with the greatest health needs. The beneficiaries of their work were identified as being ill, having a disease, or in some state of health which causes poor or subnormal functioning. Questions about the place in medicine for interventions that would enhance, and the improvement of normal functioning that this implies, were thus largely considered as tangential and only peripherally related to the responsibilities of practice (C1, C2, C4, C5, C6, C9, C10, C11, S1, S3, S4, S5, S6, S9, S10). As Juengst (1997, p. 130) notes, this has the advantage of expressing decisions about resource allocation in relatively straightforward terms:

'The advantage of the Normal Function account is that it provides one relatively unified goal for health care, towards which the burdens and benefits of various interventions can be relatively objectively titrated, balanced, and integrated.'

This approach has merit insofar as it is consistent with values frequently articulated within the empirical study. For example, the participants unanimously referred to the moral responsibility incumbent on them for justice and the prevention of harm. If it is ethically important to uphold these responsibilities via the '*titration*' (C5, S2) of assistance according to need, then the fact that enhancement may be logically consistent with the goals of medicine makes little practical difference, because in enhancement by definition we are considering people further back in the queue for assistance.

There are, therefore, good reasons for endorsing the medical status quo to some degree if it is morally important that resources are allocated according to need. To the extent that the conventional medical responsibilities outlined are worth protecting because they heal, cure, alleviate suffering and prevent harm, we ought to accept them as good reasons for not completely re-orientating the existing criteria for medical assistance.

Having said this, although it might be ethically important to allocate resources according to need, the fact that this is so does not clarify the logical ambiguity in question. A frequent criticism of the integrity of the therapy / enhancement distinction is the fluidity and contingency of the concepts used to justify it (Daniels, 2000; Savulescu, 2006; Bostrom & Roache, 2008; Buchanan, 2009; Harris, 2009).

In particular statistical norms of health and / or functioning, and their perceived value are not socially, culturally, geographically, or historically constant (Lewis, 1953; Barilan & Weintraub, 2001; Alvarez, 2008). Despite the prevailing commitment to the sick displayed by the study participants, it was clear that the fluidity and contingency of health concepts was also frequently recognised (C1, C2, C5, C9, C11, C12, C13, S2, S5, S6, S9, S11).

If the technological development that this implies is extrapolated into the future then any account of the therapy / enhancement distinction which appeals inflexibly to contemporary norms is likely to become decreasingly recognisable as change occurs (Harris, 2009; Bostrom & Sandberg, 2009; More, 2013). Taking a very long historical perspective with respect to previous human norms, we may conclude as Jones does (2006, p. 78) that '*compared with hunter-gatherers we must seem like posthumans*'. If this process of change continues to occur without end, the practical utility of conventional distinctions such as the one drawn between therapy and enhancement will decrease.

7.4) Emphasising Need and Limiting the Therapy / Enhancement Distinction

If the practical utility of the therapy / enhancement distinction decreases in correspondence with advances in medical technology, some means other than the

distinction will have to be used for guiding a fair allocation of resources. My recommendation is that in order to do so decisions should be grounded not in subjective and changing epistemological categories such as 'therapy' and 'enhancement', but in ontologically objective aspects of human functioning.

If it is possible to identify and measure human needs, rational judgements concerning the extent of the limitations that they impose can be made (Bhaskar, 1993; Sayer, 1997; Archer, 1998), such that they can be ranked in a hierarchy or continuum. If this is done effectively it can be used as a basis for the fair allocation of resources without placing any particular emphasis on where the threshold of 'normality' is drawn upon it.

Viewed from this perspective the actual needs of some will always be greater than others, irrespective of the logical strength or weakness of the therapy / enhancement distinction. If it is right that there should be a correspondence between needs and resources then people further up the hierarchy will always have a stronger prima facie claim on medical assistance than those below them no matter how normal and abnormal health are defined. The retention of a hierarchy of need is therefore necessary from the point of view of achieving a just allocation of medical resources, irrespective of the reality of the therapy / enhancement distinction.

Nevertheless the logical weakness of the distinction is significant for other reasons. In showing therapy to be a supervenient category on the fundamental concept of enhancement the ambiguity underlines the contingencies of medical practice. The medical infrastructure, its classifications, its treatment criteria and nomenclature are socially constructed artefacts (Freidson, 1970; Press, 1980; Gillett, 1994; Jordanova, 1995; Gursoy, 1996; Kleinman, 1997) tasked with the realisation of goals such as healing curing, caring, the prevention of illness and disease, the restoration of normality, and improvement of health and wellbeing (Lewis, 1976; Moravcsik, 1976; Kleinman, 1979; Fleischauer & Hermeren, 2006) (C1, C2, C4, C7, C8, S1, S3, S6). Decisions made by medical professionals about whether to grant or deny assistance in order to achieve these goals are '*institutional facts*' (Searle,

1995) about what the medical profession happens to do within a particular context.

It is for this reason that the categories of 'normal' and 'abnormal' are unstable and vulnerable to change. Actual health needs vary in severity, however the ways in which these gradations are categorised as 'normal', 'abnormal', 'healthy', 'diseased', and so forth are not static (Mechanic, 1973; Frake, 1977; Good, 1977; Unschuld, 1978; Amundson, 2000; Stempsey, 2006) (C2, C11, C12, S11). To the extent that these categories are not static, any distinction between therapy and enhancement that is grounded in them will be similarly vulnerable. Consequently, the therapy / enhancement distinction is only substantial to the extent that the account of normality that underlies it can be upheld.

Given the logical porosity of health concepts and the recognition of this within the empirical study (C2, C5, C9, C11, C12, S2, S4, S7, S9, S11) I conclude that enhancement is logically (at least) minimally consistent with the goals of medicine. For this reason pro-enhancement arguments that argue for an institutional reorientation of medicine such that it becomes more open in principle to the possibility of sanctioning enhancements in practice are justifiable, providing that an appropriate balance obtains between other morally relevant factors such as safety, cost, the size of benefits, and the effects on other members of society.

These supervening factors are important, for despite its weaknesses the therapy / enhancement distinction has some heuristic value insofar as it implies real differences in the severity of health needs. For example let us assume that a non-negotiable principle on which to base resource allocation is that resources should be allocated according to needs irrespective of one's position concerning the ethics of using or sanctioning the use of human enhancements. To the extent that therapy and enhancement represent poles of medical assistance at the lower and upper boundaries of a hierarchy of needs, then the fact that these poles contribute to the structure of this hierarchy implies that they can play a (limited) role in determining the fair allocation of resources.

Recognising the hierarchy of needs to which the poles of the distinction correspond will partially satisfy some of the criticisms levelled at enhancement in terms of the potentially deleterious impact that it could have on the fair allocation of resources if it were to proliferate (Daniels, 2000; Fukuyama, 2002; Kass, 2003; Sandel, 2004; Pellegrino, 2004; Koch, 2010). Importantly, however, it is not the distinction itself which should be retained, but rather the assumption underlying it according to which health needs are understood as real and of varying severity.

By combining the logical case against the therapy / enhancement distinction with the foregrounding of the needs of the sick in arguments in favour of it, we can integrate these advantages into a revised approach to enhancement that derives a benefit from both. Although the therapy / enhancement distinction is logically insubstantial, this does not mean that judgements about the relative severity of health needs are irrational. Consequently accepting the weakness of the distinction need not have a corrosive effect on proportionate resource allocation.

Approaching the problem in this way allows for greater flexibility in deciding what forms of assistance are possible and appropriate. Relative to a wide conception of human needs and balanced against the available resources this approach builds an acceptance of fluidity between health categories into its reasoning about the appropriate threshold of medical assistance.

7.5) Recasting Therapy and Enhancement: A New Theoretical Model

I propose a refined theoretical model that pays less attention to the therapy / enhancement distinction as such, and decreases the emphasis on whether states of health deserving assistance are 'normal' or 'abnormal'. Instead I recommend an increasing emphasis on the straightforward question of whether a need (broadly construed) can or cannot reasonably, safely, and fairly be met via medical assistance.

For example, if an enhancement would safely confer significant enough health benefits, and sufficient resources were available after all more pressing needs had been met, I argue that no substantial moral argument remains for withholding

access to it in principle (Bostrom & Roache, 2008; Harris, 2009; Sandberg & Savulescu, 2011). This would hold true even if assistance is not used to treat sickness or illness because, as Scripko (2010, p. 296) observes, '*enhancement technologies will often fulfil medicine's goal of promoting health*'.

Although unconditional endorsements of an expansion of medical services to routinely consider the provision of enhancements in the way I have described were not evident in the study, there was some conditional support. The responses of C3, C4, C9, C10, C11, C12, S2, S3, S4, S6, S9, S11 indicate that this model need not conflict with the conventional ethical responsibilities of medical practice as such, as long as all more severe or limiting health needs had been met prior to decisions about supplying enhancements.

A corresponding characterisation of health needs as varying in severity underpins the approach I recommend. My proposal, however, is that resources should be allocated according to judgements about the extent to which a need limits health and / or functioning, rather than how the form of assistance happens to be categorised.

7.5.1) A Realist Account of Needs

For the reasons I gave in chapter three, the model that I propose is realist in nature because the needs that underpin the model are understood to impose limitations which do not alter according to the epistemological category into which they are placed. They are prior to categorisation and hence they should be considered as real. The study findings show that the participants did not typically associate need with 'normal health', however this disassociation is only accurate to a limited extent.

That someone is not ill or free of disease does not mean that they have no needs. There are tasks which I am physically or intellectually unable to perform, even if I am in a state of good and normal health. I therefore have needs relative to those tasks if I wished to carry them out. If I wished to be a professional basketball

player, I would *need* to be significantly taller than I am. Powell & Buchanan (2011, p. 10) capture this insight in observing '*the ubiquity of suboptimal design*'.

If I am too short to be a professional basketball player, it is irrelevant whether or not I am considered healthy, or whether I am viewed as normal or abnormal, since none of these categorisations have any effect on my height or resolve my physical need. If this approach is applied to the full range of human ability we can construct a realist hierarchy of needs that encompasses all functional states, from those which immediately threaten life or severely limit health, to those which do not but nevertheless impede an individual's capacity to live his or her life in the way that they desire.

7.5.2) Needs and the Fact / Value Distinction

If we believe that medical resources ought to be allocated in such a way that those with the greatest need are always 'first in line' for assistance, then we cannot also believe that these states are value-neutral. Unless the limitations imposed by a need are judged negatively it is not obvious why assistance ought to be provided. Therefore in order to allocate resources according to needs, not only must we a) treat these needs as real; but we must also b) judge them as evaluative states in order to make normative conclusions about what constitutes an appropriate response to them.

Scepticism about the possibility of doing so, however, underpins the is / ought problem and by extension the apparent and more general difficulty that this problem poses for the rational incorporation of empirical data into ethical analysis (de Scheer & Widdershoven, 2004; De Vries & Gordijn, 2009; Brassington, 2013).

As I explained in chapter three, this fallacy can be negotiated by showing that needs can impose limitations that should be removed, all other things being equal, if it will confer a benefit (Sayer, 1997). This is a view consistent with the positions adopted by Toulmin (1975), Agich (1983), and Lennox (1995) concerning the intrinsically evaluative nature of different functional states. It is redolent of Hare's

(1986, p. 176) summary of this view that *'If I have bad eyesight...I ought to go to the oculist and he ought to prescribe spectacles if they will make my eyesight better.'*

The belief that health states are not value neutral is one that was reflected unanimously in the study data, and is also a premise of the arguments which form the remainder of the conclusions. The principle articulated widely within the study was that the presence of states which cause suffering or compromise health, functioning, ability, or wellbeing provides a rationally compelling moral reason to provide assistance. In this respect the theoretical model that I advance is consistent with the views expressed in the study.

7.5.3) Judging the Acceptability of Enhancements

A model of resource allocation whose primary criterion is actual need rather than perceived normality provides a more stable basis for such decisions in the face of conflicting accounts of health. In particular it provides greater stability in the event that acceleration in medical technology increases the options for effective human enhancement as predicted by Bostrom (2005), Kurzweil (2005), Bostrom & Sandberg (2009), and Harris (2009).

The question of whether or not medical assistance is classed as 'therapy' or 'enhancement' is relegated in importance. Anchoring decision-making primarily in actual needs and reducing the importance of whether the recipient's health and / or functioning is considered normal thus provide greater flexibility if technological changes becomes increasingly rapid. Consequently the decision-making process for someone seeking medical assistance would be as follows:

- 1) *Is the technology available for safely meeting this person's needs as required?*
- 2) *Could this be done without diverting resources from someone with a greater need?*
- 3) *If the answer to 1) and 2) is 'yes', assistance is justifiable even if it is 'enhances'*

We can apply this decision making process to the case of EPO and examine the results. Imagine that someone seeks EPO to enhance their endurance or exercise capacity for a professional or lifestyle purpose, and is not using it for competitive advantage in circumstances where its use is forbidden. S3's hypothetical example of someone with an arduous manual job for whom the use of EPO would enhance performance and '*make their daily grind a bit more tolerable*' is relevant here.

If a nephrologist judges that usage can be monitored and the amount required is small enough to be safe, then assuming the provision of assistance would not deprive someone whose needs are greater, there is no obvious reason why access should be denied. By contrast, if the risk to health were too great, and / or if the drug were to be used for positional gain alone in a context such as competitive sport, then assistance should be denied. Note that whether assistance is granted or denied, however, it is not whether assistance is 'therapeutic' or 'enhancing' that is of central ethical relevance (Savulescu, 2006; Harris, 2009; Sandberg & Savulescu, 2011).

In the example given here the conditions of acceptability also closely resemble justifications given in the study for the acceptability of cosmetic plastic surgery (S6, S9, C8, C12). In these cases there was a clear separation between the participants' personal views of cosmetic plastic surgery, and their opinions concerning what its legal status should be. Although several were critical of the aesthetic motivations which drive the industry and the private surgeons who work within it, they did not believe it should be illegal or think that cosmetic plastic surgery was ethically unacceptable as such.

Although the participants registered little objection to enhancement in principle, the provision of medical assistance to people who they perceived to have no need that would warrant it was typically viewed as a kind of practice that they neither identified with nor wished to engage in. Since no policy presently exists with the explicit aim of co-opting enhancements into standard medical practice and budgeting decisions it may be relatively easy for them to separate judgements of hypothetical ethical acceptability from practical ones in this way. It is, however,

unclear whether they would express similarly ambivalent views if such policies were introduced that would impinge on their current practices and values.

7.5.4) Advantages of the Model

The model that I recommend does not undermine the professional medical principle of prioritising the needs of the sick. In this respect acceptance of the logical reducibility of therapy to enhancement need not threaten the just allocation of resources. There are real physio-biological differences in health and functioning between, for example, an 80 year old person with renal anaemia receiving EPO and a professional athlete wishing to use EPO for a competitive advantage (S1). To the extent that the health needs of the 80 year old are more severe than those of the athlete, it is the difference between these two needs which should determine the allocation of resources. Consequently the model achieves three aims:

- 1) It clarifies the relationship between therapy and enhancement by disaggregating the fact that they are logically continuous from the ethical primacy of allocating medical assistance according to need.
- 2) In clarifying this relationship this approach achieves a balance between enhancement theory and the study data which protects the ethical integrity of conventional medical practice.
- 3) Given changes in norms of health, and enhancement anomalies such as beta-blockers and cosmetic surgery, the account is a guide for judging the acceptability of providing assistance to enhance in other cases, should similar challenges emerge in future.

This provides a tentative account of how enhancement could be fairly institutionalised in a way that takes into account both the implications of the logical weakness of the therapy / enhancement distinction and the practical demands of distributive justice. Despite enhancement's logical continuity with

therapy there would still be a need to ensure that resources are allocated according to need even if enhancements were to be legally permitted.

In view of the fluidity of norms of health, less emphasis would be placed on whether medical assistance restores 'normality' or boosts it. A commitment to health needs as real and limiting would be retained, however. In doing this it would be possible to reduce the philosophical problems which result from strong adherence to the distinction. It would also recognise as legitimate the desire to enhance as long as countervailing issues of justice would not result in negative outcomes for people whose health needs are greater.

7.5.5) The Persistence of Normality

Although my approach has the advantage of circumventing some of the practical difficulties associated with the delineation of therapy from enhancement, it does not completely avoid conceptual complications involved in the clear identification of normality in relation to health. Undoubtedly some conception of normality is unavoidable when considering resource allocation, because many subjectively valued goals will be consistent with the expectations and structure of society (Benedict, 1934; Kleinman, 1979; Press, 1980). For example most people, by definition, live 'normal' lives, since for something to be normal is for it to be similar to the other instances of which it is a class (Canguilhem, 1975; Mordacci, 1995; Kovacs, 1998).

One response to this challenge is to consider concerns raised over 'medicalisation' and the *de facto* reclassification of normality as abnormality via the inclusion and legalisation of treatment for it under the auspices of medicine (Illich, 1976; Conrad, 1982). Concerns about medicalisation are understandable, but they are misleading in one respect, because 'medicalisation' is ubiquitous. For example headaches are normal, but there is no stigma associated with going to buy ibuprofen, a medicine, to remove them. Birth control is also a medical intervention but, notwithstanding certain religious objections, the 'medicalisation' of this aspect of life is not especially controversial. Similarly, judgements about whether to allow the use of

an enhancement must be made on a case by case basis according to whether or not there are good reasons to be concerned about their availability.

Furthermore talk of medicalising 'normality' depends on having first decided what 'normality' *is*. This cannot be done reliably because, as Holm (2008, p. 9) points out, an alternative conception is always available if one just changes one's frame of reference, and hence there is *'no way of getting a neutral and uncontroversial measure of statistical normality'*. The concern over 'medicalisation' is that it reclassifies something which genuinely does not require medical assistance as an 'abnormality' that does, and in doing so stigmatises the individual concerned. However Amundson's (2000, p. 43) comment, raised in the literature review, that *'variation is ubiquitous'* is relevant here. He underlines the normative character of the concept of normality, and criticises it by reference to Hacking's claim that it *'uses a power as old as Aristotle to bridge the fact/value distinction, whispering in your ear that what is normal is also right'*.

A way to resist this, therefore, is to deliberately reduce the institutional significance of the therapy / enhancement distinction and the threshold of normality that it implies. If instead we were to adopt an approach in which the broad aim of distributive justice is simply to provide assistance up to as high a threshold as resources will permit, then discrimination relating to conceptions of normality can be limited.

I showed in chapter two that numerous accounts of health have been advanced, and it is a limitation of the model I recommend that it does not, ultimately, prove beyond doubt how 'normal' functioning should be understood. In view of this the presence of some conception of normality in any decision concerning the allocation of resources is unavoidable. Consequently we must also accept that because norms of health necessarily constitute the conceptual dividing line between therapy and enhancement, as long as we have a conception of normal health we will not be able to dispense completely with assumptions about the meaning of the therapy / enhancement distinction.

What we can do, however, is attenuate the importance and influence of the distinction in recognition of the fact that norms are not static and fluctuate in their reliability. If the approach that I advance works, it does so precisely because it wishes to reduce the stigma associated with 'abnormality' and engender a wider consideration of all the needs that are present across the whole of society and what can be done to meet them.

7.6) Regulating Enhancement

Hypothetical recognition was evident within the study that there are personal circumstances in which it may be reasonable for someone to allow the use of medical products for enhancement (C4, C9, C11, C12, S2, S3, S6, S9, S11). As the study data indicated, however, the safety profile of the product and the kinds of purposes for which it would be used influenced the perceived ethical acceptability of granting assistance.

Buchanan et al (2000), Bostrom (2004), and Kamm (2009) adopt a similar view to in relation to the second of these conditions, namely that an enhancement should not be permitted if it confers only a 'positional' advantage to the user over non-users, for example in the case of EPO use in professional sport. By contrast, however, these authors endorse the legalisation and regulation of enhancements if they would confer an absolute or intrinsic advantage that '*can raise the absolute quality of each person's life even if there is no change in relative advantage*' (Kamm, 2009, p. 112). Bostrom & Roache (2008), Bostrom & Sandberg (2009), and Sandberg & Savulescu (2011) have identified cognitive enhancers in particular as candidates for conferring this kind of benefit.

If the advantages conferred by a particular enhancement would be a) beneficial to health; b) intrinsically valuable rather than valued only because they increase one person's advantage over another; and c) would not divert resources away from people whose health needs are more severe or otherwise exacerbate inequalities in any socially corrosive way, there is a prima facie justification for allowing their private use.

Furthermore, if an intervention satisfied the first two of these criteria to the extent that it would benefit a sufficiently large proportion of society to receive it, there would be grounds for subsidising that intervention, even if it would be viewed as an enhancement rather than a therapy according to current classifications. In relation to the case of cognitive enhancements, Bostrom & Sandberg (2009, p. 331) list several examples of where welfare and public health related measures have been implemented beneficially:

'Many extant regulations are intended to protect and improve cognitive function. Regulation of lead in paint and tap water, requirements of boxing, bicycle, and motorcycle helmets, bans on alcohol for minors, mandatory education, folic acid fortification of cereals...'

Indeed if enhancements are judged according to whether they can act as a supplementary benefit to worthwhile pursuits and choices, as is implied by this list of examples, their control via appropriate regulatory policies *'will allow people to build human capital alongside other activities'* (Nam, 2012, p. 5). Viewed in this way there would be circumstances in which the legal control of enhancements could be considered acceptable. Moreover the study data indicates conditional acceptance of their legal use from the perspective of medical professionals working in the context of a society with mixed public and private healthcare such as the UK, assuming that they would be safe to use and beneficial in the ways outlined here.

7.6.1) A Prioritarian Approach

In view of the private and public components involved in the provision of medical services, I recommend an approach to enhancement that aims to harmonise these forms of access. This approach is consistent with the theory of prioritarianism discussed in chapter six, and furthermore is one that is largely tractable with the views expressed within the empirical study. Parfit (1997, p. 214) summarises the prioritarian position:

'If it is more important to benefit one of two people, because this person is worse off, it is irrelevant whether these people are in the same community, or are aware of each

other's existence. The greater urgency of benefiting this person does not depend on her relation to the other person, but only on her lower absolute level.'

According to this definition a prioritarian approach would be applicable to the socio-economic and political model of a country which has a mixture of both public and private healthcare provision, such as the UK (Freidson, 1970). A prioritarian approach to enhancement would have three advantages.

Firstly, it would protect the normative, needs-orientated integrity of conventional medicine in a way that was unanimously viewed as central to the ethical integrity of medicine by the study participants. Secondly, it would protect the 'negative liberty' rights (Berlin, 1969) that are highly valued in liberal societies (Hayek, 1960; Galston, 1999). Thirdly, it would in principle allow the subsidisation of or legal private access to certain enhancements if there were an equilibrium between: the benefit to the recipient when weighed against the risks; the available resources; and people whose health needs are greater or who would benefit more from using the enhancement instead.

A prioritarian system, whilst not eliminating *relative* inequality, could be used to reduce *absolute* inequality by providing enhancements according to need in the same way as conventional medicine. Thus, it is not necessarily the case that prioritarian inequalities would be unjust. They may be unjust, but injustice is not necessarily entailed simply by the presence of a relative inequality (Parfit, 1997; Arneson, 2000; Brown, 2007). Indeed prioritarianism may be harnessed to deliver the ends of justice, assuming that we have correctly identified the relevant needs and effectively calibrated a system of provision, distribution, and access to achieve this fairly. As Sandberg & Savulescu (2011, p. 104) have argued:

'A fair go entails that each person has a legitimate claim to some enhancement or medical intervention when that intervention provides that person with reasonable chance of reasonable extension of a reasonable life and / or a reasonable improvement in its quality...Enhancement would not necessarily result in injustice or

unfairness. If managed the right way, it could reduce natural inequality, injustice, and unfairness.'

Nevertheless the legalisation of products for enhancement use would have implications for justice that should be considered. Given a legal market in enhancement the benefits would inevitably accrue to those with the economic means to access them because, as Buchanan et al (2000, p. 340) observe, '*Markets enable the lucky, less vulnerable participants to detach their fortunes from their unlucky fellow citizens*': once an enhancement is made legal it would be impossible to prevent private access to it.

Even if attempts were made to prevent this the task would be impossible – no completely '*leak-proof*' (Fukuyama, 2002, p. 188) policy could be designed due to the scale and complexity of the task. The risk associated with this, raised in the study by C8 and S2, is an exacerbation of inequality between people who could derive a benefit from the enhancement and could afford to buy it, and people who could not or did not meet the criteria for receiving it via public subsidy.

This concern has been voiced particularly strongly in relation to the possibility of genetic enhancement in which there is a risk that a gulf may emerge between enhanced and unenhanced humans that cannot then be reversed (Shickle, 2000; Fukuyama, 2002; Kass, 2003; Koch, 2010). The permanent nature of these changes and the entrenchment of advantage that it would entail would be more damaging than, for example, the 'gap' between people who elect to have cosmetic plastic surgery and people who do not.

Indeed there is evidence in the study data concerning the rapid and widespread uptake of EPO within sport following its introduction to the market that these kinds of worries are not merely hypothetical but actual (C5, C7, S1, S4, S5). The thriving black market in EPO referred to by C3, C8, S2, and S9 lend support to the belief that a demand exists for enhancements which could be used by individuals for purely positional gain. Similarly C7, C8, and S9 were concerned about the possibility of inequitable policies being implemented as a result of the economic

pressure that the pharmaceutical industry could exert on policy makers in the event of a legal market in enhancements emerging.

These are all legitimate concerns. However it is important not to assume that any deleterious effects which could occur would necessarily do so because the enhancement itself is intrinsically ethically unacceptable. For example it is equally plausible that these effects could result from badly designed or poorly implemented policies. One should not infer from the fact that the provision of an enhancement may result in social injustice to the conclusion that if it did so it would necessarily be the enhancement that is responsible.

For example the study data indicate that it would, on balance, be unwise to widen access to EPO given its characteristics. Similarly however, if flu or measles vaccinations were only available privately this would be a problem because of an unjust model of distribution. If this was the case and the only people who caught flu or measles were those who could not afford the vaccination, this would be a failure of policy rather than the technology. If an enhancement is available that could be sufficiently beneficial, it is incumbent on policy makers to ensure it is managed appropriately and used to maximum benefit.

7.6.2) Enhancement's Relation to Medicine: Two Interpretations

The approach to enhancement that I have developed requires an ongoing reappraisal of the correspondence between the ethical principles of medicine and its actual practices in order to ensure that the optimum satisfaction of needs relative to resources is achieved. Despite providing greater flexibility than the conventional model in deciding who may or may not receive assistance, any decision to allow and provide enhancement may lend some immediacy to concerns about the drive to '*expand the category of illness*' (Fox, 1977, p. 18) and the subsequent '*medicalisation*' of normality (Illich, 1976; Conrad, 1982) mentioned earlier. Any institutional reconfiguration to allow or provide enhancements as a matter of course would imply a relaxation of what medicine legitimately may do, and would therefore imply one of two possible interpretations:

- 1) The boundary of 'therapy' itself is being moved to include 'enhancements' such that the latter are tacitly recast as the former.
- 2) A distinction is still made between 'therapy' and 'enhancement' by appeal to a norm of health, but it is accepted that medical assistance may reasonably go beyond therapy.

This difference between these is subtle, but significant. On the first reading, 'therapy' is recast to include certain states currently considered normal. Here states presently considered normal are medicalised, because interventions that were previously understood as conferring supra-normality would be brought under the auspices of conventional practice. A possible outcome of this, as Conrad & Potter (2004, p. 200) point out, is that it would constitute a *de facto* reclassification of health as deficiency in which '*a wide range of conditions or behaviours can be defined as a medical problem, as some kind of disorder in need of treatment*'.

Moreover, if Fukuyama (2002), Kass (2003), Sandel (2004), and Koch (2010) are right that perceived deficiency implies the normative assumption that such states should be rectified, then to recast the definition in this way may inhibit '*sympathies that an openness to the unbidden can cultivate*' (Sandel, 2004, p. 6) by recasting states that do not require improvement as abnormal. Concerns related to this emerged in the study, for example in C8's worry about '*the protection that would be available to people*' in an enhancement market. Given that a private market in enhancement would be commercially driven he was critical of sanctioning policies in which '*preying on the weak*' by the manufacturers of enhancements would be legally permitted.

On the second interpretation, a distinction would still be made between therapy and enhancement, and as such adherence to a present norm would persist. The departure here would be that in legalising access to enhancements, an admission would be made that it is reasonable for medical professionals to provide them. In this respect a concession would be made to the arguments of Bostrom & Roache

(2008), Harris (2009), Scripko (2009), Sandberg & Savulescu (2011) that the conferral of supra-normality can be a legitimate practice of medicine. This would be significant, since it would broaden the remit of medicine beyond its conventional boundaries. Here again, however, some conditional acceptance was evident within the study from S2, S3, S6, C9, C11, assuming that the circumstances were appropriate and that it would be safe to do so.

Policy responses would differ according to which of these two interpretations we favour. Assuming the UK's model of healthcare provision we would be considering circumstances where some people pay privately for medical care, but in which universal healthcare is also freely available for all. According to the first interpretation, the legalisation and inclusion of certain enhancements under the banner of therapy would necessarily entail some degree of subsidisation. On the second interpretation no subsidisation of enhancements would follow inevitably, since as the existing threshold of normality is still being adhered to as the trigger for medical assistance, it would not *prima facie* be incumbent on the state to provide them. It may, however, follow secondarily from this model that some subsidisation would be necessary.

An example of this widely referred to in the literature that I have already mentioned is the potential expansion of cognitive enhancements (Chaterjee, 2004; Greely et al, 2008; Wasson, 2011). If the arguments of Greely et al (2008), Bostrom & Roache (2008) are correct that cognitive enhancers, unlike EPO, could be widely beneficial, providing non-positional goods in a way that the exclusively positional benefits of EPO use in sport largely do not, then a case for subsidisation may present itself on two counts.

Firstly, it would be necessary in the interests of justice to offset the advantages accruing to those who can afford to access the products privately. Secondly, if the benefits that they offer for people at the lower end of the normal range of cognitive ability were great enough, their subsidisation would be justifiable under certain circumstances despite their being considered extra-therapeutic (Sandberg & Savulescu, 2011; Housden et al, 2011).

7.6.3) *Consequences of Legalisation*

Whether a) a distinction is maintained between therapy and enhancement by adherence to a norm; or b) (some) enhancements are recast as interventions that are sufficiently consistent with the goals of medicine that a doctor may provide them, the consequences for any legalisation of access are significant in each case. According to both interpretations the codification of enhancement in law and policy would change the parameters of medical decision making.

If a move were made toward the legalisation of some enhancements, then on the first model it would be necessary for medical training and education to be altered (Pellegrino, 2004; Drabiak-Syed, 2011). The biomedical model, which acts as a heuristic for treatment at present, nominally excludes 'normal health' from those states considered in need of assistance. Thus, were any enhancements to be brought under the auspices of medicine, relevant re-categorisations would have to be reflected in the training of medical professionals and the '*evolving role of physicians*' (Chatterjee, 2004, p. 972).

On the second interpretation changes to training would also be required, although the form of these may be different. According to this view the therapy / enhancement distinction is maintained, with enhancements being privately legally available, but not typically provided under conventional healthcare. Thus, training would have to reflect the fact that some people may seek enhancement (in a similar way to those who seek cosmetic surgery, for example), and therefore that the private provision of such an extra-therapeutic private service is a potential career option.

The second model in particular is worth investigating further. A suggestion put forward within the enhancement literature by Pellegrino (2004), Chatterjee (2004), and Goffete (2006) is that a potential response to enhancements may be the establishment of a parallel service providing 'enhancement medicine' alongside its conventional practices. This would be analogous in some ways to cosmetic surgery at present.

7.6.4) *'Enhancement Medicine' as a Parallel Institution?*

This idea was explored by C6 and S6. The justification for a parallel institution was grounded in a position expressed by S6 in his claim that *'we're not ethically trained to do that'*. This is revealing, since it implies the view that enhancement medicine would be different in its values from that of medical practice at present. Similarly, C8's anomalous claim that enhancement has *'almost no connection at all'* to medicine is contrary to the claim that there is an intrinsic continuity between the two. Thus, one potential response to a widespread demand for enhancement would be to design an explicitly different kind of institution such that the structural integrity of conventional medicine and its treatment criteria remain intact.

Parens (1998) warn of a scenario in which private enhancement practitioners or *'schmoctors'* provide extra therapeutic medical assistance for profit rather than egalitarian or prioritarian motivations. Pellegrino (2004, p. 2) makes a similar warning that this scenario is likely because within private medicine - unlike the trenchantly pro-NHS motivations expressed by the participants in this study - *'Enhancement will also appeal to the physician's self-interest'*. Moreover the inevitability of a parallel private market in enhancements may mean that the governance situation is more complex than simply applying a prioritarian model of resource allocation. Given the local context of the UK in which the majority of healthcare provision is publicly-funded and therefore rationed, the *'counterweight'* (Buchanan et al, 2000) of the state would be needed to prevent these kinds of scenarios from occurring or limit their impact.

One might ask whether the fact that enhancements could be socially beneficial is a good enough reason by itself for creating the conditions in which such a market could thrive alongside their public subsidisation, or whether the possibilities for justice are too high a price to pay. Several responses are available. None of them guarantee the prevention of negative consequences; however they outline respects in which worries may be overstated or misplaced.

Firstly, assuming we judge decisions about legalisation on a case by case basis and employ the appropriate calculus of safety, risks, benefits, and justice, these decisions need not be undesirable. The possibility persists, but this would depend on the kind of enhancement being considered rather than the fact that it is an enhancement as such (Bostrom & Sandberg, 2009; Scripko, 2010; Sandberg & Savulescu, 2011)

In order to maximise the potential benefits and prevent the exacerbation of inequalities between those who could pay for them privately from '*disengaged purveyors of quality of life elixirs*' (Chaterjee, 2004, p. 972) and those who could not, subsidisation in certain cases would be necessary even if these interventions were understood as existing beyond the boundaries of conventional medical practice. Consequently it would be difficult to implement this policy unless medical professionals were to accept that some enhancements may be routinely available. According to my data this policy would presently be resisted, and it would be a matter for further investigation to discover whether this view is held more widely.

Given that all of the participants interviewed were medical professionals practising within the NHS in the UK, their professional orientation must follow the model and decision making criteria used within that context. If it is true for a doctor working exclusively within the NHS to say '*we're not ethically trained for that*', it may be that medicine is not institutionally prepared to sanction the legalisation and provision of enhancements, and the challenges that this would entail. Consequently, even if one accepts the pro-enhancement arguments that call for the inclusion of enhancements within the calculus of medical resource allocation, the reorientation and institutional changes required would take considerable time and effort.

In view of the reluctance displayed amongst the study participants the establishment of a parallel service of enhancement medicine is one way in which a proliferation in enhancement technologies could be managed, despite the criticism levelled at this kind of service by Parens (1998), Pellegrino (2004), and Chaterjee (2004). According to the study data it is one that may on balance be preferable to medical professionals currently working within a framework such as the NHS than

the inclusion of enhancements within this framework. In the longer term, however, if enhancements were to emerge that could confer widespread benefits and one were serious about harnessing them to these ends, purely private availability would be untenable.

A reason why the complete separation of 'therapy' from 'enhancement' would be untenable in the longer term if enhancement were to proliferate relates to a) changes in medical ethical norms and b) advances in medical technology. For example, Bostrom & Sandberg (2009, p. 332) argue that increasing autonomy will go hand-in-hand with a growing ability to personalise medicine as medical knowledge and technology improve. They therefore predict a re-orientation of medical care towards a model of health maintenance and improvement rather than remediation because:

'Preventative and enhancing medicine are often inseparable, and both will likely be promoted by these changes'.

If people continue to live more healthily for longer, this will inevitably re-shape medical care in such a way that some 'enhancements' are available to everybody because a personalised approach *would become* the standard.

We do not know the extent to which this might occur; however it is one scenario in which the kind of internal reorientation of medicine that I propose might occur naturally and gradually in a way that also reflects changing social norms, rather than one which is forced through by policy. In this respect it is clear that the ethical and policy debate has broader implications for justice in society that extend beyond an internal re-examination of the relation between enhancement and appropriate medical practice. I will now consider some of these social implications.

7.7) Enhancement and Social Justice

If an enhancement were to be legalised it would be impossible to prevent private access to it. Consequently we might prefer to decide against legalisation, particularly in the case of powerful enhancements, on the basis that it would carry

too great a risk of the most economically fortunate to increase the positional advantage over others. Would it be acceptable that an already privileged few could become better off than before? Since a private market in enhancements will follow from their legalisation, how is their use to be controlled and restricted to 'genuine' cases alone?

One way of approaching this is to consider what tools society already employs and governs via policy to improve humans from their 'natural' state. One example is literacy (Maddox, 2008; Bostrom & Roache, 2008; Bostrom & Sandberg, 2009), which is not only considered desirable both intrinsically and positionally, but is also an ability that one is legally obliged to acquire. In this respect the enforcement of education can be viewed as state coercion, although it is acceptable in view of the scale of its benefits (Bostrom & Sandberg, 2009, p. 331):

'For literacy, the enforcement is both direct, in the form of mandatory basic education, and indirect, in the form of severe social penalties for failure to acquire reading and writing skills...Despite these enormous and partially coercive pressures, and despite the fact that literacy profoundly changes the way the brain processes language...literacy is not deemed to be problematic.'

Despite socio-economic inequalities in the standard and supply of education, its mandatory provision is preferable to no education or to it being non-obligatory. This is because, as Maddox (2008, p. 191) notes, the capabilities that it provides are *'future oriented'*, and in general anybody for anybody who becomes literate this *'enhances their wider freedoms and agency'*. If acquiring literacy is beneficial because of the advantages that follow from it, then under a wide conception of enhancement, individual enhancements need not be unjust. Rather, decisions about whether an enhancement would be socially desirable must consider many variables.

Irrespective of technological classification, decisions about legality and availability should also be broadly congruent with society's wishes and norms²⁸. Fundamental changes to medical provision should not be permitted without this kind of mandate. As C2 stated, *'for progress you need enhancements'*, but negotiation is necessary to ensure that medical assistance reflects the values that society wishes to uphold because *'we should do it in a way which is responsible and which doesn't have any adverse effects on that individual or to the society'*.

Although it is true that healthcare practices are institutionally defined, C1 pointed out that *'medicine operates within society...what we do as doctors or healthcare professionals is influenced by what society deems to be acceptable and appropriate'*. Hence to the extent that this claim properly represents the relationship between medicine and society, the institutional practices of the former cannot be completely evaluatively distinct from the latter.

The example of literacy shows that an intervention may be so widely beneficial that it is in a society's interests to legislate *for* it. It is a contingent matter as to whether or not interventions are medical in nature. Literacy is an enhancement of cognition that is not medical in nature, but it does contribute substantially to our social welfare arrangements. By contrast, vaccination is a service that is medical in nature but this too overlaps with social welfare because as Dawson (2011) points out, it provides a significant public good in limiting or eradicating disease. Whether we describe it as enhancement or a therapy is irrelevant – its utility overrides these issues. Thus, if other technologies were to emerge that are medical in nature and similarly or more beneficial in terms of social justice, there would be good reasons to legalise these as well.

The pharmaceutical industry and Parens' *'schmoctors'* are potential concerns, because their primary concern will be profit rather than meeting severe health needs or working towards widespread public health benefits. Indeed concerns over the primary motivation of the pharmaceutical industry appeared regularly in

²⁸ *Notwithstanding hypothetical instances in which it may be rational to refuse to mandate something irrespective of its popularity, for example a highly addictive and dangerous drug.*

the study data. The appropriate response to this concern, however, is to recommend that enhancements are not assumed to be homogenous, of marginal utility, or necessarily for positional advantage alone such that they should be excluded from decisions about subsidisation. The study data indicate that EPO is, ultimately, unlikely to satisfy these conditions. However this is only true of EPO. Other potential enhancement products should be taken seriously and analysed to determine whether they could be harnessed to provide a net benefit to society, and thus whether they are better candidates for legalisation and subsidisation.

Given this analysis, I argue that a rational approach to an enhancement technology would be to pose the question 'are there things we can do to benefit society and enhance the healthy living of its members?'. If the answer is yes then its inclusion under policy should be considered, irrespective of whether it is presently understood as a therapy or an enhancement, and thus nominally interior or exterior to the boundaries of medical practice. Medicine is part of society and not isolated from it. It is an institution that everybody has to use and as such should reflect society's values. The porous boundary between medicine and welfare / public health is particularly relevant to enhancement because this must be brought into any calculus about what forms of medical assistance should be legal and on what terms.

7.8) Situating the Model and Balancing Logical Ambiguity with Practical Value

Various theoretical positions found in the literature reflect aspects of my data in different ways. For example Juengst (1997), Lin & Allhoff (2008), and Scripko (2010) argue that enhancement and therapy are continuous to the extent that some of the goals of the former are served by the latter. Some recognition of this view was evident within my data in relation to discussions of borderline enhancements such as beta-blockers and cosmetic plastic surgery (C3, S11, S9).

Similarly C2 stated directly that enhancements are essential for progress, and identified his smartphone as a '*proper enhancement*'. In doing so he offered

opinions redolent of transhumanist views concerning the indispensability of technological enhancement to human life (Bostrom, 2005; Harris, 2009; More, 2013), and the symbiotic integration of mankind with his innovations (Clark & Chalmers, 1998; Clark, 2004; Kurzweil, 2005).

Undoubtedly there are other similarities to be found, however some are more relevant than others in terms of providing orientation towards to the specific aims of this thesis. In this thesis I have attempted to put forward ethical conclusions that are not only theoretically significant but also practical and applicable. For this reason it is not necessary to situate the conclusions exhaustively within the whole of the literature. I have identified four theoretical positions which reflect the conclusions that I have arrived at and the approach to enhancement that I recommend. The location can be summarised as the intersection of four quotes - from John Harris, Norman Daniels, Nils Holtug, and Germund Hesslow.

I conclude that the therapy / enhancement distinction is, ultimately, of only limited utility, since it is logically ambiguous and the categorisations of the relative health of different states may fluctuate, given the likelihood of ongoing changes in health norms (Hare, 1986; Shickle, 2000; Boyd, 2000; Stempsey, 2006; Bostrom & Sandberg, 2009; Bess, 2010; Serna, 2012) (S2, S11, C2, C11).

I argue that 'enhancements' can have morally acceptable, beneficial uses insofar as they would improve health and / or functioning; however a condition on this must be imposed. Given the primacy of assisting people whose health needs are greater, a condition of ethical acceptability of enhancements is that this does not divert medical resources away from being able to meet those needs successfully (Pellegrino, 2004; Allhoff, 2005; Brownsword, 2012), (C9, C11, C12, S2, S3, S6, S9).

Despite recognition of this by the study participants, a practical ethical commitment to providing medical assistance according to need overrode any logical consequences entailed by the logical weakness of the therapy / enhancement distinction. However as I have argued, it is possible to uphold the fair allocation of limited resources by reference to need alone, without relying on the

therapy / enhancement distinction too heavily as an arbiter of distributive justice. I therefore concur with Harris' (2009, p. 154) argument that:

'The overwhelming moral imperative for both therapy and enhancement is to prevent harm and confer benefit. Bathed in that moral light, it is unimportant whether the protection or benefit conferred is classified as enhancement or improvement, protection or therapy.'

Despite this the therapy / enhancement distinction is a useful, though limited, heuristic for practical purposes of justice. The distinction implies a hierarchy of needs that can be prioritised such that the available resources can be 'titrated' (S2) in a way that favours those whose needs are most urgent or severe. Therefore, as long as not too much is expected of the distinction and its logical vulnerability is kept in mind, some conditional institutional retention of the hierarchy represented by the distinction is desirable. Consequently I suggest that an appropriate balance with my data is also reflected in Norman Daniels' (2000, p. 309) analysis of the therapy / enhancement distinction:

'...the treatment-enhancement distinction by itself does not specify the boundary between obligatory and nonobligatory medical services. Some obligations derive from considerations beyond the primary rationale, and the primary rationale includes a respect for reasonable resource constraints.'

A flexible approach focusing squarely on need *qua* need which does not automatically exclude an enhancement from policy consideration simply because it is an enhancement has two advantages. It enables medical professionals to retain their commitment to prioritising assistance to those with the greatest health needs. It also sanctions access to certain enhancements in principle if the benefits that this would confer were sufficiently great and the resources were available. The implication of such an approach is that decisions to legalise or subsidise enhancements should only be made once greater needs have been met. This is reflective of the argument that Holtug (1999, p. 143) makes in relation to genetic enhancements:

'...justice sometimes gives us a pro tanto reason for making genetic enhancements available; however...justice generally gives us stronger reasons to perform other tasks such as providing treatments for people with severe diseases...'

Nevertheless assuming that this condition can be met, by reducing the emphasis on whether or not assistance treats disease or illness for the reasons I have given, the view I take is similar to Hesslow's (1993, p. 7) theory of health. Recognising the relativity of health concepts he recommends placing greater emphasis on whether it is possible to safely assist and confer benefits, rather than whether a state of 'ill-health' as such is the object of assistance:

'...disease is so frequently associated with demand for treatment...that it is generally practical to use the disease label as a justification for medical intervention. I have no quarrel with this everyday usage of the term "disease", but we must not let it mislead us into thinking that it is having a disease per se that is crucial rather than the potential benefits of treatment...'

The key condition that would have to be observed in order for the recommended approach to work would be regular re-assessment of whether the balance between needs and resources was being met optimally at all times. This re-assessment would not necessarily exclude the possibility of assistance on the basis that its recipients are receiving an 'enhancement' rather than a therapy, however, because according to the revised model it would be recognised that norms of health fluctuate and categorisations may not remain static. What would be of greater importance is whether, when balanced against other morally relevant factors, it is possible to assist someone safely in a way that does not disadvantage others.

7.9) Contributions of Critical Realism to Empirical Bioethics

A persistent issue of controversy in moral philosophy is whether ethical judgements are true in the sense that they genuinely show that someone else ought to do X; or whether such judgements are merely perspectival, only relatively true to individuals, and closer in nature to rhetoric (Archer, 1998) or expressions of taste (Hartun, 1954). Expressed in simpler terms, Toulmin (1960) explains this

in pointing out that the fact that I like to eat a cream bun provides no compelling reason for you to eat one as well – it merely provides information about a preference.

The controversy is acutely controversial when moral reasoning is based on empirical data, since a diverse variety of contextually-bound moral viewpoints strongly indicate a plurality of ethical norms (Evans-Pritchard, 1951; Marshall, 1992; Kleinman, 1999) rather than a single ethical norm about which there can be no disagreement. An observation that moral norms are plural, however, is not especially helpful if practical ethical solutions are sought. Irrespective of the presence of a spread of opinions it is not possible to advocate one particular response or course of action unless we have some set of values according to which that response can be rationally defended.

This tension is brought sharply into focus in empirical bioethics. On one hand, insofar as bioethics is a sub-category of moral philosophy it attempts to produce conclusions that are normatively compelling. This is to say that it must be able to provide a non-relative justification for why someone should act in a particular way (Archer, 1998; Southwood, 2008; Kolodny, 2008; Harris, 2012). On the other hand, the descriptive and interpretive nature of social science research emphasise the relativity and context-bounded nature of truth claims.

If truth claims really are relative (Berger & Luckmann, 1966; Von Glasersfeld, 1990) then the kinds of rational normative arguments developed using this approach cannot be action-guiding in the way that they claim to be. For ethical analysis to have any value it must be able to go beyond the description of individual moral viewpoints and show in non-relative terms whether they are true or false, or as Railton (1986, p. 165) explains, it must demonstrate:

'...that moral judgments can bear truth values in a fundamentally non-epistemic sense of truth; that moral properties are objective, though relational; that moral properties supervene upon natural properties...'

Since the aim of ethical analysis is to enable moral progress, it is incumbent on any philosophically driven analysis such as this to show how progress could be possible. In this respect critical realism is valuable because it provides the means for discerning between better and worse justifications for a claim, statement, or belief. We can again recall Hare's quote (1986) concerning the rationality of seeking assistance from an ophthalmologist in the event that he develops 'bad' eyesight in support of this: if one's eyesight limits one's abilities there is a good reason for seeking to improve it.

This is redolent of Sayer's (1997) stepwise account of critical realist ethical analysis in which he shows that the presence of a need entails the judgement that, all other things being equal, it is reasonable to seek to meet that need. The entailment is grounded in the recognition that, were it I who was in need rather than someone else, it would be rational, all other things being equal, for me to do the same. Whether or not assistance in fact should be granted would depend on whether meeting the need would produce deleterious effects for others, and in the event that it would assistance can be denied.

The critical realist position holds that the ontology of the world imposes physical limitations on our abilities. It is not disputable, for example, whether I would float or fall to the ground if I were to jump out of a window (Easton, 2010). Similarly in relation to Hare's position (1986), if I cannot see clearly because of the physiology of my eye there can be no disagreement about whether or not this is the case. Whether or not the ability to see clearly is categorised as a fault, a variation of normality, or a disease, is an epistemically relative matter. What is not relative is the fact that the physiology of my eye affects the clarity of my vision. Critical realism makes this difference clear, and in doing so grounds the basis for our ethical judgements explicitly in ontological states of affairs rather than in contestable epistemic categories (Bhaskar, 1993; Sayer, 1997; Archer, 1998).

If a need is present which can be met via medical assistance then how we categorise this need is not of primary ethical relevance, even if I have 'normal' eyesight and wish to have it 'enhanced'. In chapter six I gave an example of critical

realist analysis being used to show when epistemological accounts of the relative 'naturalness' of EPO and other technologies were used as a basis for drawing misleading moral distinctions. As the analysis showed, although the views of the participants was understandable, it became clear that the differences in 'naturalness' were not objective ontological differences that were apprehended, but subjectively epistemic categorisations that had been imposed on the world.

The significance of this for applied ethics research is that it makes explicit what there is in virtue of which discourse, argument, disagreement, and knowledge is possible and applicable. The critical realist analytic approach adopted in chapter six showed how knowledge is constituted by both inductively and deductively derived sources of information. In this way critical realism vindicates the ability of logical analysis to yield the kinds of non-relative truths necessary for the justification of normative conclusions, whilst also giving an account of the physical world that is not reducible to my perceptions of it and thus not beyond rational scrutiny by others.

It is this which enables us to circumvent the conventional, contingent, and changing epistemological categories of 'therapy' and 'enhancement' and ground a defence of the ethical allocation of resources in ontological characteristics of the world. These characteristics are, as I have argued, whether a need can be met via medical assistance, and whether to do so is safe, equitable, and does not cause injustice to others.

7.10) Limitations of the Investigation

7.10.1) Scope of Study

The first limitation relates to the scope of the empirical study. The data on which the philosophical and ethical analyses are based derive from two small groups of

medical specialists commenting on enhancement in the context of just one product. Concerns about the generalisability of the findings may therefore be valid²⁹.

Due to the constraints bearing on the project, it was only possible to carry out a limited empirical study with the aim of advancing conclusions that can be generalised analytically, rather than statistically. Furthermore all of the participants were employees of the NHS and consequently the data represent only the views of professionals who have chosen to work in state-funded rather than private medicine. Given the issues relating to justice and the market raised over chapters six and seven in particular it would be useful to investigate the views of professionals who have chosen to work privately. In order to find out whether the views expressed in this study were themselves representative of the field or anomalous, further large scale studies would need to be carried out.

Having said this, my aim in this project has been primarily a philosophical one. It was motivated by a conceptual ambiguity, and the aim was therefore not to report what medical professionals think about enhancement with any claims as to the generality of these views. The purpose was to deepen our understanding of the concept of human enhancement, and to use the data as contextually informed information that could refine theory. The data were used as a point of departure for conceptual analysis, rather than for the development of a general theory about medical professional understanding of the therapy / enhancement distinction.

7.10.2) Heuristic Judgement

Despite the advantages of the refined account of therapy and enhancement that I have advanced, it is vulnerable in certain respects and so does not solve all potential difficulties relating to the distinction. The most significant of these is that it is a heuristic for medical decision making, i.e. a 'rule of thumb', rather than a theoretically infallible method for doing so. In this respect it shares a weakness with the heuristic that has been the target for analysis and revision in this thesis. This is the conventional reading of the distinction which holds that the two

²⁹ *Although the use of critical realism as the philosophical methodology offsets some of the limitations of the study, for the reasons previously given.*

concepts can be clearly identified because one restores normality and the other confers supra-normality.

The standard therapy / enhancement distinction is, as indicated in chapter one, itself a heuristic for medical decision making. In extreme cases it is effective, for example with respect to a cancer patient receiving chemotherapy compared to an athlete receiving EPO. It is far less effective in more borderline cases, however, for example someone seeking cosmetic plastic surgery or beta-blockers in the absence of disease. This is because in more borderline cases a persuasive argument can be made to show that it is either a therapy or an enhancement.

The primary aim of this thesis was to clarify the relationship between therapy and enhancement and find a way to circumvent the difficulties associated with having to use heuristics. In one respect the approach I recommend is partially, but significantly, successful. According to the new model that I have developed it is not important whether an intervention is 'therapeutic' or 'enhances'. This is because, following a critical analysis, we have been able to separate the objective ontological character of needs from the subjective epistemological categorisation of those needs.

According to my approach a bodily state need not be categorised as 'healthy' or 'ill' in order to be recognised as being a need for which, assuming an equilibrium of other ethically relevant factors, it would be reasonable to grant assistance. The advantage of this is that it does not rely too heavily on fluctuating conceptions of health, and instead emphasises characteristics of health which are objective and mind-independent, for example an observation as to whether person X can perform activity Y. Despite these advantages, however, although it resolves the heuristic that it was intended to resolve, it simultaneously replaces it with another. The new heuristic relates to making contestable 'rule of thumb' judgements about the ethically relevant supervening factors which would weigh in favour or against the use of a particular enhancement.

For example, according to the new model it will be permissible to allow or provide an enhancement if a) it is safe to do so; and b) to do so would not produce any net deleterious effects by diverting resources away from someone whose needs are greater. Predicting the accuracy of a judgement made about these two conditions will always involve some degree of uncertainty. We cannot know exactly what the risk will be of using a medical product, and a decision would be made on the probability that the benefits will outweigh those risks.

Similarly, given that it is impossible to identify and factor in every socio-economic variable affected by a decision to provide medical assistance, the decision that it would be acceptable to permit enhancement in a particular case would inevitably rest on a judgement that it would produce no deleterious effects on others, but only to the extent that relevant variables can be used and weighed. Given also that effective enhancement is a new phenomenon, the predictions that one can make about the long-term social and medical effects of an expansion in enhancement technology might have are very limited.

Viewed from this perspective the model that I have developed and defended cannot completely escape the possibility that it is vulnerable to error in ethical decision making. Insofar as it employs a heuristic there will always be borderline cases where the acceptability of a judgement may be contested on the basis that certain outcomes will be unpredictable and different individuals may weigh the various morally relevant factors which come to bear on a decision in different ways. There may, indeed, be controversy regarding how different kinds of need are to be weighed against each other in order to ascertain whose needs are more acute.

Despite this heuristic weakness and the potential source of error that it entails for ethical decision making, however, I suggest that it nevertheless represents an advantage over the conventional understanding of the therapy / enhancement distinction. This is because the heuristic employed in the conventional distinction will be too inflexible to cope if advances in medical technology accelerate significantly. The decision to provide medical assistance turns on the identification

of a norm of health of one kind or another – this could be a norm in statistical, social, or experiential terms or any variant or combination of these.

The distinction is only meaningful and effective for medical decision making to the extent that the norm is static, however. The more rapidly norms change, or the more diverse they become, the less useful the distinction will be in distinguishing between whose functioning is sufficiently ‘abnormal’ or ‘dysfunctional’ that assistance should be granted. If human enhancement technologies cause a significant enough diversification in health norms, or if they are sufficiently effective that they generate new norms at an increasingly fast rate, they will reduce the utility that the conventional ‘therapy / enhancement distinction’ has for underpinning decisions about the allocation of medical resources.

Consequently, although the refined account developed here employs a different heuristic, in reducing reliance on the epistemological categories of ‘therapy’ and ‘enhancement’ and instead emphasising the objective ontological character of needs it is better equipped to deal with a rapidly changing technological environment. For this reason I argue that the weakness associated with the new model is a price worth paying because to the extent that it is explicitly needs-based my approach is consistent with a crucial ethical feature of conventional medical practice. Furthermore it shows how enhancement could be employed to deliver, rather than inhibit, wider ends of justice in society. For this reason it also effective in anticipating the potential changes that expansion in human enhancement technologies may produce in future.

7.11) An Avenue for Future Research: Enhancement and Public Health

EPO has a narrow and well defined range of enhancement uses which are only likely to appeal or be beneficial to a marginal community of professional athletes. Moreover since its enhancement use in this context offers only a positional advantage, the risk of its performance benefits being unethically exploited is high.

However there may be products with enhancement potential that offer benefits which are a) much wider in scale across a population, and b) intrinsic, or valuable

for their own sake, rather than just positional. The enhancement application of certain drugs to improve cognition may be one example (Sandberg & Savulescu, 2011), and vaccination is a clear example of another (Dawson, 2011).

Vaccination can be legitimately construed as an enhancement, since it boosts species-typical immunological resistance to illness caused by exposure to a pathogen: without it the threat would be greater (Juengst, 1997; Bostrom, 2008). It can of course equally be argued that it is a therapy, since it very clearly prevents harm (Holm & McNamee, 2010; Dawson, 2011), hence its present inclusion within a range of standard medical services. Vaccinations can offer widespread intrinsic public health benefits. If it is the case that vaccinations can be understood as an intrinsic good rather than a positional one, then perhaps its (relatively) unproblematic medical legitimacy is connected to its public utility³⁰.

Following this we may ask whether there are analogous cases within the present debate about enhancement. If, for example, it is true that the enhancement of cognition would be widely beneficial because of the intrinsic and non-relative benefits that it confers (Bostrom & Roache, 2008; Harris, 2009; Sandberg & Savulescu, 2011) in the same way that it is intrinsically beneficial to receive an enhancement of one's normal immune response in order to prevent illness, then a comparison with vaccination may be valid. Thus, if the comparison between the two holds sufficiently strongly, we can make the tentative hypothesis that the provision of or access to certain enhancements (which may in principle be cognitive, physical, or genetic) may be considered a legitimate goal of public health, given an appropriate balance between benefit, cost, safety, and justice in access.

To take this one step further, I advance a similarly tentative but more general hypothesis that a medical intervention's status as a therapy or an enhancement becomes irrelevant beyond a certain threshold of public health utility. Certainly in the case of vaccination it can be argued that once the benefits on offer are sufficiently widespread, medicine can institutionally co-opt it without difficulty

³⁰ *Notwithstanding debates over the safety of certain vaccines, e.g. the alleged but disproven connection between autism and the MMR vaccine.*

even if it can be legitimately understood as an enhancement, because its positive impact on health and ability to reduce suffering is so large.

This study and its tentative recommendations about the conditions under which the legalisation of enhancements could be socially beneficial may be useful as a starting point for a fuller investigation. Such an investigation would inevitably need to consider questions of distributive justice if the intrinsic or positional nature of enhancement use has a bearing on whether particular interventions can be judged as ethically acceptable. EPO identifies itself as something which offers very little in terms of public health benefit when used as an enhancement. This assists, however, in clarifying what characteristics a product should have to be considered seriously in terms of enhancements that may be beneficial to public health. Given the scale of importance of public health medicine, moreover, such an investigation may be needed and justifiable.

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APPENDIX A: FMDCE RESEARCH APPROVAL LETTER



Faculty of Medicine and Dentistry

Committee for Ethics (FCE)

University of Bristol Faculty of Medicine & Dentistry,

First Floor South, Senate House,

Tyndall Avenue, Bristol

BS8 1TH

Tel: 0117 331 8197

Mr Alex McKeown

University of Bristol

20th December, 2011

Dear Alex,

Application number: 111208

Title: 'An investigation into how the concept of 'enhancement' is understood by clinicians, medical researchers and engineers'

Your application has been granted **full approval** and you may commence your study.

The FCE expects to be notified of any significant deviations from this research proposal. The FCE also expects to be notified of any unforeseen ethical events which may arise during the course of this study.

On completion of this study the FCE and the peer reviewers would like to see a report of the outcome.

Yours faithfully,

David Jessop

Chair, Faculty of Medicine and Dentistry Committee for Ethics

APPENDIX B: PARTICIPANT CONSENT FORM

Participant ID:

Consent Form

'An investigation into how the concept of 'enhancement' is understood by clinicians, medical researchers and engineers'

Researcher: Alex McKeown

Please initial box

- 1. I confirm that I have read and understood the information sheet datedfor the above study and have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

- 3. I understand that some things I say may be quoted word-for-word in publications or at academic conferences but that my identity will be withheld.

- 4. I agree for the interview to be audio-recorded.

- 5. I agree to take part in the above study.

Participant Date Signature

Person obtaining consent Date Signature

APPENDIX C: PARTICIPANT INFORMATION SHEET

Date:

ALEX McKEOWN

'An investigation into how the concept of 'enhancement' is understood by clinicians, medical researchers and engineers'

INFORMATION SHEET

About the Researcher

My name is Alex McKeown. I am a PhD student at the Centre for Ethics in Medicine at the University of Bristol, in the School of Social and Community Medicine, although I am actually based in London. I am supervised by Professor Ruud ter Meulen and Dr. Helen Lambert. This study has been reviewed and approved by the Faculty of Medicine and Dentistry Ethics Committee at the University of Bristol.

Invitation

I am inviting you to take part in a research study which will form a part of my PhD thesis. Please take time to read the information contained here carefully before you decide whether to agree to take part. The information here will help you to understand why this research is being carried out and what your participation would involve. If you have any questions, please feel free to get in touch with me via the details on this form.

The study in which I am inviting you to participate aims to understand how clinicians, and medical researchers and engineers understand the concept of 'human enhancement'. I am asking these questions because of the emergence of controversial questions surrounding the use of medical technologies for purposes beyond the purely medical or therapeutic. This field is relatively new and advancing quickly. Further investigation is required in order to understand the concept of human enhancement itself, and how we should manage these technologies as they continue to develop and advance.

Before you decide if you would like to take part, please read this information so that you understand what is involved and why the study is being done.

Why have I been invited?

I have invited you to take part in an interview for this research study because your work involves the use of a medical product (Erythropoietin) which, in other contexts, is sometimes used 'off-label' for 'enhancement' purposes. I would like to hear your opinions on human enhancement, health, and medicine and the conceptual and ethical questions raised by them. I am seeking your independent view as a medical professional with knowledge in this field of medicine, and not necessarily as an employee of the NHS. For this study I will be interviewing between 20 and 30 participants in total.

Do I have to take part?

You do not have to participate in this study if you don't want to – it is entirely up to you. After reading this sheet I hope you will have enough information to decide whether or not you would like to participate.

If you decide that you would like to participate, I will ask you to sign a consent form to show that you have agreed to take part in an interview. I will then give you a copy of the consent form. You need to sign the consent form and return it to me if you wish to take part, however you are free to change your mind after you have signed the form and can withdraw from the study at any point if you wish. You will not have to provide any reason for this if you choose not to. If you do withdraw, any information that you have already provided will be destroyed.

After the interview I will ask if you are happy for your response to be included in the research project. At this point I will ask you if you would like to read over what you have said once the interview has been typed up.

What will happen if I take part?

I will talk to you about your understanding of human enhancement in relation to medical products developed for clinical or therapeutic purposes. I will also ask you about your views and opinions of human enhancement more widely, and of developments in medicine that may make it possible to enhance human in the future. The information that you provide will be used for my research and will be included in my PhD thesis. Any information that you provide will be anonymised before any public use – whether in my thesis, in academic journals, or when presented at conferences.

If you agree to participate, the interview will be digitally recorded and then typed up. Your name will not appear on the recording or on the typed copy of the interview of the interview. You may refuse to answer any questions put to you, and you can end the interview at any point if you wish. The interview is likely to last between 30 and 60 minutes. It can be held anywhere that is convenient for you.

What are the possible benefits / disadvantages of taking part?

The benefit of your participation is that you will be helping a study whose goal is to improve our understanding of human enhancement and its implications. The possibility of human enhancement raises many ethical questions, and the information that you give will help to provide a framework for the better understanding and resolution of these questions.

At the end of the interview I will ask you if you would like to receive a summary of the results of the study when it is completed. I do not anticipate that there will be any disadvantages to participating in the study.

Will my taking part in this study be kept confidential?

You will not be identified in any published material but your occupation (e.g. clinician, or researcher / engineer) may be reported together with the quotations. I will not disclose anything you tell me during the interview to anybody not involved in the study. I aim to publish the results of this research in academic journals. This may include using direct quotations of your speech, though your identity will not be revealed. I will give you the opportunity to review this typed copy of your interview to indicate anything that you do not want me to quote.

The interview recordings and typed copies will be kept in password-protected files on the University of Bristol network, and also locked in a filing cabinet. A coding key will be kept which links the interview data to the participant information. This will be for my use only so that I can return the typed copies to you for checking. Once this has been done the coding key will be destroyed. Only I (the researcher) will have long term access to identifiable information. Data will be kept for no longer than 12 months after the study has finished, at which point it will be destroyed.

What if there is a problem?

If you take part, I hope that you will find it a positive experience and will value the opportunity to give your opinion. If you do have a concern about any aspect of the study, however, please feel free to speak to me or my supervisors and we will do our best to answer your questions. Contact details for all of us can be found at the end of this sheet.

Who is organising and funding this research?

The research is being organised by myself, by Ruud ter Meulen (Chair and Director of the Centre of Ethics in Medicine at the University of Bristol), and by Dr. Helen Lambert (Reader in Medical Anthropology in the School of Social and Community Medicine at the University of Bristol).

I am funding the research myself. All research carried out in the name of the University of Bristol is looked at by the Committee for Research of the University of Bristol to protect your safety, rights, wellbeing, and dignity.

Contacts for further information

If you have any questions about the research, please contact:

Mr Alex McKeown

Professor Ruud ter Meulen

APPENDIX D: BREAKDOWN OF STUDY PARTICIPANTS

Interview	Sex	Group	Code
1	Male	Renal Scientist	S1
2	Male	Clinical Nephrologist	C1
3	Male	Renal Pharmacist	P1
4	Male	Renal Scientist	S2
5	Male	Clinical Nephrologist	C2
6	Male	Clinical Nephrologist	C3
7	Male	Renal Scientist	S3
8	Male	Clinical Nephrologist	C4
9	Male	Clinical Nephrologist	C5
10	Male	Clinical Nephrologist	C6
11	Male	Clinical Nephrologist	C7
12	Male	Renal Scientist	S4
13	Male	Renal Scientist	S5
14	Male	Clinical Nephrologist	C8
15	Male	Clinical Nephrologist	C9
16	Female	Clinical Nephrologist	C10
17	Male	Renal Scientist	S6
18	Female	Clinical Nephrologist	C11
19	Male	Renal Scientist	S7
20	Female	Renal Scientist	S8
21	Male	Clinical Nephrologist	C12
22	Male	Renal Scientist	S9
23	Male	Renal Scientist	S10
24	Male	Clinical Nephrologist	C13
25	Male	Renal Scientist	S11

APPENDIX E: INTERVIEW TOPIC GUIDE – CLINICIAN GROUP

1) Description of the product

1.1) Can you tell me a bit about how you use EPO in clinical practice?

1.2) What does EPO do?

- *What is its biological action?*
- *What is its therapeutic aim?*

1.3) How is EPO administered?

- *And how frequently is it used?*
- *Dosing?*
- *Nursing practice?*

1.4) What conditions do you treat using EPO?

1.5) Roughly how many people receive EPO?

- *Regionally / Nationally?*
- *Over what period of time?*

1.6) Are there any particular groups by whom EPO tends to be used predominantly?

- *Any particular age group?*
- *Difference in prevalence between men and women?*
- *Particular characteristics of EPO users, or restrictions on who can use it, e.g. children?*

2) Impact on Users

2.1) How effective is EPO?

2.2) What are the effects of EPO on the physical symptoms of users?

- *How long does this last?*
- *Are there any side effects?*

2.3) Does EPO have any wider impact on users, beyond the alleviation of symptoms? If so, what are they?

2.4) Are there any risks associated with EPO? If so, what are they?

3) Background and personal experiences

3.1) Could you tell me a bit more specifically about the work that you do here?

3.2) How did you come to practice renal medicine?

3.3) What is it that particularly interests you about working in this field

3.4) Has EPO or its use changed over the course of your work in the field, and if so in what ways?

3.5) Do you anticipate any changes in EPO or its use in future?

- *Do you think EPO use will grow, or be replaced by other therapeutic alternatives?*
- *If so, why?*
- *What do you think about this?*

4) Enhancement and Ethics

4.1) Do you face any particular challenges in the course of your work involving EPO?

- *E.g. do you encounter any ethical issues associated with the prescription or use of EPO? If so, what?*

4.2) What are your views on the 'off-label' use of EPO as a blood doping product?

4.3) Why?

- *(Depending on response) How do you think it compares to other, legal, 'doping' enhancement techniques such as high-altitude training or the use of oxygen chambers?*
- *These example are all health-related interventions administered by trained health professionals outside a purely clinical context, so do you think it is possible to distinguish between medical and non-medical uses of technologies? If so, how?*

4.4) Looking at this issue more broadly, in your view is EPO different or distinct in any way from other technologies that are used to improve health, for example:

- *Uncontroversial 'over the counter' products, e.g. vitamin supplements?*
- *Everyday uses of technologies, e.g. riding a bike regularly?*

- *(If further prompt needed) Many medical products only have a therapeutic use, whereas EPO seems to be something that can be used by healthy people as well, so do you think there is any difference between EPO and other, perhaps less controversial forms of health / performance enhancement?*

4.5) Widening the question a bit further still, in your view is EPO different or distinct from any other technology (i.e. not necessarily a medical product), which enables us to do something that we wouldn't otherwise be able to, for example:

- *Telephones, for communicating remotely over long distances?*
- *Cars, for travelling further and more quickly than our bodies allow us to on their own?*

5) Regulation

5.1) How do you distinguish between medical or health-related products which should be provided by the State on the one hand, and those to which private access should not be denied on the other?

- *(Depending on their answer) Do you think the current regulation of EPO is appropriate, and if so, why?*

5.2) Do you think there are any medical products to which access should be particularly tightly restricted, and if so, what are they?

5.3) If so, why?

APPENDIX F: INTERVIEW TOPIC GUIDE – SCIENTIST GROUP

1) Description of the product

1.1) Can you tell me a bit about how EPO is used?

1.2) What does EPO do?

- *What is its biological action?*
- *What is its therapeutic aim?*

1.3) How is EPO administered?

- *And how frequently is it used?*
- *Dosing?*
- *Nursing practice?*

1.4) What conditions is EPO used to treat?

1.5) Roughly how many people receive EPO?

- *Regionally / Nationally?*
- *Over what period of time?*

1.6) Are there any particular groups by whom EPO tends to be used predominantly?

- *Any particular age group?*
- *Difference in prevalence between men and women?*
- *Particular characteristics of EPO users, or restrictions on who can use it, e.g. children?*

2) Impact on Users

2.1) How effective is EPO?

2.2) What are the effects of EPO on the physical symptoms of users?

- *How long does this last?*
- *Are there any side effects?*

2.3) Does EPO have any wider impact on users, beyond the alleviation of symptoms? If so, what are they?

2.4) Are there any risks associated with EPO? If so, what are they?

3) Background and personal experiences

3.1) Could you tell me a bit more specifically about the work that you do here?

3.2) How did you come to work in renal medicine research?

3.3) What is it that particularly interests you about working in this field?

3.4) Has EPO or its use changed over the course of your work in the field, and if so in what ways?

3.5) Do you anticipate any changes in EPO or its use in future?

- *Do you think EPO use will grow, or be replaced by other therapeutic alternatives?*
- *If so, why?*
- *What do you think about this?*

4) Enhancement and Ethics

4.1) Do you face any particular challenges in the course of your work involving EPO?

- *E.g. do you encounter any ethical issues associated with its clinical prescription or use of EPO? If so, what?*

4.2) What are your views on the 'off-label' use of EPO as a blood doping product?

4.3) Why?

- *(Depending on response) How do you think it compares to other, legal, 'doping' enhancement techniques such as high-altitude training or the use of oxygen chambers?*
- *These examples are all health-related interventions (typically) administered by trained health professionals outside a purely clinical context, so do you think it is possible to distinguish between medical and non-medical uses of technologies? If so, how?*

4.4) Looking at this issue more broadly, in your view is EPO different or distinct in any way from other technologies that are used to improve health, for example:

- *Uncontroversial 'over the counter' products, e.g. vitamin supplements?*

- *Everyday uses of technologies, e.g. riding a bike regularly?*
- *(If further prompt needed) Many medical products only have a therapeutic use, whereas EPO seems to be something that can be used by healthy people as well, so do you think there is any difference between EPO and other, perhaps less controversial forms of health / performance enhancement?*

4.5) Widening the question a bit further still, in your view is EPO different or distinct from any other technology (i.e. not necessarily a medical product), which enables us to do something that we wouldn't otherwise be able to, for example:

- *Telephones, for communicating remotely over long distances?*
- *Cars, for travelling further and more quickly than our bodies allow us to on their own?*

5) Regulation

5.1) How do you distinguish between medical or health-related products which should be provided by the State on the one hand, and those to which private access should not be denied on the other?

- *(Depending on their answer) Do you think the current regulation of EPO is appropriate, and if so, why?*

5.2) Do you think there are any medical products to which access should be particularly tightly restricted, and if so, what are they?

5.3) If so, why?

APPENDIX G: CODING STRUCTURE

