Chosen Children?
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An empirical study and a philosophical analysis of moral aspects of pre-implantation genetic diagnosis and germ-line gene therapy

Kristin Zeiler

Linköping Studies in Arts and Science No. 340
Dissertations on Health and Society No. 8
Linköpings universitet, Department of Health and Society
Linköping 2005
At the Faculty of Arts and Science at Linköpings universitet, research and doctoral studies are carried out within broad problem areas. Research is organized in interdisciplinary research environments and doctoral studies mainly in graduate schools. Jointly, they publish the series Linköping Studies in Arts and Science. This thesis comes from tema Health and Society at the Department of Health and Society.

Distributed by:
Department of Health and Society
Linköpings universitet
S-581 83 Linköping

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Upplaga 1:1
ISSN 0282-9800
ISSN 1651-1646

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Tryckeri: Unitryck
To Johannes
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Foreword

No human being is an island. This proverb has a clear bearing on this study that highlights the complex context in which certain medical technologies are offered and certain genetic information is sought for, as regards future children, and in which people engage in delicate reproductive choices. It is also suitable as a starting-point in this acknowledgement to those that have contributed, in different ways, to the process that has resulted in this book. I have met and got to know a large number of people. I would like to thank some of these in particular.

I work in the field of bioethics, an area in which philosophy, sociology, theology and medicine, among other disciplines, meet. I am grateful to my three supervisors, each of which has a different academic background. My main supervisor, Professor Lennart Nordenfelt, has been a brilliant discussion partner, most knowledgeable, constructive in his remarks, attentive, and minute as regards philosophical details. My mentor in the world of sociology and co-supervisor, Dr Gunilla Tegern, encouraged my first idea to combine empirical research with ethics. Her knowledge in sociology, her advice, support and most careful reading of various texts have been indispensable for my work. While Lennart and Gunilla have accompanied me on this journey right from the beginning, Dr Karin Sporre, Department of Religious Studies, Högskolan Dalarna, has been an important second co-supervisor during its later part. I am particularly grateful for her important remarks from the perspective of feminist ethics and for her encouragement and attention to various details in the final version of the book. To these three, my warmest thanks. I am also grateful to those who have read certain chapters of the book, among whom I would like to mention, in particular, Dr Per-Erik Liss, Dr Bengt Richt and Professor Stellan Welin.
As part of my work on this project, I spent eight months at Cardiff University, Wales, invited by Dr Andrew Edgar, School of English, Communication and Philosophy; for this I am grateful. I would also like to thank Andrew for his pedagogical and interesting contribution as opponent at my final seminar. I thank also Professor Stephen Pattison, School of Religious and Theological Studies, Cardiff University, for encouragement and comments on my work and for inviting me to thought-provoking lunch seminars with the professional values-group, and Professor Angus Clarke, Institute of Medical Genetics, University of Wales College of Medicine, for giving of his time when I first arrived in Cardiff and for guidance in the selection of the British interviewees. For guidance in the selection of the Italian interviewees, I am particularly grateful to Professor Maurizio Mori, Department of Philosophy, University of Turin. I thank also Fr. Angelo Serra S.J., Professor Emeritus of Human Genetics, and Professor Antonio Spagnolo, Centre for Bioethics, both at the Catholic University of the Sacred Heart, Rome. As regards the selection of the Swedish interviewees and insightful remarks on the sections entitled ‘The Technologies’ and ‘What Technologies Can Be Used For’ my thanks goes to Professor Jan Wahlström, Department of Clinical Genetics, Sahlgrenska University Hospital/East, Gothenburg. Jan Wahlström and Professor Nils Uddenberg also contributed to the discussion at the set-up of the study. Professor Barbro Wijma, Division of Gender and Medicine, Linköping University Hospital, has read and commented on Appendix A. Thank you.

When I started as a PhD student, I did so in the company of five more persons: Anita Andersson, Stina Backman, Fredrik Jakobsson, Ann-Christin Jonsson and Andrea Schmidt. Sharing the first year, and a small room, provided the opportunity for interesting interdisciplinary discussion and – not least – friendship, for which I am grateful. I have also had the opportunity to present parts of my work at ethics seminars at the Department of Theology, Uppsala University, and at the Centre for Applied Ethics, Linköping University. For the feedback at those seminars, thank you. Furthermore, during the last two years the participants in the recently started Linköping bioethics group and the Ethics, Society and Life Sciences seminar have been a reliable source of
intense discussion, laugh and after-sits at the university café. Thank you, all of you. Thank you also, all other colleagues at Department of Health and Society.

My deep acknowledgement goes also to the anonymous interviewees in the study, without whom this book would not have been possible. The ELSA National Research Program, Swedish Foundation for Strategic Research, has financed this project as a whole, the Swedish Church financed the research stay in Italy and the Swedish Foundation for International Cooperation in Research and Higher Education financed the research stay in the UK. Thank you. Special thanks are also due to three persons who have contributed with creativity, skill and time in the process that has resulted in this book: my brother Göran Bäckman has designed the cover of the book; Monika Samuelsson has given the manuscript its form as a book; Malcolm Forbes has helped me improve my English style. Thank you, very much!

Last, but not least, this journey has been very much enriched by my husband, Johannes. His love, support, and enthusiasm in accompanying me during the longer stays abroad have given me the requisite strength and energy. Our children, Lukas and Julia, have provided me with two wonderful reasons for not bringing work with me home and with much, much joy.

Kristin Zeiler
Stora Askö 2005
In the twentieth century, assisted reproductive technologies made it possible for couples with fertility difficulties to try for pregnancy through new technological means. If an ex-corporeal assisted reproductive technology is used, it is also possible to combine it with genetic testing of embryos and, if so, to choose which embryo(s) to implant. In the future, it may be possible to perform gene therapy on embryos before implantation in order to introduce missing genes or replace mutant ones. If so, for which genetic conditions, if any, should germ-line gene therapy be used? Though the use of technologies for embryo diagnosis and the (hypothetical) use of technologies for gene therapy on embryos have different implications, they also have one thing in common. If used, they result in children whose genetic set-up has been the basis for some kind of choice.¹

In the 1960s when assisted reproductive technologies such as in vitro fertilisation were still only hypothetical scenarios, the theologian Helmut Thielicke argued that the field of reproductive technologies was characterised by the presence of Grenzsituationen. We are impelled, he said, to search for the core questions of such situations (Thielicke 1964:725).² I take these borderline situations to be situations in which what we previously have held impossible is no longer so, which call for a (re-)examination of what we may have considered well-established and/or taken-for-granted moral boundaries, and I concur with Thielicke regarding their significance. Borderline situations urge us to search for andanalyse core questions of these situations. In this dissertation, I will focus on the moral aspects of two technologies, pre-implantation genetic diagnosis and germ-line gene therapy, as described by interviewed medical professionals. In my view, these two technologies do result in borderline situations.
Not only are new ways to perform old medical practices possible, or potentially possible, but also new practices that call for a new understanding of the range of human activity.

Pre-implantation genetic diagnosis (hereafter referred to as PGD) involves genetic testing of embryos and allows selective transfer of embryos. It is performed after *in vitro* fertilisation for the purpose of identifying the presence of genes that will or might result in genetic disease. PGD can also be performed for so-called social sex selection, i.e. selection of embryos for social as opposed to medical reasons. Germ-line gene therapy (hereafter referred to as GLGT) means that gene therapy affects the germ-line and therefore also the genome of future generations. GLGT has been discussed as a means to treatment of certain mitochondrial diseases in embryos before implantation.

This book is a study in empirical ethics in the sense that I combine empirical research with a philosophical, conceptual analysis. Several of the topics to be discussed are also common in discussions of other technological developments than those concerning reproduction. Hopefully, the study can contribute to a general discussion of technological changes and human values. The study is not normatively ethical in the more traditional sense that I will argue for or against the use of a certain technology. In the elaboration of the framework that supports the combination of methods, I will draw on work by feminist ethicists, among others, but this is not a gender study. Finally, though both PGD and GLGT will be discussed throughout the study, GLGT will be discussed to a much lesser extent than PGD. This is the case since interviewees discussed GLGT to a much lesser extent than PGD and since I intend to explore aspects of these technologies as described by the interviewees.

**Aims**

The study’s overarching aim is to combine empirical research and a philosophical, conceptual analysis in the field of bioethics. This aim can be divided into three more specific aims, which are closely related.
The combination of analytic methods – qualitative and philosophical, conceptual methods – that I use is still not very common in sociology or in ethics. A consequent first aim is to elaborate on a few theoretical key concepts that support the combination of analytic methods. The theoretical key concepts form what I call the study’s framework.

The second aim is empirical in character. The aim is to explore moral aspects of use of pre-implantation genetic diagnosis and hypothetical use of germ-line gene therapy as understood by eighteen interviewed Swedish, British and Italian geneticists and gynaecologists with the aid of qualitative analysis of the empirical data. What moral aspects of the use or hypothetical use of the technologies did interviewees find it relevant, interesting or important to discuss?

The third aim is conceptual in character. The aim is to perform a philosophical, conceptual analysis of certain concepts that are discerned as central in the qualitative analysis of the empirical data.

Background

The technologies

PGD requires that a woman and a man have used some kind of ex-corporeal assisted reproductive technology, which is also the case if germ-line gene therapy is to be performed on embryos. One of the most common technologies for ex-corporeal assisted reproduction is in vitro fertilisation (in vitro meaning that it is performed outside the body, literally in glass).

In vitro fertilisation (hereafter also referred to as IVF) involves ovarian stimulation in order to cause a woman to produce extra oocytes. If present, oocytes, i.e. immature egg cells, are retrieved and placed in a culture medium that allows them to mature further. Mature eggs are put in a Petri dish with sperm and if fertilisation occurs, embryos are returned to the culture medium for further development. In some cases, eggs are instead fertilised by means of intracytoplasmic sperm injection. This involves injection of a single sperm into an egg with a glass needle and use of technology for micro-manipulating single cells and embryos without
destroying them (technology for holding an unfertilised egg with a pipette while injecting the sperm).

PGD involves either analysing one or two cells obtained from a six to ten cell-stage embryo – a stage reached three days after insemination – or polar body biopsy. In both cases, the aim of PGD has been described as obtaining the birth of a healthy child in a family at high risk for a genetic disease and as sparing the woman the distress of a possible abortion or induced premature delivery after amniocentesis (ESHRE 2001:1047).

In the first case, embryos are cultivated in vitro and a biopsy of one or two cells is taken from the embryo. A genetic analysis is performed on these cells, which allows transfer and implantation of embryos without the specific genetic disease. In some cases, this analysis can be performed by means of fluorescent marking of chromosomes or parts of chromosomes (fluorescent in situ hybridisation). Fluorescent in situ hybridisation implies that biomedical substances are used in order to make certain segments of chromosomes shine when exposed to ultra-violet light. It can be used to indicate sex as well as certain structural and numerical changes in the chromosomes. In the case of single-gene disease, and as it is not possible to detect a mutation in the DNA from a single cell without amplifying the relevant DNA sequence, all single-gene genetic analyses rely on single-cell polymerase chain reaction for such amplification (Braude et al 2002). Polymerase chain reaction is used to amplify DNA to indicate single-gene diseases either when a certain DNA sequence mutation is identified or in linkage analysis when such a mutation is statistically linked to some other identifiable DNA sequence.

Genetic analysis can be performed after conception, on embryos. It can also be performed before conception, such as is the case in polar body biopsy. Polar body biopsy involves the drawing out of the first and/or second polar body of the egg cell with a biopsy pipette and then the performance of a genetic analysis. While genetic analysis of the polar body can give knowledge of whether a particular gene is mutated in the resulting egg cell, it can only provide information on maternal genes (Verlinsky et al 1990, Strom et al 2000).

There are difficulties with all the alternatives and the risk of error due to the human factor is always present. Consequently, there are recom-
mendations that PGD, if resulting in a pregnancy, shall be combined with prenatal diagnosis (SMER 2004:6) or, at least, that such combination shall be discussed with the woman and man concerned (Thornhill et al 2005:37, 46).

Pre-implantation genetic screening10 for abnormal number of chromosomes (aneuploidy) can be offered to all couples who undergo an ex-corporeal assisted reproductive technology (not only to those at risk for a certain genetic disease). The main purpose of pre-implantation genetic screening is to increase the success-rate of ex-corporeal assisted reproductive technologies,11 particularly for women above a certain age and women who have had previous miscarriages (Munné et al 1999). These women’s embryos may, to a larger extent than other women’s embryos, carry chromosomal deviations. Such deviations have been considered a main reason why implantations fail or the women miscarry. Embryos with chromosomal deviations can be sorted out after genetic screening (Wilton 2002, Rubio et al 2003, Werlin et al 2004).

Whereas PGD and pre-implantation genetic screening are performed in some European countries today (Sermon 2005 et al),12 this is not the case with the second technology discussed in this study. Germ-line gene therapy is not performed on humans.

The term gene therapy encompasses different strategies designed to overcome or alleviate disease by introducing or replacing genes into the cell of an affected individual. Such a transfer can be performed with different technologies, biological as well as non-biological,13 and genetic material may be directly transferred into cells within a person (in vivo gene therapy). It may also be inserted in vitro, if cells are removed from the person, genetic material transferred and inserted in the cells and the cells replaced within the person.

Gene transmission that affects the germ cells has been discussed as an undesirable side-effect of in utero or adult somatic gene therapy (Coutelle et al 2003). It is argued that during gene delivery, foreign DNA may be inserted into the germ cell genome and thereby transmitted to future generations. The question has been whether – and if so, what level of – insertion is tolerable (Kazazian 1999, Coutell and Rodeck 2002). GLGT has been discussed as means to treatment of cer-
tain mitochondrial diseases, i.e. diseases due to DNA deviations in genes in the mitochondrial DNA, in embryos. Then, the idea is to exchange the cytoplasm, so that the cell nucleus of one egg cell is transferred into an egg cell of another woman (whose cytoplasm contain no deviant mitochondria DNA) from which the cell nucleus has been removed. Transplanting the cell nucleus from an aged woman’s oocyte into a younger woman’s oocyte has also been proposed as a way to reduce the incidence of oocyte aneuploidy (Takeushi et al 2001, Hansson and Wahlström 2003).

What Technologies Can Be Used For

National policies concerning what to use PGD for vary, but the methods can be used in order to search for certain genetic diseases, of varying severity, and for sex selection. PGD can be used in order to detect numerical chromosome abnormalities (present if the number of chromosomes is not 46) and to detect some, but not all, structural chromosome abnormalities. Structural abnormalities are present when a chromosomal rearrangement has taken place (the ‘normal’ structure of the chromosome is changed), such as translocations, in which sequences on one or more chromosomes have changed place. Structural abnormalities can be due to loss or reduction of chromosomal segment (deletions), to an increase of chromosomal segment (duplications or expansions) or to changes in which chromosomal segments on one or more chromosomes have changed place (insertions or translocations). PGD is mainly used for so-called balanced or reciprocal translocations, in which no chromosomal segments are lost or increased, that result in certain reproductive difficulties. It can also be used to detect chromosomal microdeletions, in which small chromosomal segments are deleted. Furthermore, PGD can be used for single-gene diseases. Such diseases are due to a mutant allele of a single gene, either in the autosomes (non-sex chromosomes) or, in sex-linked single-gene diseases, in the sex chromosomes. Single-gene diseases may be recessive as well as dominant and PGD can be used for all such diseases, in principle, as long as the mutation is known. Finally, PGD can be used for selection of embryos on the basis of sex for medical reasons (in order
to avoid the birth of children with an X-linked disease, all male embryos are disposed of) as well as in order to get a male or female child for non-medical reasons (so-called social sex selection). PGD by means of polar body biopsy is only relevant with regard to certain genetic deviations in the woman’s genome, such as balanced translocations, i.e. changes in which DNA sequences on one or more chromosomes have changed place but in which no DNA sequences are lost or increased.

At present, if used at all, PGD is used to prevent X-linked recessive diseases (Veiga et al 1994, Vandervorst et al 2000) and the unbalanced transmission of parental balanced translocations (Scriven et al 2001, Munné et al 2000). Pre-implantation genetic screening is carried out for infertile patients who undergo IVF with the aim of increasing the IVF pregnancy rate (Thornhill et al 2005) and to improve IVF results in repetitive implantation failure, increased maternal age (Gianaroli et al 1999, Kahraman et al 2000) and recurrent miscarriage patients (Pellicer et al 1999, Rubio et al 2003).

As has been said, germ-line gene therapy has been discussed as a possibility in the case of certain mitochondrial diseases (SOU 2004:20: 318-323).

**Bioethical Policies and Legal Restrictions in the Chosen Countries**

I have chosen to interview gynaecologists and geneticists in the UK, Italy and Sweden. My motives for doing so will be discussed in the next chapter. In short, I take interviewees from the UK, Italy and Sweden to be interesting to listen to since they are all in Europe,16 since there are differences between these European countries with regard to what are seen as important bioethical topics and legal approaches to the technologies discussed and since these differences can enable a wide spectrum of reflections on the technologies, which was considered important in the selection of interviewees. I will give a description of national bioethical recommendations and laws with regard to PGD and GLGT, but it is important to note that national differences do not structure the study as a whole.
The UK

The first child born after use of IVF, world-wide, was born in the UK in 1978. Research for the development of PGD was initiated some years later, during the 1980s, and it led to the first report of successful use of PGD, at world level, at Hammersmith Hospital, London (Handyside et al 1990). In 1990, Parliament voted on the Government’s Human Fertilisation and Embryology Bill and approved that in vitro fertilisation should be legally accepted and regulated. The Human Fertilisation and Embryology Authority (hereafter referred to as HFEA), a standing national committee that dealt with bioethical ethical issues, was also established at this time.

HFEA has been engaged in discussions of PGD since the beginning of the 1990s. According to the Human Fertilisation and Embryology Act (1990) when assisted reproductive technology is used, the welfare of the child shall be considered. HFEA has stated that PGD is expected to be available only where there is a ‘significant risk of a serious genetic condition being present in the embryo.’ The decision to use PGD is also expected ‘to be made in consideration of the unique circumstances of those seeking treatments, rather than the fact that they carry a particular genetic condition.’ The seriousness of the condition is expected to be a matter of discussion in the clinical encounter, between people seeking treatment and the clinical team (HFEA 2003c:123-124). Indications for the use of PGD are also expected to be consistent with the current practice of prenatal diagnosis. Finally, it has been recommended that no list of serious conditions for which PGD is acceptable should be drawn up (HFEA and HGC 2001:rec.9, also HFEA 2003b).

For the understanding of differences between the three countries in the study, it is also relevant that the HFEA has granted a licence for PGD in combination with so-called PGD HLA typing. PGD HLA typing allows the selection of embryos in order to bring about the birth of a child who can provide a matched tissue donation for an existing sibling (HFEA 2001, 2005a). It has also been recommended that pre-implantation genetic screening should be allowed but used only for screening for abnormal number of chromosomes for categories of patients such as women over 35 years of age, women with a history of recur-
rent miscarriage, women with several previous failed IVF attempts in which embryos have been transferred and women with a family history of aneuploidy (not caused by translocations of other chromosomal rearrangements) (HFEA 2003c:125).

With regard to germ-line gene therapy, discussion was (re-)evoked in 1989 when the US researcher W.F. Anderson sought approval for research involving gene therapy in utero from the Recombinant DNA Advisory Committee, National Institutes of Health, USA (Anderson 1989a, 1989b). In the UK, the Government set up the Committee on Ethics and Gene Therapy the same year, with the task of drawing up ethical guidelines for treatment by genetic modification of human body cells. Four years later, in 1993, the government established the Gene Therapy Advisory Committee (GTAC), to oversee and implement uses of gene therapy (GTAC 1995). The committee has stated that in utero gene therapy may give rise to germ-line effects and that ‘in view of safety and ethical difficulties germ-line interventions are off limits at present’ (GTAC 1998). However, research with the aim of developing technologies for germ-line gene therapy is not explicitly forbidden in the UK, though ‘altering the genetic structure of any cell while it forms part of an embryo’ is (HFE Act 1990).

Italy
The Italian discussion of ex-corporeal assisted reproductive technologies and of PGD has to a large extent focused on different understandings of the moral status of the human embryo, its dignity and personhood. According to the official teaching of the Roman-Catholic Church, any loss of embryos, such as is possible after the use of in vitro fertilisation, is morally unacceptable. Human existence begins at conception and the embryo should be respected as a human person. It has also been argued that the use of ex-corporeal assisted reproductive technologies are morally unacceptable since they violate the ‘inseparability principle,’ according to which procreation, marital love and the conjugal act must not be separated (Congregation for the Doctrine of Faith 1987:II.B.4).

The question of the moral status of the human embryo also appears in some of the writings of Il Comitato Nazionale per la Bioetica (here-
after referred to as CNB), the Italian National Committee for Bio-
ethics, established in 1990. CNB has published a number of documents
on ethics and new medical technologies but it has not managed to
reach a consensus on the moral status of embryos, which has had con-
sequences for the discussion of PGD. In this sense, the committee can
be seen as exemplifying the tension between different groups in Italian
society with regard to sexual and medical ethics.25

CNB’s first document established that somatic gene therapy was
morally permissible and medically desirable, whereas germ-line gene
therapy was not acceptable ‘in the present circumstances’ (CNB 1991).
Several documents have also discussed the moral status and treatment
of embryos, but shared views have been difficult to obtain.26 In June
1996, CNB discussed PGD. No consensus was reached on the status
and treatment of embryos, therefore some members considered PGD
to be morally illicit and some did not. CNB was unable to formulate
any recommendations with regard to the use of PGD, but it did state
that the human embryo, at least, is not merely a matter of biological
material (CNB 1996).27

Until 2003, PGD was not performed in public hospitals, but re-
mained unregulated in private ones. Since 2004, Italy has one of the
strictest regulations in Europe. Though embryo biopsy as such is not
illegal, all embryos must be transferred to the uterus, which means that
if PGD or pre-implantation genetic screening should be used, affected
embryos must still be implanted. Furthermore, couples at risk for genet-
disease but who have no fertility difficulties do not meet the law’s
requirement that the assisted reproductive technologies necessary for
PGD be provided only to infertile couples (Legge 19 Febbraio 2004
n.40, Norme in Materia di Procreazione Medicalmente Assistita [Ital-
ian law on assisted reproductive technologies]). For the understanding
of the Italian situation, it is also noteworthy that the result of the refer-
endum in June 2005, in which the Italians voted on the issue of whether
to change the law, was invalid because of too small a number of voters
(Governo Italiano, Presidenza del Consiglio dei Ministri 2005). Pope
Benedict XVI explicitly urged Roman-Catholics not to vote, so that the
results would be invalid and the law not revised.
Germ-line gene therapy was discussed and rejected by CNB in 1991. However, Pope John Paul II did not always make a distinction between somatic and germ-line gene therapy. All kinds of germ-line gene therapy, provided that medical accuracy and safety could be guaranteed, that no embryos are disposed and that the inseparability principle is not infringed, have not been banned (Grima 1994). Pope Benedict XIV has not yet addressed these issues as Pope.

Sweden
PGD has been discussed in white papers since 1985 (SOU 1985:5), but it was only after the successful use in the UK that policy discussions became more detailed. The guidelines, formulated by Socialstyrelsen, the National Board of Health and Welfare, recommended that PGD should only be used by couples who had a genetic disposition to a severe genetic disease, and for the diagnosis of ‘severe, progressive, hereditary diseases that lead to an early death’ and where ‘no cure or treatment’ was available. Sex selection should only be allowed if necessary as a step in diagnosis for a sex-linked disease (Bet. 1994/95: SoU18:13). In 1994, the same year as the policy on PGD was formulated, the first clinical applications occurred in Sweden.

The Swedish guidelines on PGD have been criticised. Critics from within handicap movements have argued that PGD could strengthen attitudes detrimental to people with certain handicaps and diseases (DHR 1998, 2001). The usefulness of the notion of severe disease has also been questioned (DHR 2001, SMER 2004), and it has been argued that it is pedagogically problematic to explain to couples that prenatal diagnosis is available to them (and possible abortion) for conditions that it is not permissible to search for with PGD (SMER 2004).

In 2002, an informal advisory group for moral issues in PGD suggested a set of more flexible conditions for the use of PGD (Wahlström et al 2002). It was suggested that the severity of the disease should no longer be a necessary condition, nor should genetic diseases need to lead to death at an early age where no cure or treatment was available. Instead, the necessary conditions for the use of PGD should be that a couple was at high risk for a specific single-gene or chromosomal dis-
ease that implied a high risk of having a child with the disease; that IVF was sufficiently safe for the particular couple; that the couple had been given sufficient (written and oral) information about the nature of the disease, their risk for the particular disease, the alternatives to PGD and the positive and negative aspects of PGD; that the couple continued to ask for PGD in a well-thought-through manner and that they be offered conventional prenatal diagnosis as a matter of control. A set of ‘relevant conditions’ as regards the assessment of couples’ need for PGD were also elaborated. By large, Statens Medicinsk Etiska Råd (SMER), the Swedish National Council on Medical Ethics, approved of the proposal – but the notion of severe genetic diseases was re-introduced (SMER 2004). The reasoning of SMER was also approved of in a white paper of 2004 (SOU 2004:20).

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The white paper of 2004 also stated that pre-implantation genetic screening should not be used as a matter of routine but that it should be allowed within distinct research projects that had been approved by a research ethical council (SOU 2004:20:300).

With regard to germ-line gene therapy, research on embryos with the aim of developing methods for germ-line interventions has been explicitly forbidden in Sweden since 1991 (Lag om åtgärder i forskning- eller behandlingssyfte med befruktade ägg från människa SFS 1991:115 [the Swedish Embryo Research Act]). In 2004, changes in the law were suggested. It was suggested that research on embryos with the aim of developing methods for germ-line interventions should no longer be forbidden, but that it should be forbidden to try to interfere with the germ-line (SOU 2004:20:317). However, such changes have not (yet) been made.

Similarities and Differences
The UK has more flexible guidelines than Sweden. In the Swedish guidelines from 1994, it has been recommended that PGD should only be used by couples who have a genetic disposition to a severe genetic disease and for the diagnosis of severe, progressive, hereditary diseases that lead to an early death and where no cure or treatment is available. While the reasoning in the white paper of 2004 (SOU 2004:20) comes
closer to the one in the UK, the genetic disease searched for shall still be ‘severe.’ Italy has had neither policy guidelines nor national bodies that regulate PGD clinics and it has been the most unregulated country of the three – and was the most unregulated country at the time of the interviews. Since 2004 embryo transfer has been strictly regulated in Italian law.

However, the UK has also a more regulated praxis than Sweden. In the UK, if a certain couple would like to use PGD for a genetic condition for which the PGD clinic in question has not been licensed to offer it, it is the professionals at the PGD unit who apply for such a licence at the HFEA. In Sweden, Socialstyrelsen (the National Board of Health and Welfare) shall report all uses of PGD, but there is no license system. In Italy, at the time of the interviews, no national licensing or monitoring board existed (and since 2004 Italian law makes PGD pointless since all fertilised embryos must be implanted).

With regard to germ-line gene therapy, all three countries have banned such interventions. Sweden has the most restrictive view. However, it is now suggested that research on embryos with the aim of developing methods for germ-line interventions should no longer be forbidden, but that it should be forbidden to try to interfere with the germ-line.

Situating the Study in the Earlier Discussion
Moral Aspects of PGD
Medical professionals, politicians, ethicists, sociologists, representatives of disabled people’s movements and many others have discussed moral aspects of PGD. It has been held that PGD is less problematic than prenatal diagnosis and possible abortion (Cameron and Williamson 2003) since it enables couples to have an unaffected child without having to undergo terminations of pregnancy and since embryos, not foetuses, are disposed of (Draper and Chadwick 1999). It has also been held that PGD is positive since it can be seen as a form of preventive medical treatment of diseases – i.e. preventive genetics (Al-Odaib et al 2003).
Furthermore, it has been argued that PGD has the benefit of making certain reproductive choices possible for some and that reproductive freedom or autonomy, which can be articulated through these choices, is a moral value (Buchanan et al. 2000:214-222) or a negative right (Robertson 1994:22-23). Reproductive freedom, it has been suggested, can be described as the same sort of freedom that allows one to choose one’s own way of living (Harris 2000b:35).

Pre-implantation genetic screening has been described as positive as a means to improve the take-home-baby rate of IVF. If such screening is used, more women and men with infertility difficulties may receive a biological child than if it is not (Rubio et al. 2003). The use of PGD and preimplantation genetic screening can also be underpinned by the idea that there is a moral value in bringing additional children into existence (for example through successful IVF treatments) provided that no one is harmed by the existence of these children (Tännsjö 1991:32-49). When it comes to some untreatable and most severe diseases, it has also been argued that it can be reasonable to claim that it would have been better for the child, from its own point of view, never to have existed (Munthe 1999a:93).

The objections to use of PGD can be divided into four major groups. First, certain objections are related to the use of ex-corporeal assisted reproductive technologies. It has been argued that reproductive technologies are morally questionable since they enhance medical professionals’ power over women’s bodies, which is undesirable (Draper and Chadwick 1999, Raymond 1995:79), and that the rhetoric of reproductive choice in fact prevents us from examining the context in which reproduction becomes institutionalised (Raymond 1995:ix-xii). There are also objections to assisted reproductive technologies based on the health risks involved primarily for women who undergo treatment, such as risks related to the hormone stimulation, but also health risks for the child that result from the treatment (Land and Evers 2003, Lambert 2002, Thompson et al 2002). Other objections take a certain understanding of what is a morally desirable way of living or a certain understanding of the embryo as their point of departure. It has been held that uses of the technologies are morally questionable since they conflict with natural life processes, imply an
undesirable dominion over nature and/or conflict with the inseparability principle according to which procreation, marital love and the conjugal act must not be separated (Congregation for the Doctrine of the Faith 1987:intro. 3.I.5, II.4.II.6). Ex-corporeal assisted reproductive technologies have also been held to be morally questionable if they result in the disposal of embryos since human beings, from conception, are to be respected as persons (John Paul II 1995). Disposal of embryos has also been described as a violation of the dignity of human life in its earliest phase (Østnor and Thunberg 1995:63).

Second, there are objections to the use of PGD as such, with regard to risks, to be distinguished from risks accompanying the assisted reproductive technologies. It has been claimed that there is a risk of diagnostic errors (Sermon 1998, Reubinoff and Shushan 1996).

Third, there are objections that take their point of departure in the attitudes towards women and men with genetic disorders. It has been held that the development and use of PGD signalises that all human beings do not have the same value, which makes it morally questionable (DHR 1998). It has also been held that the future of humankind will be fashioned by the attitudes that we adopt to the genetically handicapped, that the use of PGD is part of a culture of undesirable eugenics and that intolerance of people with genetic diseases prepares the emotional climate in which PGD is accepted (Herranz 1999:191-192, 198).

Fourth, there are slippery slope objections. Such objections can take a logical form, as when it is held that there is no logically sustainable distinction between acceptable and non-acceptable uses of PGD. These objections can also imply that allowing some uses of PGD is the first step on a slippery slope leading to changed attitudes in society and, as a consequence of this, to a future allowance of what we now take to be morally undesirable scenarios, such as a free-market eugenics (King et al 1999), to negative consequences for people with genetic disease or disability or to risk of misuse.

These are the main arguments for and against PGD in the international bioethical literature. There are also a number of studies that explore the experiences and attitudes of women and men who have a genetic disease or are carriers of such a disease and/or who have under-
gone or will undergo PGD. These studies are particularly interesting as a contrast to the present one on medical professionals’ views on PGD. I will now turn to this research.

In an Italian study performed in order to ascertain the degree of acceptability of PGD, 180 women at risk for beta thalassemia were asked whether they found PGD acceptable. All of the 60 women with previous experience of prenatal diagnosis and abortion said they would prefer PGD if they should try for another pregnancy, to be compared with one third of the 120 women without such experience. The researchers concluded that it seemed as if obstetric experience was an important factor in the reproductive choice of all these women (Palomba et al 1994). A similar conclusion was drawn by the researchers in another Italian quantitative study of attitudes among ‘potential users’ in Sicily (Chamayou et al 1998). A questionnaire was sent to, among others, 50 couples who were at risk for beta thalassaeia and 74 couples who underwent an assisted reproductive technology programme for infertility reasons. Nine out of ten of the 50 respondents who had experience of prenatal diagnosis and selective termination of beta thalassemia-affected foetuses or who, unaware of their carrier status, had given birth to an affected child described PGD as an excellent alternative, as better or slightly better than prenatal diagnosis and selective termination of pregnancy. Almost three out of four of them said they were willing to undergo PGD. Almost three out of four of these respondents also described the possibility of being assured that the embryo implanted did not have beta thalassemia as what determined their willingness to undergo PGD. Almost all of the 74 respondents who had fertility difficulties and who underwent an ex-corporeal assisted reproductive technology, but who were not carriers of beta thalassemia, said they were willing to undergo pre-implantation genetic screening for aneuploidy. The researchers stated that the aim of pre-implantation genetic testing for both of these groups was to enable the birth of an unaffected child without the need for selective termination of pregnancy (Chamayou et al 1998). There is also a small quantitative study from the UK of experiences and attitudes of 36 women who had undergone PGD and who had had different previous reproductive experience before this.
asked about perceived advantages, almost all said they strongly agreed that the advantage with PGD was that only unaffected embryos would be transferred to the woman’s uterus and that termination of pregnancy could be avoided.41 A little more than half of the women strongly agreed that the low success rate was a disadvantage and a little less than half of them described the treatment cycle as ‘extremely stressful.’42 Of those contemplating a further pregnancy, three out of four of the respondents said they would like to try PGD.43 As in the previous study, the researchers conclude that the experience of prenatal diagnosis and selective termination could be an ‘unwelcome memory’ that led ‘to a demand for an alternative approach’ (Lavery et al 2002).

The possible correlation between experience of prenatal diagnosis and abortion and a positive attitude to PGD can also be discussed in relation to a UK study on 244 women’s attitudes and preferences regarding family limitation, prenatal diagnosis through chorionic villus biopsy, abortion and PGD. In this study, little more than four out of ten women said they preferred prenatal diagnosis, whereas little less than four out of ten said they preferred PGD.44 However, women with experience of assisted reproductive technologies and women who had had genetic counselling for a genetic condition did say they preferred PGD to other reproductive alternatives (Miedzybrodzka et al 1993). Another UK quantitative study, in which 245 carriers of different recessive disorders were asked how they viewed PGD, prenatal diagnosis, donor insemination, egg donation and adoption indicated low preferences for adoption, donor insemination and egg donation. Despite some support for PGD, it did not displace prenatal diagnosis as the most preferable reproductive option (Snowdon and Green 1997). 45

There may be different reasons why women with experience of prenatal diagnosis prefer or do not prefer PGD or prenatal diagnosis – not least cultural, social and/or religious reasons. The described UK study (Snowdon and Green 1997) of carriers of different recessive disorders also revealed a number of gender differences, particularly with regard to perceptions of the disadvantages of PGD. The women described the practical difficulties of PGD (such as low success rate and long waiting list) and issues involving embryos (creation as well as what to do with
spare embryos) as more important than did the men, whereas the men described the impact on their partners as a more important disadvantage. Almost all women and men indicated that they viewed early reassurance, the implantation of an embryo without the particular genetic disease and the opportunity to avoid abortion as important advantages of PGD (Snowdon and Green 1997).

The possible demand for PGD by groups with genetic disease needs also to be discussed in relation to a Danish survey of ‘potential users of PGD.’ This survey indicates varying attitudes depending on which genetic disease women and men were at risk for (Højgaard et al 2002). The respondents were either members of Landsforeningen til bekæmpelse af Cystisk Fibrose [National Association Against Cystic Fibrosis, my translation from Danish] or women and men who had been treated/counselling for haemophilia A or B (Højgaard 2002:102-103). The survey indicated a noteworthy difference between the two groups when it came to whether they would like to use PGD or prenatal diagnosis or try for pregnancy without using diagnostic methods. Half of the respondents who were members of the cystic fibrosis association responded that their first choice was PGD. This proportion was remarkably lower for the other respondents: about two out of ten carriers of haemophilia A or B and one out of ten women and men affected with or carriers of haemophilia A or B said they would choose PGD as their first option. Correspondingly, whereas one fourth of the members of the cystic fibrosis association gave prenatal diagnosis as their first choice, this was the case for four out of ten of those affected with or carriers of haemophilia A or B (Højgaard 2002:108-109). The experienced severity of the disease mattered for respondents’ reproductive choices, as did their assumptions regarding their own risk of having a child affected by the disease or a carrier. However, there were no significant differences with regard to reproductive choices depending on whether couples had experience of prenatal diagnosis and abortion in the group of people affected with or carrier of haemophilia A or B (to be contrasted with some of the studies above). In the group of people affected with or carriers of cystic fibrosis, those with no experience of abortion were more negative to it than those who had aborted foetuses for medical reasons.
The examples so far have been quantitative. There is also an ethnographic study of PGD in which in-depth interviews were performed with patients at two PGD units in the UK. On the basis of an analysis of the many ways in which PGD ‘patients’ got to PGD clinics, the reasons why they did so, how they experienced the procedures involved in PGD and how they moved on from PGD, Sarah Franklin and Celia Roberts conclude that PGD seems to be a site of extreme ambivalences in terms of how to understand, describe and value the technology (Franklin and Roberts forthcoming). They also conclude that PGD patients make decisions about treatments in complex ways and that they are aware of implications of PGD at the personal, familial, societal as well as clinical levels (Roberts and Franklin 2004). Patients were very sensitive to, attentive to and concerned with the ethical and social issues at stake; they described the choices as neither trivial nor simple and their accounts were often highly nuanced (Roberts and Franklin 2004).

Patients’ perspectives can be quite different from those of professionals and the above studies provide an interesting perspective in dialogue with the results of the present study. Did the views of medical professionals harmonise with the views of patients and, if so, in what sense?

To my knowledge, there is only one previously published study that has discussed medical professionals’ views on PGD. The aim of this study was not to examine moral aspects of PGD but to analyse how patients’ selections of treatments in the area of reproductive genetics were handled by assisted reproductive technology clinicians in the USA. Different morally complex case scenarios were presented to and evaluated by 184 directors of assisted reproductive technology clinics. One of the scenarios focused on social sex selection through the use of PGD. The clinicians were asked if they would offer PGD for this purpose. Responses to the scenario were two out of ten ‘yes’ and eight out of ten ‘no.’ Those who believed in denying treatment said that they did so since they were concerned about a general misuse of medical technology and the use of PGD for non-disease conditions. Some stated that they felt that this particular use of PGD was unethical and/or a slippery slope to greater misuse (Stern et al 2003).
This study takes place in a different national context than mine and I did not explicitly address the issue of sex selection for non-medical reasons. Still, this study is interesting as a contrast to the present one. The lack of previous studies that explicitly explore medical professionals’ views on moral aspects of PGD also motivates this study.50

Finally, there are two noteworthy theoretical studies of moral aspects of PGD. The Danish survey described above is a part of a larger study on prerequisites and consequences of the use of PGD (Ingerslev et al 2002),51 which also contains a normative, ethical analysis of PGD. Here, it is held that PGD and selective transfer of embryos is a morally better alternative than prenatal diagnosis and abortion, but that it should take place within the framework of public health care in order for it to be fairly distributed (Andersen 2002:75-100). Another normative, ethical analysis of PGD has been performed by the philosopher Christian Munthe. His comprehensive Pure Selection (1999a) is a case study of the development of PGD in Sweden as well as a normative analysis of most of the arguments described earlier. The study scrutinises the logic and moral relevance of each argument and Munthe argues for the use of PGD in situations where it can be reasonable to claim that it would have been better for the child, from its own point of view, never to have existed. In some cases of extreme severe and untreatable diseases, Munthe argues, the realisation of an embryo’s potential to develop into a child can mean that the resulting child is harmed (Munthe 1999a:93).

These ethical analyses are primarily important to the present one since they present and analyse a range of possible normative standpoints and arguments. This is particularly the case with Munthe’s study, which puts forward and discusses a wide array of arguments for and against the use of PGD. Were all of these articulated also by the medical professionals, were some arguments more discussed than others, and if so, which? While Munthe discusses possible arguments of different kinds, the present study focuses not on possible arguments but on moral aspects that the invited medical professionals described as morally relevant, interesting and/or important.
Moral Aspects of Germ-line Gene Therapy

Medical professionals, politicians, ethicists, sociologists, representatives of disabled people’s movements and many others have also discussed moral aspects of germ-line gene therapy. GLGT has been held to be positive since it has the benefit of actually treating a disease and curing a patient (Walters and Palmer 1997:74-76). It has also been held that GLGT may be a much more efficient treatment than somatic gene therapy and that it, in contrast to somatic gene therapy, may reduce the incidence of certain genetic diseases in the human gene pool (Walters and Palmer 1997:62-63). More moderately, it has been stated that GLGT could be explored in the case of human embryos after thorough experimentation in suitable animal models, if it is the only way to cure a genetic disease (ESHRE 2001:1048). In these statements, it is implied that had not GLGT been used, the embryo would have developed into a child with a genetic disease. Others question this idea and claim that it is unlikely that the resulting child would be the same as the one that would have resulted if GLGT had not been used, and that GLGT therefore does not qualify as treatment of disease (Munthe 1999b:161-164). Instead, genetic interventions into germ-line cells are described as selections of embryos (if GLGT in fact results in a different embryo than before treatment) that may be motivated by a wish to meet some couples’ wants and needs (Munthe 1999b:164).

There are eight major kinds of objections to germ-line gene therapy, some of which are similar to the objections to PGD.

First, if GLGT takes place in the context of ex-corporeal assisted reproductive technologies such as would be the case if used for mitochondrial genetic diseases, the same objections apply to GLGT as to PGD (such as objections based on medical professionals’ power over women’s bodies, on health risks for women and future children, on a certain understanding of what is a morally desirable way of living and on a certain understanding of the embryo).

Second, there are risk objections with GLGT. The health risks of GLGT concern the embryo on whom therapy is performed or the embryo who results from genetically altered gametes (Watt 1999:257) in terms of unforeseen genetic damage (ESHRE 2001: 1048).
genetically modified embryo is successfully implanted and carried to term, health risks can also concern this child's future children. Such risks are often described as due to the limited knowledge (Spicker 1998). We do not know where the inserted gene will be placed, therapy is difficult to carry out and unacceptable side-effects are to be expected, which makes GLGT morally questionable.

Third, there are objections based on the undesirability of embryo experimentation, necessary for the development of technologies for GLGT. Experimentation on embryos is regarded as morally problematic (Watt 1999:258) for much the same reasons as is embryo disposal. Furthermore, it has been held that even if we reach a stage where experimentation need no longer take place, moral problems arise in terms of condoning previous experimentation that has paved the way for the current therapy. If women and men make use of GLGT for their children in the future when experimentation is no longer necessary, they may take the risk of condoning the means by which GLGT was developed (Watt 1999:259).

Fourth, it has been held that future persons have a right to an unmodified genetic inheritance (European Parliamentary Assembly 1982, questioned by Renzong 1998). It has been asked how we can allow ourselves to ignore the right to bodily integrity of future others' since no informed consent of the future generations can be obtained (Sutton 1997:68). Lack of informed consent, it has been suggested, makes at least non-therapeutic interventions seem wrong (Watt 1999:266).

Fifth, it has been objected that the use of GLGT implies a change in the prerequisites of the future person concerned, which will undermine our moral community. In this line of reasoning, children born after the use of GLGT will be genetically programmed in accordance with their parents' wishes, which make them unable to act autonomously in the same sense as did their parents. They cannot be considered as authors of their own life-stories in the same sense as their parents and they will no longer be equals vis-à-vis the previous generations, which is morally problematic (Habermas 2003).

Sixth, there are objections that start in a certain understanding of what is a desirable way of living that apply to GLGT as such (and not
only to assisted reproductive technologies). It has been stated that we need to consider carefully whether the use of GLGT is not one step too far for human beings in terms of medical interference and that the phrase ‘playing God’ may be relevant as a moral warning (Polkinghorne 2004). It has also been asked if there is not a risk that those who do not fit an alleged genetic norm may be seen as non-normal and in need of therapy/correction, which is understood as problematic or at least questionable (Lebaczq 1999:90-91, Wolf 1995).

Seventh, there are slippery-slope objections. In the logical form of the argument, it is held that if we permit somatic gene therapy we will also accept GLGT in the future or if we accept GLGT for therapeutic reasons we will also accept enhancements, since there is no logically sustainable distinction between these uses.\footnote{It has also been held that allowance of some versions of gene therapy, such as somatic gene therapy will ultimately lead to eugenic societies or to other equally undesirable scenarios (discussed by McGlennan 1995, Launis 2002).} Eighth and finally, it has been argued that the availability of PGD does provide a strong argument against GLGT, except in rare cases when all potential children have a high risk of being affected with the particular genetic disease (Richter and Bacchetta 1998). Why use GLGT when one can select embryos with PGD?

There are three published studies that have dealt explicitly with moral aspects not only of gene therapy in general but also of germ-line gene therapy. The first study, by LeRoy Walters and Julie Gage Palmer (1997), resulted in a set of questions that the researchers thought needed to be addressed in relation to somatic as well as germ-line gene therapy, such as what is the disease to be treated, what alternative treatments are available, what is the potential harm and the potential benefit of the treatment, how will the selection of patients be conducted (in order to be fair to all patients), how will informed consent be obtained and how will privacy and confidentiality of patients be preserved (Walters and Palmer 1997:88-89). With regard to GLGT, they concluded that a voluntary programme of this therapy was morally acceptable, provided that it was technically safe and accurate (Walters and Palmer 1997:92).
Chapter 1

The second study is a qualitative study that analyses the public’s perception of gene therapy, germ-line gene therapy included (Iredal et al 2003). It is noteworthy since interviewees were people with cystic fibrosis and members of their families, students from science evening classes and lay members of the public selected from the practice list of the local general practitioner. The study indicated a support for somatic gene therapy but ambivalence towards germ-line gene therapy. Interviewees also made a clear distinction between therapy and enhancement. The majority of the interviewees opposed the latter.

Walters and Palmer’s study is interesting since it describes a spectrum of different questions that arise if GLGT is to be discussed from a moral point of view. The study by Iredale et al provides the present study with another kind of contrast: the contrast between lay people’s (students included) and medical professionals’ views.

Finally, there is a British study on the public’s attitudes to selection of desirable characteristics in children through gene therapy, prenatal screening and selective termination of pregnancy or vitamin supplements. The study indicated that there was relatively little support for gene therapy with this particular purpose but that the proportion of respondents who would consider such therapy was significantly greater than in a survey performed one year earlier (Marteau et al 1995). This small but increasing interest among the respondents also motivates the present study’s focus on PGD as well as GLGT.

Studies that combine qualitative research with a philosophical/ethical analysis
The present study combines systematic empirical, qualitative research with a philosophical, conceptual analysis. While there are much research that analyse moral issues either empirically or philosophically/ethically, four studies that combine these approaches, in different ways, are particularly interesting for the present one.57

Concepts from ethical theories can be used as tools in the analysis of empirical data. This is the case in a study in which the ethicist Gunilla Silfverberg analyses professional ethics in interviews with home helpers and managers in home help services. Silfverberg argues that a con-
text-sensitive, situation-dependent virtue ethics provides more functional concepts for analysis of the data than do universal principles as present in universalist normative ethical theories (Silfverberg 1996:17-24). Her study is an interesting example of how concepts from within certain ethical theories, in this case Aristotelian theory, can be used in the analysis of data. Silfverberg also explains that she has worked with the analysis of empirical data and analysis of texts on ethical theories by turns (Silfverberg 1996:22).58

A different approach is available in the multinational study Dignity and Older Europeans. A “circular” process has been used in which an analysis of philosophical literature on the concept of dignity was first undertaken, followed by an analysis of the concept of dignity as used in health care policy documents (reference was also made to dictionary definitions of dignity, in different languages). In the next step, a critical examination of popular/lay understandings (in focus groups) of dignity was conducted, which in the last step was used for the further development of the concept (Calnan and Tadd 2005:11-13). Whereas Silfverberg generated her data for analysis herself, as I have done, empirical researchers (in most cases) performed the empirical research in Dignity and Older Europeans, and philosophers performed the conceptual analysis. Furthermore, Dignity and Older Europeans did not start with the empirical research.

There may be theoretical as well as practical reasons for the approach of Dignity and Older Europeans. I have chosen a different route, whereby the empirical data directs the choice of concepts for conceptual analysis, and I have a more explorative stance in mind than that in the Dignity and Older Europeans study.

Empirical research and ethical analysis has also been combined in interesting ways in a study by Ruth Chadwick et al (1998) on genetic screening and ethics in Europe. The study surveyed the extent to which genetic screening programmes had been developed in different European countries. It analysed social policy responses and developed a normative ethical framework for addressing issues of genetic screening and ethics.59 In terms of methodology, Chadwick et al combined several analytic approaches, such as conceptual analysis, development of a nor-
mative framework through the application of ethical theory and empirical research by questionnaire (Chadwick et al 1998:256). Mairi Levitt (one of the sociologists in that project) has argued that philosophical and sociological bioethics are ‘better together in bioethics’ (Levitt 2003:17). Together, philosophical and sociological bioethics can set an issue in its historical, social, cultural and political context, give voice to otherwise unheard stakeholders or consider ethical concerns presented by health professionals and others (Levitt 2003:17).

Finally, the role of empirical research in bioethics and the question of how results from empirical research can be used in ethical analysis has been thoroughly discussed in the European EMPIRE project. In this project, an overview of a wide range of methods was sought, with the aim of distinguishing the more productive or more suitable methods for bioethics and then defining the most common difficulties. However, the range of methods and goals made the task complicated. Instead, the researchers formulated a set of recommendations for the use of empirical data in bioethics, such as the recommendation that bioethicists should understand and recognize the many factors that can influence a moral dilemma (cultural tendencies, institutional arrangements, religious beliefs etc.) and that moral concepts derive their meaning and force for social actors from the cultural and social surroundings in which they are embedded. The EMPIRE researchers also concluded that discussion of the relevance of empirical research in ethics is often complicated by misunderstandings on both sides (social scientists on one side and ethicists on the other side). Whereas results from empirical research can inform ethical analysis, such results are often significantly simplified when used in ethical analysis (EMPIRE project 2003:36-38).

Disposition

Chapter two of this book describes the study’s framework as well as the methods used, such as semi-structured qualitative research interviews, qualitative analysis and a philosophical, conceptual analysis of certain concepts that were discerned as central in the qualitative analysis. The
results of the qualitative analysis are presented and discussed in the fol-
lowing four chapters, in each of which a core theme is presented and
discussed. Chapter three discusses issues related to medical progress.
Chapter four discusses genetic disease, quality of life and health. Chap-
ter five discusses different conditions for choice with regard to the two
technologies and chapter six discusses interviewees’ descriptions of
uses that were possibly beyond the boundary of the acceptable or the
desirable. Each of these four empirically oriented chapters contains a
summary and a concluding discussion.

Throughout the qualitative analysis, the concepts of choice and
autonomous choice and ambivalence, trust and ambivalence in trust
relations were discerned as central, and these concepts are analysed in
the two philosophically oriented chapters. Reasons why these concepts
are chosen for philosophical, conceptual analysis are explored in the
section Interlude, which functions as a bridge between the empirically
and the philosophically oriented chapters. Chapter seven contains a
conceptual analysis of choice and autonomous choice. Chapter eight
contains a conceptual analysis of ambivalence, trust and ambivalence
in trust relations. In both chapter seven and chapter eight, conceptual
tools are elaborated that are also used in the discussion of certain as-
pects of the empirical data. Each of these chapters also contains a con-
cluding discussion. The last chapter, chapter nine, summarises the
main results of the study. It also contains a final discussion of in what
sense PGD and GMT imply new ways to perform old medical practices
and new practices and what ‘old’ and what ‘new’ moral questions PGD
and GLGT evoke. It discusses similarities and differences between the
use of PGD and GLGT. Against the background of this, the concept of
genetic identity is also discussed.
An Ethical Disease?

A major transformation of medical ethics has taken place during the last 35 years. Contemporary medical ethics, some claim, no longer focuses on the ‘internal morality’ of medicine. The norms and values intrinsic to the medical practice are no longer understood as having special significance for the interpretation and resolution of moral dilemmas within that practice, nor as providing necessary starting-points for moral reflection in medicine. Instead, much medical ethics focuses on norms and values in the prevailing society and culture. It appeals to a set of general ethical principles that can be applied to various dilemmas. The result is a serious tension between theory and practice: contemporary ethical analysis in medicine is at risk of being too decontextualised and abstract as well as underdeveloped on the side of theory (ten Have and Lelie 1998:263-268, Fulford et al 1994:1-2). On the one hand, some hold that there is a significant difference between theoretical discussion in medical ethics and discussion in clinic, which not only isolates ethics from practice but also undermines the validity of its claims (Hedgecoe 2004:121). On the other hand, others claim that medical ethics has come dangerously close to being a technical enterprise performed in isolation from the deep reflection about human life, how it ought to be lived and ended, as a consequence of the demand for immediately useful answers (Elliot 1999:xii). It has failed to pursue substantive ethical discussions as a consequence of being too much engaged in ‘political’ ethics, in making determinations of what ought to be allowed, protected or advanced in public life (Callahan 2000:685). The critical stance, which should be fundamental to ethics, is at risk of being silenced or lost (Doucet 1998:54-55).
The diagnosis of contemporary medical ethics varies, but the frustration of some of those engaged in the field is evident. A case can be made for a chronological development within Western ethics in medicine during the twentieth century that clarifies some of the dissatisfaction and the call, by some, for empirical ethics in medicine (such as Hedgecoe 2004, Haines 2002, Sherwin 2001, Anton 2001, Bosk 2000, Hoffmaster 1993 and 1994, Arnold and Forrow 1993).

During the first part of the twentieth century, Western medical ethics was mainly an intradisciplinary medical enterprise (ten Have and Leie 1998, Veatch 2004). It was engaged in the needs internal to medicine and in the establishment and revision of codes of conduct to which physicians should be obliged to adhere, based on self-reflection from within the medical profession (Pigman and Carmichael 1950, Ivy 1948). The need for codes and a continuous ethical reflection grew particularly urgent when the injustices and inhumanities committed within medicine during the Second World War were revealed (The J.A.M.A’s editorial 1949) and when morally questionably human experimentation was reported after the war (Beecher 1966). It was also a response to the new medical knowledge and subsequently developed technologies, such as the discovery of the genetic code in 1953.

If medical ethics in the early twentieth century was characterised by its intradisciplinary stance and its focus on physicians’ conduct and codes of conduct, the Protestant theologian Joseph Fletcher’s work on patients’ perspectives and agency in medicine (1954) can illustrate the shift in emphasis that gradually took place in the mid-twentieth century. There was a shift in terms of what moral issues were discussed (which meant not that earlier questions were dismissed, but that new or renewed questions were added) as well as of who discussed them.

In substantial terms, the ethical analysis was fuelled by the introduction of contraceptives, legal abortion, possibilities of organ transplantations, different kinds of life-supportive and life-sustaining technologies. It was also fuelled by the development of gene technologies and reproductive technologies, such as assisted reproductive technologies, recombinant DNA technologies and donor of sperm. This evoked fascination as well as concern about the implication of changes in the
human genome for human self-understanding (Thielicke 1964, Rahner 1972) and fears of abuse among medical professionals and the public. Discussions of rights also grew stronger, partly as a reaction against the paternalism of the past, as did the call for solidarity with vulnerable and marginalised groups of people (Doucet 1998:33-34). Medical ethics became a social and societal concern. It was also gradually opening up to other disciplines. In terms of persons engaged in discussion, the many new substantial issues evoked the interest of several of the moral philosophers who had primarily been concerned with metaphysical and meta-ethical positions.\textsuperscript{5} The atmosphere during and after the second Vatican council (1962-65) also paved the way for new meetings between theologians within different traditions.\textsuperscript{6}

These changes, combined with the growing awareness of the lack of a self-evident common framework of moral guide-lines, contributed to the development of medical ethics and influenced what came to be called the field of bioethics: analysis of moral issues evoked by new biological knowledge and applications, in medicine and elsewhere.\textsuperscript{7} From 1970 onwards, several centres were established that focused specifically on the study of bioethical issues.\textsuperscript{8} Though people from many disciplines engaged in the bioethical discussion at the start, representing social science, law, medicine, biology etc., bioethics gradually became a field anchored in philosophy or theology.\textsuperscript{9}

The processes during the mid-twentieth century also paved the way for the construction and establishment of a set of ethical principles that ought to guide medical praxis independently of which ethical theory one might prefer. The principles of the Belmont Report by the USA National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, later elaborated on by Tom Beauchamp and James Childress (2001 [1979]), were met with sympathy. Though there were several other ethical theories/perspectives present, such as personalist ethical analysis (Durand 1999), ethics of responsibility (Jonas 1991 [1979]), and a variety of deontological or teleological approaches, they can hardly be compared with the principlism of Beauchamp and Childress in terms of how quickly they became integrated into medical ethical discussion and how common they became.\textsuperscript{10}
During the later part of the twentieth century (the 1980s and onwards) there was perceived to be a growing gap between theoretical reflection and practical moral difficulties. Many academics from theology, philosophy and sociology and others who engaged themselves in the field had little or no inside medical knowledge (ten Have and Lelie 1998:264) and these academics were sometimes accused of contributing mostly with reflection on notions and arguments and not providing answers to moral dilemmas. Furthermore, sympathy for the principle-based approaches to ethics in medicine was somewhat fading. Despite many variations in content and foci, a common line of criticism of the principle-based approach to ethics can be discerned. It was argued that a theoretical ethical discussion in medicine needed be conducted in proximity to the complexities of everyday life and that, correspondingly, principle-based approaches that encouraged decontextualised ethical analysis were inadequate (Winkler 1993, Sherwin 1989, Clouser and Gert 1990). It was held that the principle-based approach to ethics failed to make phenomenological interpretations of human action or of ‘thick’ concepts, such as health, death, pain and life (Lantz 2000). It was also held that caution was necessary when making statements about the content of a common, generalisable morality in the form of a set of principles, since these principles were neither as neutral nor as universal as had been claimed (Carrese and Rhodes 1995, Donchin 2001, Tangwa 1999). 11

Bioethics and medical ethics during the later part of the twentieth century can be characterised by self-criticism and a renewed discussion of the goals and methods. Deontological and teleological ethical traditions as well as Beauchamp and Childress’ biomedical ethical principles (in which aspects of some deontological and teleological ethical traditions are combined) are strong. Still, the late twentieth century also encompassed a (re-)newed interest in conceptions of ethics in medicine such as narrative ethics, virtue ethics, feminist ethics, casuistry, communitarianism, hermeneutical and phenomenological approaches to ethics – and empirical ethics. Despite their many differences, these conceptions represent an attempt to bridge the gap between theory and praxis. In order to succeed in this, some claim that a ‘new bioethics’ is needed (Kleinman 1999), and that this will involve an ‘empirical turn’ in ethics (Borry et al 2005).
Why Empirical Ethics in Medicine?

Empirical research and ethics are sometimes described as separate phenomena, the one concerned with description, reconstruction and analysis, the other with conceptual clarification and normative justification (Schmidt 1994:318). Such a description has the benefit of clarifying differences in goals, tasks and methods between the two. It fails to acknowledge the importance of attending to the relationship between theoretical, conceptual concerns and concerns evoked from a certain concrete practice. I hold such an attention to be important for discussion in bioethics: the gap between theory and practice needs to be bridged for the sake of a more nuanced and full-fledged theoretical ethical discussion and, also if theoretical ethical reflection should have a bearing on what takes place and can take place in actual clinical settings.

Empirical research is valuable since it allows the exploration of moral experiences, norms, values and convictions, i.e. moral constituents of particular medical practices. I consider such an exploration necessary in new and quickly developing areas of high moral complexity, since without it we may not grasp the complexity of moral issues within such areas. Complexities in practice may not be foreseen, and if foreseen, their nuances may not be grasped. The understanding of the moral constituents of the particular practice is crucial if the gap between theory and practice is to be bridged.

Empirical research is also valuable since it, if concerned with moral questions as social questions, highlights the social processes through which something becomes a moral question worthy of being addressed as well as the processes that make certain moral questions become marginalised, i.e. not addressed or described as unimportant. This does not mean that moral questions discussed in practice are necessarily the most important ones to someone else. It means that empirical research in ethics focuses on moral aspects that actors with experience of that practice consider difficult, interesting and/or relevant, which again is important in order to bridge the gap between theory and practice.

Conceptual analysis also contributes to empirical research. A conceptual discussion can structure, clarify and make useful distinctions that can contribute to the further discussion of the empirical results.
I concur with the feminist philosopher Susan Sherwin (1996) in holding that the connection between theory and practice runs both ways. For the present study, this means that conceptual discussion of terms used in a certain clinical setting benefits from being set in relation to the experiences from within that practice and that the explorations of the particular practice benefits from a conceptual discussion and elaboration. This view must not be confused with the view that for example the results of empirical research on attitudes as such can justify a certain standpoint in normative ethics. This is not the place to enter into a discussion of the role of empirical research in normative ethical discussion: this study does not make a claim for such a combination, but for the combination of empirical research and philosophical, conceptual analysis.

The Framework

Key Concepts

The framework has been developed in consistency with the methods chosen. Its key concepts are moral perception, concrete others, ethics, morality, empirical ethics and bioethics.

Moral perception entails that some issues are perceived as moral issues, some situations as moral situations and some situations as morally important situations. I concur with the philosopher Martha Nussbaum in arguing that in seeing and hearing, we see and hear a world already ‘interpreted and humanized by our faculties and concepts’ and that moral perception influences how we interpret the world and what ‘discriminations of colour and shape’ we make (Nussbaum 1990:164). Moral perception is in this sense a matter of sensitivity and it has an influence on how we interpret a given situation as well as, probably, how we respond to it (Blum 1991).

Moral perception presupposes certain abilities with both cognitive and emotional dimensions, such as the ability to discern a morally complex situation with emotional nuances (compare the ability of fine-tuned perception in Nussbaum 1990:84, 155-157, also Walker 1999,
The abilities involved in perception can be more or less developed and be made more or less sensitive to nuances (Sherwin 2001). Moral perception is also, always, situated. There is no moral perception from nowhere and moral perception is always a matter of an embodied vision of a concrete moral self.19

As a matter of moral epistemology, I cannot take for granted that what I perceive as important moral issues from my perspective – due to my perception – are also seen as important moral issues by all others, not even within my own socio-cultural context. Depending on in what position we are, in what social relations, what sex and ethnicity we have, what our previous experiences are, our moral perception can vary. This understanding has consequences for how I understand my position as a researcher. When I engage in the analysis of empirical data, I do so trained as an ethicist and not as a sociologist. Whereas a sociologist may have focused more on the social processes that make PGD an issue for discussion, I have focused on the morality of the technology. My understanding of moral perception also motivates the empirical research in ethics. When I approach a morally complex practice, it is important that I listen to others’ reflections from within that practice – if I want to understand the morality of the practice. Obviously also of importance is my ability to explore and understand differences in perception.

The question of how to understand what issues others perceive as moral issues (and how they do so) is one of the core questions in the ongoing discussion of what Seyla Benhabib (1992:178-182) labels the generalised other versus the concrete other. The generalised other is the other human being who is as I am and to whom I can generalise starting in my own experiences. The concrete other is necessarily distinct and different from me, without being completely other (which would make communication impossible), and she or he has a distinct history and identity. This distinctiveness also matters for her or his moral perception, for what she or he perceives – and for what I myself perceive in terms of morality. I also concur with the feminist philosopher Virginia Held (1993) and with Benhabib (1992) in holding that in the domain of concrete others, the self is constituted to an important degree by relations with others.20 These
relations with concrete flesh-and-blood others with whom we have real
ties, Held suggests (1993:57-58) may be much more significant and sali-
ent than the interest of any individual self in isolation and, if so, this also
motivates empirical research in ethics.

Concrete others, with experience from within a certain practice,
can perceive moral complexities and nuances from within that practice
in a different sense than I can, as a researcher without such experiences.

I also distinguish between *morality* and *ethics*. Ethics is the system-
atic analysis of morality. Morality includes moral experiences, moral
norms and values as well as what is/has been understood as or is antici-
pated as morally right or good in terms of acts, standpoints, ideas or
ways of living. I concur with Iris Marion Young (and others) in holding
that not only public issues such as the just distribution of health re-
sources but also private issues such as the experience of disease or
gendered division of child-caring should be welcomed in ethical discus-
sion. The latter should not be a priori banished into the silence of the
private (Young 1990:73-76).\(^{21}\)

The label *empirical ethics* will be used for research that combines
empirical research with philosophical, theological or ethical analysis of
moral issues, not for empirical research on morally complex issues in
general.\(^{22}\) The label *bioethics* will be used for research on moral issues
evoked by new biological knowledge and applications, in medicine
and elsewhere, in a wide sense. I stipulate that bioethics also includes
moral issues evoked in the clinical encounter, when new biological ap-
plications – such as new technologies – are topics for discussion. Hence,
the label empirical ethics clarifies what kinds of analyses are performed
whereas the label bioethics clarifies what kind of moral issues are ad-
dressed.

The moral issues can also be related to or lead to other issues regarding
the meaning(s) of life, views on humankind, on the nature of knowledge
or God; and, I hold, the ethical analysis needs to embrace analysis of
*morally relevant life interpretations* if these have implications for moral
standpoints.
Objects for Study

The objects for study are morally relevant life interpretations, norms, values and moral experiences. Morally relevant life interpretations are interpretations of how human life is and should be, interpretations of the meaning(s) of life, of what are important ways of handling difficulties in life, such as disease, death, suffering, despair and guilt, but also have to do with understanding of the greatness of life, of love and happiness that are not necessarily moral but that clarify why something is seen as morally relevant and/or as evoking moral questions. In this sense, life interpretations are morally relevant without necessarily being moral in character. I also take morally relevant life interpretations to include interpretations of notions that are not typical moral notions (such as right or duty) but that have moral implications and contribute to the understanding of how human life is or ought to be. Health and disease are examples of such notions. These notions are not only interesting with regard to acquiring a deeper understanding of what is at stake in a morally problematic situation, but the particular interpretation of them can influence what are seen as moral aspects or issues. As a slight tangent, I will now briefly comment on the related notion of lifeviews, in order to clarify the difference.

The notion of lifeview has been systematically structured by the theologian Anders Jeffner (1988). The overarching purpose of lifeview studies as understood by Jeffner is to explore and describe complexes of representations and values within a population, starting within the individual human being’s reflections rather than with a pre-defined system of dogmas, representations, values or the like. The purpose is also to explore the interplay between three important elements in Jeffner’s definition of a lifeview, namely theoretical and evaluative assumptions, value systems and basic attitudes (Jeffner 1988:3-4). This first strand of Scandinavian lifeview research focuses primarily on the theoretical-cognitive aspects of lifeviews, whereas a second strand emphasises the functional aspects (Lindfelt 2001:301-304). Within the second strand, a lifeview has been defined as ‘the verbal expression of the (adult) human being’s fundamental way of orientating herself or himself in life’ (Kurtén 1995:19 [my translation from Swedish]).
In both cases, the aim of lifeview research is primarily to explore lifeviews. As a possible secondary issue, the aim can be to explore whether there are statistically significant moral differences in attitudes between groups of people with different lifeviews (Kallenberg et al 1996:106-111) or to explore whether there are moral difficulties deriving from or articulated within the perspective of a certain lifeview. It may also be argued that a certain lifeview has moral dimensions in terms of a quest for living as learning, if authenticity and trustworthiness are crucial elements in someone’s lifeview. In either case, within lifeview research, the analysis of a lifeview (its content or function) is primary to the analysis of moral questions. Within the present study, this is not the case, and this is the reason why I have chosen the concept of morally relevant life interpretations instead of lifeviews. It indicates the different purpose and focus of this project.

Concerning the concept norm, I understand it in two senses. A norm is a prescribed guide for conduct or a pattern of normatively governed behaviour. Whereas the first use of the concept focuses only on what is prescribed, the second use also encompasses actual behaviour. I understand a value as something that is considered worth having, getting, acting for, since it is considered valuable for its own sake or as a means to something else. A value can also be something that is described as valuable, again for its own sake or as a means, within a certain practice or culture. In the latter sense, values can be non-evaluated and descriptive.

Finally, experience, the theological ethicist Margaret A Farley (1996:135) says, in a quote that catches some of the doubleness of the notion, is ‘given but not primitive, immediate but not innocent of interpretation, personal but not isolated, unique but not without a social matrix.’ Moral experience, Held states, as opposed to experience in general, is the experience of consciously choosing to act, or to refrain from acting, on grounds by which we are trying conscientiously to be guided. Moral experience is the experience of accepting or rejecting moral positions for what we take to be good moral reasons or well-founded moral intuitions or on the basis of what we take to be jus-
tifiable moral feelings. Moral experience is the experience of approving or disapproving of actions or states of affairs of which we are aware and of evaluating the feelings we have and the relationships we are in (Held 1993:24.)

I understand moral experience in the Heldian sense. It is the experience of consciously choosing, of consciously approving or disapproving of actions or states of affairs. It is also the experience of a changed life situation whereby I engage in reflection on, exploration and evaluation of, moral aspects of that situation.

To say that moral experience is interesting for ethics implies a certain focus. It says less about in what sense experience matters. The benefit of analysis of moral experience in this project is that it can indicate phenomena in need of discussion and complexities and nuances of those phenomena.28

Ethical reflection can, of course, be articulated through the use of narratives as well as in arguments and arguments can be explicit or implicit. How can we gain access to such reflection? I believe that a certain kind of empirical research is important with regard to this.

Empirical Data, Its Character and What It Can Be Used For

In order to explore moral aspects of uses of PGD and GLGT, as described by the interviewees, it was not sufficient to use philosophical thought-experiments nor questionnaires. Topics for discussion could not be decided on beforehand without risking missing crucial aspects. I also considered it important that interviewees could expand, sometimes at length, on moral issues that they thought to be interesting, relevant or difficult from within their professional experience (and to give concrete examples from their work). Qualitative interviews served this purpose and open-ended questions gave the interviewees the opportunity to choose what issues to expand on. It enabled me, as the interviewer, to follow up what they said with further questions.29

As commented upon earlier, the ability to explore and understand differences in what are perceived as moral issues within a certain practice is
crucial in any analysis of morally complex practices. Interpretation of empirical data needs also be done with care and caution since the discussed moral issues are likely to be influenced by the interview context, the interviewee and the interviewer. I understand the interviews in interactional terms and I concur with those who claim that communication is ‘mutually other-oriented’ (Linell 1998:35). In communicating, we at least most often try to orient ourselves towards the other, which also matters for how and what we communicate. As a consequence, the empirical data cannot be understood as indicating what the interviewees ‘really’ thought, but only what they chose to tell under the given circumstances.

The distinction between ideas and assumptions as objects for study and ideas and assumptions held to be true is important in this discussion (Tegern 1994:36-38). My interest was directed at what moral aspects of use of the technologies interviewees chose to speak of. An interviewee may consciously or subconsciously choose to focus on what she or he considers ‘right’ experiences or reflections (experiences and reflections that the interviewee expects that the interviewer wants to hear or that the interviewee considers show a correct moral reflection in some sense). The interviewee may choose to talk about experiences and reflections that she or he, for different reasons, wants to, or has the energy to discuss. She or he may choose to talk about certain experiences in order to position her- or himself in ongoing discussions (which can indicate what is at stake in the particular practice).

What interviewees chose to tell is interesting for the exploration and understanding of the clinical practice. I concur with the researchers who hold that we, when communicating our view on a certain phenomenon, use conceptions and assumptions present in the particular practice/culture/society in which we work and/or to which we belong (Gee 2002:16, 86) and that we, as individuals, when interpreting and discussing a certain phenomenon, draw upon the different kinds of ideas present in our surroundings (Radley 1994). In this sense, the analysis of what conceptions and assumptions interviewees articulated contributes to the understanding of the morality of the practice in which couples can be referred to PGD units or in which PGD can be offered, or in which GLGT may, possibly, be a future technology.
Qualitative Research Interviews

Selection of and Invitation to the Interviewees

I concur with the many feminist ethicists who claim that the voices of the marginalised need to be listened to, which in the context of medicine would mean patients or the public and not medical professionals (Overall 1996:167-168, Grey 1993:16, Sherwin 2001:185). However, I have chosen to interview medical professionals for two major reasons. I consider medical professionals to be interesting as interviewees since they both contribute to and shape the discourse concerning what the moral dilemmas and possibilities are in the clinic and are themselves shaped by this discourse. I also consider medical professionals to be interesting as interviewees since their views on moral aspects of PGD and GLGT have seldom been analysed systematically, this in contrast to the views of different patient groups (see Ch. 1, Situation the Study in Earlier Discussion).

My reasons for not interviewing patients instead of professionals, apart from the fact that such interviewing have been done by others, were ethical and methodological. If couples with less than positive or even traumatic experiences of PGD should be chosen, this would raise questions regarding the responsibility for any emotional distress the interviews as such evoked. If only couples who did go through a successful PGD should be chosen as interviewees, the stories told might be mainly the ‘positive stories.’ Other, less positive stories might not be told as a result of the choice of these interviewees. Since the purpose was to get a wide spectrum of reflection, such a choice of interviewees was considered as less appropriate. The choice to invite geneticists and gynaecologists as interviewees was based on the idea that they, as part of their professional belonging, would be aware of on-going and new genetic research and applications. 32

Interviewees were chosen so that a broad spectrum of reflections was encouraged, and it was assumed that such a spectrum was enabled by the choice of nationalities. Ten women and eight men were invited, both junior and senior geneticists and gynaecologists,33 and they had varying professional experience. Two of the Italian interviewees worked or had worked with PGD, two of the British interviewees...
worked with PGD, and three of the Swedish interviewees worked with PGD. The other interviewees worked at other clinical units and/or in research. One of the Italian interviewees describes himself as Roman-Catholic and four describe themselves as liberal Roman-Catholics. Two of the six British interviewees were Anglicans, and two of the six Swedish interviewees were Lutherans. The other Italian, four British and four Swedish interviewees did not describe themselves as religious in any confessional sense. One of the interviewees explained that while she was happy to discuss PGD, she did not want to discuss GLGT. I agreed to discuss only the former technology with her since I considered her to be an important interviewee.

Choosing professionals as interviewees meant that first-hand experiences of women and men at risk for a genetic disorder were mainly being left out, if geneticists and gynaecologists did not choose to tell their own personal experiences as patients within reproductive genetics. As will be seen, though, they sometimes did choose to do so.

Four test interviews were conducted before the proper interviewing started, and the initial contacts with interviewees were made through mail or e-mail. Interviewees were given a description of the project, a description of the purpose of the interviews and an invitation to participate.

Description of Interviews

All interviews were tape-recorded and transcribed. Interviews in Italy were performed in May 2000, interviews in Britain were performed in February-May 2001 and most interviews in Sweden were performed in 2000-2001. For practical reasons, one Swedish interview was done in February 2002 and one in October 2004.

The interview content may be influenced by the local geographical context, i.e. where it takes place. Whereas I would have preferred a neutral place, outside the clinic, this was often more complicated for the interviewees and I performed all but four interviews at the interviewees’ clinic/unit (one of the interviews was performed at a hotel, one in the interviewee’s home, one at a monastery and one at a café). Interviews lasted from 50 minutes to two hours.
The interview guide was semi-structured. Formulations of questions varied as well as what was focused on in the discussion, but certain topics were addressed in all interviews (see appendix B). Each interview was opened with a short description of the purpose of the study and the interviewee was asked if, and if so how, she or he had been in contact with PGD. Interviewees were asked how they would describe the positive aspects and the negative aspects of the use of PGD, from their perspective, and if there were any experiences that had made them reflect on moral aspects of PGD in particular. They were also asked how they would describe the previous situation (before PGD existed), the present one (when PGD was possible for certain genetic diseases) and what, if any, differences there were for them as professionals as well as for their patients (as they interpreted it). All interviewees had been in contact with PGD in at least a loose sense, either through discussions at ‘ordinary’ clinics of gynaecology, medical genetics or clinical genetics or through their concrete work at PGD centres. This was not the case with germ-line gene therapy. The majority of the questions asked were related to PGD, and interviewees’ reflections were longer and more detailed when related to PGD. Some interviewees also excused themselves for not being up-to-date on the developments of germ-line gene therapy and for not having spent time to reflect on it, whereas this was never the case with PGD. Questions concerning germ-line gene therapy were asked in the later parts of the interviews. The open-ended questions were also followed by questions directed at certain specific concepts (see, again, appendix B). In conclusion, interviewees were asked if there were any experiences that they considered more relevant than others when it came to what they thought of the technologies and whether there were any parts of their possible life interpretations that they considered relevant to what they thought of the technologies and that they had not talked about earlier on in the interview.

The Italian interviews were done first and a preliminary analysis of these interviews was made before continuing with the interviewing. The aim of this preliminary analysis was to explore the interviews and see if the interviewees spontaneously added certain themes, and if so, if such themes should be added to the interview guide. One such theme
was found, the concern with how the notion of health should be understood. Health as a theme to address was added to the interview guide used in Britain and Sweden.

**Quality, Validity and Ethics**

In order to enhance quality, I performed all interviews myself. In order to enhance validity, I undertook different kinds of analytic steps (see section *Qualitative Analysis*, below) in order to make sure that my choice of methods did explore what I intended to explore: the moral constituents articulated by the interviewees. I also performed test interviews as a start. Selected transcribed interviews have been discussed with researchers at my department for the purpose of elucidating possible interpretations of the data. As a matter of research ethics, interviewees were informed that so would be the case when they were first approached.

To be translated, the philosopher Susan Sontag (2001:339, 347) says, is to die a bit. This also catches a dilemma of cross-cultural analysis. When a word is translated, it is sometimes difficult to find a word in the other language that has the same connotations and meaning. This dilemma is discussed by Dorothy C. Wertz (1998c:157), a sociologist with experience from several multi-national quantitative studies in the field of ethics/genetics. She exemplifies her point with the politically correct person-first language used in the USA in descriptions of people with a genetic condition (child with CF instead of CF child). According to Wertz, these choices of English words for the sake of avoiding demeaning descriptions have no clear equivalent in a Latin language as French. However, though correct in the USA, person-first language needs not be correct in Britain. As an example, the term ‘disabled people’ has been claimed as being preferable in Britain, as opposed to the American ‘people with disability,’ since the former signifies that people with disability are disabled by an exclusionary society (Shakespeare 1999:686).

Language-differences such as these will frustrate an absolute comparability of concepts, and these difficulties need to be acknowledged and taken into account. Three languages were used in the empirical
data. English was used in the British interviews and Swedish in the Swedish interviews. Italian interviewees were asked which language they preferred, Italian or English, and two of them said they could just as well speak English. In these interviews, we spoke English. In the case of one of the Italian interviews, the interviewee said he could just as well speak English, but as the interview proceeded we changed to Italian. In the other three, we spoke Italian. I have transcribed some of the Swedish interviews; another native Swede has transcribed the rest of the Swedish interviews. In order to enhance quality, a native Italian has transcribed the Italian interviews and a native Briton and a Swede living in Britain have transcribed the British interviews. In the next step, I have listened to the tapes three times each in order to make sure that the transcripts were correct. In the following chapters of this book, Italian and Swedish excerpts are translated into and presented in English. In order to enhance quality, and with the aim of translating and interpreting the data as carefully and cautiously as possible, I have sometimes discussed the translation with native Italian- or English-speaking people; and in some cases, the Italian or Swedish original excerpt will be found in a footnote.

As part of the invitation, interviewees were guaranteed anonymity and were offered the opportunity to read the interviews after they had been transcribed; they were also asked if they wanted to do so after the interview. The project follows the ethical guidelines of humanistic research (Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning 2002 [Principles for Research Ethics in the Humanities and Social Sciences, my translation from Swedish]). In order to guarantee anonymity, I have chosen not to indicate the positions of the particular interviewees, and all names are fictitious. I have also considered it necessary, as it were, to change the sex of one of the interviewees. This is, of course, a strange approach, but after many discussions with colleagues, I considered this to be the best way to maintain anonymity.37 Interviewees were chosen since they were professionals and the questions discussed were not considered personally sensitive for them, and the analyses have dealt with what interviewees chose to express verbally.38 It is important to note that the objects for study were
the moral constituents (values, norms, moral experiences and morally
relevant life interpretations) that the interviewees chose to talk about,
not the interviewees as persons.

In the presentation of the analysis of the data, I have sometimes
presented excerpts from the interviews. My choice of excerpts has been
made on the basis that they should exemplify and clarify certain values,
norms, moral experiences and morally relevant life interpretations that
an interviewee expressed. In the presentation of the analyses of the
data, one interviewee is quoted more often than the others. This inter-
viewee was more articulate than the others, but similar reflections were
present in other interviews as well.

Finally, owing to the small number of participants, the data is not
generalisable in a statistical sense.

Methods of Analysis

Transcription

Interviews were transcribed word-for-word and intonations or dialects
were not indicated. Longer pauses (>1 sec) were indicated, as well as
intrusions into the person’s speaking sentences. For the sake of enhanc-
ing the readability for those not used to reading transcripts, pauses and
intrusions are not present in the excerpts presented in the book. The
excerpts have also been modified slightly in order to fulfill minimal
grammatical requirements.

Qualitative Analysis

In the selection of analytic methods, it is important that the methods
chosen fit the purpose of the study and the interview questions asked
and not the other way around (Holm 1997:80). Since one of my aims
was to explore what moral aspects of the use of PGD or the hypotheti-
cal use of GLGT interviewees described as relevant, important and/or
interesting and since the interviews were semi-structured in order to
allow this, it was suitable to perform analysis of the data through line-

Codes have been generated from the line-by-line analysis and they are closely related to smaller sections of the empirical material. They have been reviewed and provisionally arranged under more general topics, from which core themes have constructed. The core themes represent the most generalised level, the codes are closest to the data. I have looked for patterns (compare ‘pattern coding’ in Miles and Huberman 1994:69-72) as well as for what differentiates one interview or one section of an interview from others. Four core themes were constructed and they are presented in one chapter each (Chs. 3-6).

I have also conducted a slightly different reading of the interviews, when I marked values, norms, moral experiences and morally relevant life interpretations in order to make sure that these were part of the construction of topics and themes – which indeed they were.

Furthermore, I considered it useful to explore and analyse narratives within the data since many interviewees used narratives in their moral reflections. I understand a narrative as a story of a sequence of events that has happened in the past, that is told in order to make some sort of point. It has an internal logic that makes sense to the narrator (Denzin 1989). I understand narratives as embedded in the social context in which they are related (Herrenstein-Smith 1981). By using the narrative form, we assign meaning to events, place events within a certain order and evaluate them and invest them with significance – and often with a moral significance (Polanyi 1989:20).

Following the researchers who have explored the story-line of narratives, I have explored the narratives’ key events, i.e. events that bring about a change in the story, that are relevant to the narrative’s moral or point and that the narrator evaluates (Polanyi 1989:21). Stories with a moral or a point have a long tradition and they are told with a certain purpose; a number of different morals/points can also be identified within one and the same narrative (Adelswärd 1997). I have focused on the overall moral of the story, articulated when the interviewee said how the story should be understood, explained and/or valued. In this

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sense, the interviewed medical professionals became ‘storytellers’ (Ettorre 1999). What I label the ‘overall moral’ can also express and mirror the narratives’ value systems (Adelswärd 1997) or explanatory systems (Linde 1986). In congruence with the interactional perspective on interviews, I concur with those who hold that the interviewer can contribute to the narrator’s evaluation of the particular story, through her or his ways of responding to what is told (for a discussion of this phenomenon, see Adelswärd 1991, Duranti 1986:240).41

Throughout the analysis of the empirical data, I have constructed analytic terms, which I use as tools in order to conceptualise certain aspects of the data. These terms are presented together with the results of the qualitative analysis. Some of them are used in the next analytic step, in the philosophical, conceptual analysis.

Finally, the different qualitative analytic steps – coding, arrangement of topics, construction of core themes, identification of values, norms, moral experiences and morally relevant life interpretations, analysis of narratives and construction of analytic terms – have resulted in the identification of four concepts that were central to the interviewees’ reasoning and that are further discussed in the conceptual analysis.

**Philosophical, Conceptual Analysis**

A conceptual analysis can start with a search for core elements that can be found in prevalent uses of the concept. Such core elements can be further elaborated in such a way that they become coherent and useful for scientific purposes. In this sense, though the basis is an already existing concept, the concept is also reconstructed and influenced by the process of analysis (Nordenfelt 1987:11). Such has also been done in this study. I have used the results of the qualitative analysis in the elaboration and discussion of a set of distinct characteristics of each concept. These characteristics are also reconstructed and influenced by the process of analysis.

Furthermore, I decided that the characteristics needed to fulfil the criteria of being logically consistent, coherent and empirically possible. As an example, the characterisation of the concept of autonomous choice
needs to be logically consistent and coherent and there should be no ‘empirically grounded or theoretically derived knowledge’ that makes it either impossible or most unlikely that anyone will have autonomous choice, given how I have characterised it (see also Dworkin 1996:7).42

My intention was also to elaborate and discuss concepts in such a way that they were applicable to the empirical data; they should make possible a discussion of the previous results of the analysis of the empirical data.

I also considered it important to note that just as the identification and description of moral issues within a certain practice depends on one’s moral perception and is a matter of moral activity, so also is the choice of concepts for conceptual analysis. The concepts we choose to invoke when we structure our moral thoughts as well as the ways in which we interpret and analyse these concepts can have moral consequences when they are applied to our actual moral life (Sherwin 1996:190). In this sense, I concur with Susan Sherwin (1996) in holding that the conceptual analysis needs also to take into account the effects that its use is likely to produce when applied to the context in question.

Finally, conceptual analyses are always (more or less) normative.43 They are designed to be as correct and useful for a certain purpose as possible. This normativity at the conceptual level can be distinguished from normativity in normative ethics. Using the former, we may be able to argue that if certain crucial conditions for, for example, autonomous choice are not met, a certain person in a certain situation does not have such a choice. It says nothing about whether she or he ought to have autonomous choice. These kinds of normative discussions are sometimes combined and sometimes confused. As part of the conceptual discussion, the latter kind of normative discussion will be kept at a minimum.

Presentation of the Qualitative Analysis

A certain section within an interview cannot be understood as an isolated utterance, able to be torn out of its place within the interview, without the risk of its losing or changing its meaning. Consequently, when I present the analysis I will create a new context where utterances

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from different interviews are brought together. Thereby I also create a meta-narrative.

The results of the different analytic steps in the qualitative analysis are not separated in the presentation. I regard the narrative exploration as a part of the construction of core themes and I have presented results of the narrative exploration when I have considered it helpful for the reader’s understanding of a certain theme. As part of my intention to focus not only on patterns but also on differences, I have also stated whether a certain view was common or not in the empirical data. Likewise, excerpts are presented when this has been considered to be helpful to the reader, as a means to allow a closer understanding of the reflections put forward by the interviewees. I have tried to describe what some call the co-text of the interview: sequences of relevant utterances prior to the utterance quoted, where in the interview something is said and what questions are asked before an interviewee brings up a certain topic (Linell 1998:128). This information is sometimes part of the text and sometimes present only in footnotes. The coined analytic terms are presented in italics in chapters three, four, five and six.

Finally, the reading of the interviews with special attention to values, norms, moral experiences and morally relevant life interpretations showed that none of these were lacking in the qualitative analysis; all were already part of that first step of the work. I summarise which values, norms, moral experiences and morally relevant life interpretations have been discussed in the end of each of the empirically oriented chapters. Such a list of these markers of a moral discussion could also have been presented in the beginning of each of these chapters. My reason for not doing so is that it could encourage a non-interactionalistic understanding of my data, which I take to be unfortunate: what is said takes place in a certain context. In the end of each of the empirically oriented chapters, I also discuss certain aspects of the results in relation to previous research and I make some further distinctions of relevance to the results in the particular chapter.
The analysis of the empirical data resulted in four core themes: medical progress, genetic disease, quality of life and health, conditions of choice and uses beyond the boundary. The first of these, the core theme of medical progress, is presented and discussed in this chapter.

Some interviewees told narratives of progress, i.e. stories that indicated that there was an on-going technical progression within medicine. Technologies had been or were being developed which were, in different senses, described as better than previous technologies. These narratives were often told as a response to questions if – and if so, how – the interviewees perceived the difference between the previous situations when PGD had not been available and the present situations when PGD was available for certain genetic diseases. They occurred at the beginning of the interviews. Narratives of progress also, sometimes, served as a point of reference. Some interviewees returned to these stories and they then told other stories that highlighted concerns that they had as regards uses of PGD and, sometimes, their ambivalence regarding how to describe and evaluate the use of PGD. Just as narratives of progress were told at the beginning of some of the interviews, I present these narratives in this first empirical chapter. It will serve as a point of reference against which interviewees’ other stories and reflections can be contrasted and against which the ambivalence can be explored. Interviewees did not encompass GLGT as a matter of progress. GLGT is briefly discussed in the last section of this chapter.

Narratives of Progress

Screening tests, which identify groups of pregnant women who are more likely to be carrying a child with a genetic disease than other preg-
nant women, have been available since the 1950s as have methods for prenatal diagnosis of foetal cells by the use of amniocentesis. Amniocentesis is usually performed between weeks sixteen and twenty in the pregnancy and the results are often given three to four weeks later (Green and Statham 1999:141-142). Studies have shown that many women consider this waiting period stressful and it has been assumed that another, more recent method for prenatal diagnosis, chorionic villus sampling may be less stressful (Green and Statham 1999:148). The refinement of the technologies for early sampling of foetal cells combined with the development of technologies for rapid genetic analysis have also made it possible to perform tests and obtain results in the first trimester of pregnancy (Snowdon and Green 1997:341) – in some cases as early as in the seventh week of pregnancy (Bussani et al 2004). However, if prenatal diagnosis is to be combined with selective termination of pregnancy it rests on the acceptability of such termination. Methods such as amniocentesis and chorionic villus sampling were available in what I call the pre-PGD era. They are also used in the PGD-era in Sweden, Italy and the UK. In the PGD-era, it is also possible to perform genetic diagnosis of embryos. Interviewees described the difference between (different) previous and present situations in detail.

Despite other differences in experiences and views, all interviewees were agreed on one point. The situation for couples at high risk for genetic diseases was not better before PGD (though a few held that it was equally problematic now). According to most of the interviewees, use of PGD could have medical, technological and moral complications or even back-lashes, it could be perplexing and delicate, but at least it was an alternative for certain couples at risk for certain conditions. It was in some important ways better for some couples than were previous alternatives. Several of the interviewees, when asked to compare the pre-PGD and the present situation, described previous situations as in different senses undesirable.

When describing the earlier situation when only amniocentesis was available (and when amniocentesis was less accurate than at present), some interviewees explained that this situation was ‘horrific,’ as for example did Joyce. It was ‘hugely distressing’ to the family. It was also
distressing to the medical professionals involved (9.12). Joyce told stories of young women whose brothers had been affected with a severe X-bound genetic disease and who were ‘desperate to avoid themselves having an affected child’ (9.12). She also explained that some women did not dare to become pregnant since they suspected that they were carriers of a genetic disease. Other women, who expected either themselves or their partners to be carriers of a severe X-bound genetic disease, would terminate any male pregnancy in order to escape the risk of giving birth to a severely sick son. Daughters were born, this interviewee recalled, since they would either be non-affected or be carriers (9.12). Joyce also told the story of some of the women she met in counselling, who had only a ten per cent or twenty per cent risk of being carriers. ‘You knew,’ she said,

and they knew, that the baby, that they’d aborted, was probably normal. They just couldn’t take that chance and that was awful, I mean, it was so tragic for them. (9.12)

Sometimes, she explained,

you were almost screaming out “oh for goodness sake, just take a chance because it will probably be all right.” But you knew it wasn’t probably going to be all right. You knew you couldn’t encourage people to take that risk. (9.12)

Joyce, as well as other interviewees, described chorionic villus sampling as a break-through and an important change in the options available. They described it as a method that could give women earlier information and this was important. ‘Compared to the horrors of a very late termination,’ Joyce explained, chorionic villus sampling ‘was an incredible advance and they [the couples who used it] certainly were able to cope with that much better’ (9.12). The refinement of the technologies used represented further steps forward and, Joyce said, the women concerned could plan future pregnancies to an extent that had not been possible before. Women could also be given secure information about the genetic status of the foetuses. According to Joyce, ‘you’re now do-
ing a termination because of the certainty of something, because you’ve got a precise molecular diagnosis’ and this was not the case before (9.12). As narratives of progress unfolded, different steps in this progress could be discerned and further progress was sometimes described as expected.

If amniocentesis represented the first step in the stair of progression, chorionic villus sampling was commonly described as the next step. Whereas Joyce’s narrative of progress ended with the recent refinement of technologies for prenatal diagnosis, other interviewees’ narratives encompassed PGD as a matter of progress. When different methods for prenatal diagnosis were compared with PGD, the availability of the latter was described as having positive consequences for women and men at high risk for genetic diseases, and particularly so since PGD would mean a selection of embryos before implantation. Information could be given much earlier than in any kind of prenatal diagnosis – and abortion was never an issue.

Some interviewees also described PGD as having positive consequences for them as medical professionals in their everyday work. Such was the case when Åsa explained that for some women and men, who may have gone through prenatal diagnosis and abortion or miscarried several times, in vitro fertilisation (or another kind of ex-corporeal assisted reproductive technology) and PGD was a ‘last straw to clutch at.’ She also said that ‘it always feels good to have been able to offer something more [to these couples]’ (16.26). Such was also the case when Andrew explained that the possibility of PGD made his everyday work ‘easier’ even if it did not always result in the birth of a healthy child.

Andrew told a narrative of progress that started with a description of the pre-PGD situation as ‘frustrating’ and as offering little possibility of acting. There was little or nothing ‘to offer.’ In his words:

I would meet somebody with a translocation who had recurrent miscarriages. In the cases of translocation, it used to be, it would be very frustrating. I would see somebody with recurrent miscarriages who had a translocation or a husband with a translocation. You couldn’t do anything other than roll the dice each time. Maybe you’d get lucky. Whereas now you can actually offer something concrete. (8.20)
The metaphor ‘roll the dice’ is to be noted. The rolling of the dice, used by the Romans in order to find out what destiny, fate or chance had in store, was used as a means to describe the conditions of hazard that couples had to live under – conditions that doctors could not change. Before PGD and particularly before prenatal diagnoses, rolling the dice was a necessity because of the absence of alternatives. Couples who knew that they were at risk for a particular condition had to choose between not becoming parents and accepting that the child born might have a serious condition (or, when adoption was available, adopting). This was no longer the case. Rolling the dice was no longer necessary.

Andrew’s narrative continued with him explaining that before he started at the PGD clinic, he had not reflected on the situations of some of the couples that he now met every day. Meeting them was an ‘eye-opener.’

I had never met with the kind of tragedy that you see day to day in the PGD clinic [...] They were always in genetics, but it hadn’t crossed my mind that they existed, to be honest. It was a real eye-opener to see them. I think it must have been really difficult to have been a geneticist before PGD was available, to see couples with these awful conditions and not be able to offer anything at all. At least for some of them, now there’s something to offer. It doesn’t always help but at least there’s something else for them, if they want it. (8.20)

The introduction of PGD is the peak and the turning-point of this narrative. Before PGD was available, there was nothing to offer to some couples and this lack of options, Andrew stated, must have made the work ‘really difficult.’ An evaluation was also present in the statement that ‘at least for some of them, now there’s something to offer.’

The primary focus in these narratives of progress was on women and men at high risk for a particular genetic disease, less on the future children.
In What Senses Did PGD Mean Progress and For Whom?

PGD was described as a better alternative than previous alternatives, for some women and men at risk for a genetic disease. Interviewees articulated four major reasons why PGD was part of a positive development for patients ‘at risk.’ PGD was described as a means of achieving biological parenthood for couples who dared not try for pregnancy knowing that they were at risk for a genetic disease, and biological parenthood was described as important. It was described as a psychologically and/or morally easier means to avoid the birth of a child with a genetic disease than prenatal diagnosis and selective termination of pregnancy. A few interviewees also described PGD as technically better than technologies for genetic diagnosis of foetuses. Finally, PGD was described as positive since it meant that some couples were given choice and the possibility of (some) reproductive control, independently of whether PGD resulted in the birth of a healthy child. There was something to offer to patients and this was described as positive also for the interviewees themselves as professionals. These reasons are elaborated in the following four sections.

A Means of Achieving Biological Parenthood

The use of PGD was described as positive for couples who knew they were at risk for a genetic disease, who could not accept selective termination of pregnancy and who had not dared to try for pregnancy before PGD was available. For these couples, interviewees said, PGD was positive since children and parenthood were important to them.

As an example, Andrew explained that parenthood might be overwhelming and had indeed been overwhelming in his own experience. He described it as ‘the one thing that most people have grown up tending to expect,’ which made it ‘so important to be able to offer things like that [in vitro fertilisation and PGD], because it’s one of the central values in so many people’s lives’ (8.62). In vitro fertilisation and PGD were means through which parenthood became possible, for some,
and Andrew was enthusiastic about PGD ‘when,’ as he put it, ‘it works.’ When this is the case, he said, it is ‘fantastic […] You know, I mean, it’s their life’s goal’ (8.10).

When Andrew reflected on the importance of parenthood he did not explicitly specify whether he meant biological or social parenthood, but Hilda did. Not only did she hold that parenthood was important (‘to have children’), but especially so biological parenthood (‘to have children of our own’). She stated that though she had no children, she considered children as

enormously important for almost all of us. [It is] not only [important] to have children, but to have children of our own. That’s probably programmed in us in some way, that we have this enormously strong instinct. (15.24)

Biological parenthood was described as important and biological reasons were given for this importance. It was described as an instinct and as something that was ‘programmed’ in us. In a similar way, Ian described partners who did not contribute with their own germ cells and who often did

not feel quite the same way about the child because it’s not genetically theirs as a couple. I think that introduces a lot of conflicts into the relationship. So for a lot of conditions, being able to actually offer them their own child unaffected, I think is a big advantage (12.14.)

Medical professionals who discussed parenthood as something important often described a concern for biological children as present among women and men who wanted to use reproductive technologies. They attributed this view to the couples and, less often, to themselves, as for example did Hilda.

Only one interviewee discussed the alternative of adoption in any detail. He explained that he was upset about the criteria that women and men needed to meet in order to qualify for adoption. The criteria were ‘disgusting,’ Jörgen said, such as the criterion that ‘one should not be hard of hearing or speak Swedish with an American accent’ (18.10).
Jörgen explained that such criteria for adoption had made him help more women and men with for example handicaps, who would not meet the criteria for adoption.

A Psychologically and/or Morally Easier Means
Most interviewees also described the use of PGD as a psychologically and/or morally easier means to a child without a particular genetic disease than were prenatal diagnosis and selective termination of pregnancy. As an example, Steven told the story of couples who had

had a couple of pregnancies and they’re left with no surviving child. They desperately want another child but they don’t feel able to go through the distress of a prenatal diagnosis and perhaps a termination. I think for couples in that position the PGD, since it has become more readily available, could be very, very helpful (7.14).

Interviewees established that many couples they met wanted to avoid or minimise the risk of implanting an embryo with a particular genetic disease. Thus, there was a need for PGD. Interviewees also told stories of how painful life with a genetic disease could be (to be explored in the next chapter), and when so doing, they legitimated the use of PGD. Such was the case when Andrew explained that he would support couples who wanted to use PGD and that to see one’s child suffer and ‘having to struggle the whole way through its life and then probably lose it’ was ‘just the worst scenario’ (8.24).

It is noteworthy that though the use of PGD was described as psychologically easier than that of previous technologies, it was not described as easy. Rather, it was described as the best alternative for some couples among the quite distressing alternatives. Many interviewees discussed the agonies that women and men at risk for a genetic disease could experience before as well as after they had decided to use PGD. Women and men, they explained, could have difficulty in explaining their decision to other family members who may have or be carriers of the same condition, who may not share their understanding of life with that condition and who may not want to use PGD for themselves.
Some interviewees also stated that they supported the woman and man in their decision, given that it was within the law, and that enhancing the possibility for these women and men to get a child without the particular condition was important. In this sense, support was given but conditionally, and the legal regulations or policies, if there were no laws, were described as setting the boundary for which uses of PGD these interviewees supported.

This view can be exemplified by Joyce in a section where she compared previous and present situations and explained that she would support couples at high risk for a genetic disease ‘in whatever choice they make, provided it’s within the laws of the country and within existing resources’ (9.34).²

Finally, the use of PGD was described as positive for couples who considered it morally problematic to terminate pregnancies but who saw no or less moral difficulties with embryo selection and embryo disposal.

**A Technically Better Means**

Several of the interviewees described the present use of PGD as resulting in accurate and relevant genetic information. A few of the interviewees also described PGD as technically better than that of the technologies for prenatal diagnosis, since it resulted in just the genetic information that was needed and no extra information. Such was the case when Evelyn described technical safety as enhanced through developments at her unit. When asked if there were any new difficulties for her, as a professional, in her meeting with couples who wanted to use PGD, Evelyn contrasted IVF/PGD with prenatal diagnosis. The risks of getting too much information was less with PGD than with prenatal diagnosis, she said, the reason being technological developments. ‘Technically’, Evelyn explained, ‘the testing is different’ (11.22).

If you are looking to exclude a particular chromosome abnormality the way testing is done at the moment that’s actually all you test for. In that sense, PGD has actually made life simpler [...] You are less likely to inadvertently generate information that you aren’t specifically looking for. (11.22)
Evelyn explained that she and her colleagues were developing technologies that enabled them to ‘exclude the affected state without revealing the carrier status of the embryo and without compromising the accuracy of the test’ (11.8). It was possible to sort out only affected embryos and not get information as to whether the resulting embryos were non-affected or carriers. This, Evelyn said, led to fewer moral difficulties with regard to how to handle unwanted genetic information. As regards technical safety, Jörgen also told the story of a woman and man who had undergone an early form of sex selection for medical reasons. The couple had had two boys who had died at the age of one and three years. In order for the couple to receive an unaffected girl, extracorporeal assisted reproductive technology was combined with technologies for separation of X- and Y-sperm on the basis of difference in weight. However, Jörgen said, the technology for separation of sperm at that time was not one hundred per cent safe and he and his colleagues had been unable to tell from the ultrasound whether the child was a girl or a boy. They asked the woman if she wanted to use amniocentesis. She declined the proposal, saying that ‘it has been tough, and I trust you, you have done a good job.’ However, she gave birth to a healthy boy. Two years later, the woman and man came back, and this time they used PGD and the woman gave birth to a girl (18.2). In this sense, technologies were getting better and better.

One More Choice

Finally, PGD was described as positive for some couples at risk for a genetic disease since they were given one more alternative. An excerpt from the interview with Joyce can serve as an example. PGD was important if couples received a healthy child but, even so, it was ‘more important’ that couples were given a choice. She explained that

usually most people’s desired outcome is the birth of a healthy child but what’s more important to me, I think, is the fact that people are given a choice. (9.34)
This excerpt highlights the contrast between what Joyce considered to be the most important outcome according to the couples concerned, i.e. the birth of a healthy child, and her own emphasis on choice. It is noteworthy that some of the interviewees described the possibility of choosing whether to use PGD or not as positive in itself, independently of whether couples did use PGD and independently of whether its use resulted in the birth of a child without a particular genetic disease. In situations where no healthy embryos were found (and consequently, in most cases, no embryos were implanted) or in situations where healthy embryos were found but where pregnancy failed, Andrew explained, the use of PGD could still ‘be very therapeutic, because it can mean that although they might not get pregnant, at least they can control what happens to them’ (8.48). In the context of PGD, the statement that ‘at least, they can control what happens to them’ means ‘at least, affected children will not be born without them knowing it, provided that the diagnosis is accurate.’

The possibility of one further reproductive option was described as therapeutic, for some (8.48). What I call *choice provision* was described as important. The availability of PGD was described as a means to provide choice.

**Progress and Germ-line Gene Therapy?**

No interviewee described GLGT as a step forward in a medical progression and there were no *narratives of progress* in which germ-line gene therapy was described as one further step in such a progression. Instead, interviewees articulated reluctance towards the future use of GLGT in the language of lack of medical knowledge and risk to future generations. Some interviewees described it as unsafe (9.38) and still part of science fiction, others described it as much less straightforward than PGD (7.49). A few interviewees also described GLGT as possibly going to be positive in the future, though unrealistic at the moment. In the future, GLGT could be not much different from ‘taking a pill’ given that technological safety was ensured (1.83). However, even in this last kind of description GLGT was not described as a step forward in the medical progression.
Summary and Concluding Remarks

Summary
Interviewees compared PGD and selective transfer of embryos with technologies for prenatal diagnosis of foetuses and selective termination of pregnancy. In doing so, some of them told narratives of progress that indicated that there was an on-going technical progression within medicine. Some interviewees described PGD and selective transfer of embryos as positive and as a means of having biological children for those women and men who for different reasons had not dared to try for pregnancy before PGD was available. Most interviewees also described PGD and selective transfer of embryos as psychologically easier for some of the women and men at risk for a genetic disease, and sometimes as morally easier than the use of technologies for prenatal diagnosis and possible selective termination of pregnancy. A few interviewees also described technologies for PGD as technically better than previous technologies. Finally, PGD was described as positive as one more reproductive option for couples concerned.

Most interviewees were hesitant with regard to future use of GLGT. A few described it as possibly positive in the future, but even so, GLGT was not described as a step forward in a medical progression.

Concluding Remarks
When the results of the present study are compared with those of studies on patients’ attitudes to, perceptions of and experiences of IVF/PGD, the different results sometimes harmonise. There are also interesting differences.

Respondents in a UK quantitative study who had experience of PGD (Lavery et al 2002) considered the advantage of PGD to be the transfer of only unaffected embryos and avoidance of selective termination of pregnancy. Similar results emerged in another UK quantitative study. Almost all of the 245 respondents, who were carriers of different recessive genetic diseases but who had no experience of PGD, agreed that the birth of a child who would not inherit the genetic dis-
ease that the respondent was a carrier of was an important or very important advantage of PGD.\textsuperscript{13} Almost all also agreed that the possibility of knowing, from the start, that the child would not have the genetic disease was an important or very important advantage of PGD. Most of them agreed that ‘no need to terminate pregnancy’ was an important or very important advantage of PGD (Snowdon and Green 1997:345).\textsuperscript{14} Such was also the case in an Italian study of attitudes of potential users in Sicily towards PGD for beta thalassemia and pre-implantation genetic screening for aneuploidy (Chamayou et al 1998).\textsuperscript{15} About half of the couples who had experience of prenatal diagnosis and who had chosen selective termination of affected foetuses or who, unaware of their carrier status, had given birth to an affected child, as well as couples with fertility difficulties, described the possibility of avoiding ‘the death of the foetus by abortion’ as the greatest advantage of PGD/pre-implantation genetic screening.\textsuperscript{18} The possibility of avoiding ‘psychophysical trauma during abortion’ was rated as the second greatest advantage of PGD by the respondents who either had experience of selective termination of affected foetuses or who, unaware of their carrier status, had given birth to an affected child. These respondents rated the possibility of avoiding stress and anxiety while waiting for the PND results as the third advantage of PGD.\textsuperscript{17} Couples with fertility difficulties rated the advantages of pre-implantation genetic screening in a similar way.\textsuperscript{18}

The results of these studies of the advantages of PGD seem to harmonise with the interviewees’ descriptions of what they thought mattered to couples concerned in the present study: the birth of a child without the particular genetic disease, early reassurance and no termination of pregnancy. Snowdon and Green’s study (1997:345) also showed that many respondents described the birth of a child who would be genetically related to both partners as an important or very important advantage of PGD.\textsuperscript{19} Biological parenthood could be an issue for some of the couples concerned, as also suggested by some of the interviewees here.

Two differences between the results of the present study and previous studies are also noteworthy. Snowdon and Green’s study (1997:345) indi-
cated that about half of the respondents described the possibility of finding out whether or not the child would be a carrier of the disease as an important or very important advantage of PGD. This, however, was described as impossible by one of the interviewees in this book – and positively so. This interviewee explained that the way PGD was done at the moment, at her clinic, only resulted in genetic information as to whether the embryo would be affected or not. This was positive since it led to fewer moral difficulties in respect of how to handle unwanted genetic information, such as information of carrier status. Though only one interviewee discussed this, it may be asked whether – and, if so, to what extent – patients and professionals share views of how PGD should be used and what genetic information is desirable. Furthermore, the interviewees in this book described the importance of giving and being given one more reproductive option, independently of whether PGD was used and independently of whether its possible use resulted in the birth of a child without a particular genetic disease. This was never framed as a possible advantage of PGD in the pre-defined alternatives put forward in the quantitative research projects described.

The importance of choice provision as described by some of the interviewees, which is lacking in these studies on attitudes of women and men concerned, does recur in descriptions of genetic counselling in the bioethical literature. Genetic counselling, some suggest, ‘does not aim to prevent couples from having children with genetic diseases. Preventing genetic disorders, although important, is secondary to good clinical practice, which identifies couples at risk and by empathic counselling allows them to make their own informed choice’ (Harris 1998:335). As remarked by Lene Koch and Mette Nordahl Svendsen (2005:823), this presentation results in a distinction between the goals of disease prevention and informed choice. Informed choice is described as primary to disease prevention.21

However, there is a similar emphasis when the results of my project and Roberts and Franklin’s project (2004) are compared as regards another aspect of choice. In both projects, respondents emphasise that the use of PGD was not easy. Roberts and Franklin concluded that many patients were eager to distinguish the choice to use PGD from trivial
“‘consumer’ or narcissistic’ choices. Instead, the choice to use PGD was a ‘choice out of necessity’ (Roberts and Franklin 2004:288). In a related manner, several of my interviewees underlined that the choice to use PGD was by no means easy for couples. The description of assisted reproductive technologies and PGD as a ‘last straw to clutch at’, as one interviewee put it, also concurs with the description of ‘last chance babies’ in studies of the experiences and views of women undergoing IVF (Modell 1989). However, if IVF or IVF and PGD should qualify as a last straw or a last chance, this either implies that what is discussed is only biological children or that (if present in a general discussion about having children) adoption is not an acceptable or possible alternative.

Narratives of progress indicated that there was a medical progression. In some cases, PGD was described as a further step forward in this progression.22 Was this also the view of women and men in the previous quantitative studies? Whereas the UK study by Snowdon and Green (1997) indicated that many respondents were positive towards PGD, PGD did not replace prenatal diagnosis as their first choice if they should try for another pregnancy (Snowdon and Green 1997).23 This can also be compared with the results of the Italian study by Chamayou et al (1998). Almost ¾ of the respondents who had experience of prenatal diagnosis and selective termination of beta thalassemia-affected foetuses or who, unaware of their carrier status, had given birth to an affected child described PGD and selective transfer of embryos as better than prenatal diagnosis and selective termination of pregnancy. Almost ¾ of them said they were willing to undergo PGD in the future.24

Not very surprisingly, almost all of the respondents who had fertility difficulties and who underwent IVF treatments or intracytoplasmic sperm injection (but who were not carriers of beta thalassemia) said they were willing to undergo pre-implantation genetic screening for aneuploidy.25 These respondents had undergone or would undergo assisted reproductive technology treatment in order to try for pregnancy in the first place. Consequently, there would be no possible extra burden of such treatment for them. Such was not the case for the other respondents.
To conclude, a number of values have been described in this chapter: the value of parenthood and in particular of biological parenthood, the value of having the possibility to try to avoid the birth of a child with a genetic disease, if couples concerned so wanted (also if its use did not result in the birth of a child), the value of minimising distress for couples concerned and the value of just getting the information needed. Interviewees were careful to describe the possibility of avoiding certain genetic diseases as important, not avoidance of these genetic diseases as such.

Three moral experiences – i.e. experiences of consciously choosing, of consciously approving or disapproving of actions or states of affairs as well as experiences of a changed life situation whereby interviewees reflect on, explore and evaluate moral aspects of that situation – were also described in some detail. This was the case with the experience of frustration in the pre-PGD situation when there were no secure diagnostic methods, the experience of having something to offer to couples and, though less often, the experience of having children.
Discussions of genetic disease, quality of life and health formed a sec-
ond core theme. Some such discussions contained stories of how life
with genetic disease could be or was, which I have labelled narratives of
life with genetic disease. With some exceptions, these narratives indi-
cated that life with genetic disease could be problematic or painful.
Some of the narratives also spoke of hope in terms of future choice. In
the future, some couples could use an ex-corporeal assisted reproduc-
tive technology and PGD. They could try to avoid implantation of
embryos with a particular genetic disease. Furthermore, when narratives of progress and narratives of life with genetic disease were com-
bined, these two kinds of narratives resulted in a certain logic. Life with
genetic disease could be tragic, some couples had a medical need, PGD
meant progress and it was a means to meet the medical need.

Narratives of life with genetic disease are presented and discussed in
the first section of this chapter, as are interviewees’ discussions of for
what genetic conditions PGD were used. Whereas few interviewees
wanted to describe genetic conditions that they thought it should or
should not be allowed to test for, they did describe conditions that PGD
was used for and they evaluated these uses. A few interviewees also
commented on germ-line gene therapy at the embryonic stage as a
means to treat an embryo and cure it from a particular genetic disease.
Finally, a few interviewees discussed infertility as a disease.

The second section of this chapter presents and discusses the inter-
viewees’ view that notions such as severe genetic disease and quality of
life were difficult to define in any objective manner and, in some cases,
that the lack of relevant definitions was problematic. When this was
the case, some interviewees told narratives of concern that typically focused on the difficulty of defining genetic disease and quality of life in any objective manner. This difficulty was also sometimes named as a reason why interviewees were hesitant and ambivalent in their evaluations of possible uses of PGD. The second section also presents and discusses the notion of health as used by the interviewees. These discussions of health were often short and vague. Interviewees did not enter into the discussion of what conditions germ-line gene therapy may or should be used for.

It has been suggested that one of the new moral issues raised by the possibility of using PGD concerns the handling of affected embryos (Draper and Chadwick 1999). Should it be assumed that it is morally problematic for medical professionals to implant ‘genetically abnormal’ embryos? (Draper and Chadwick 1999:114). What if a deaf couple want to implant an embryo with a genetic condition that results in deafness? (Chadwick and Levitt 1998). The question of whether to implant affected embryos is addressed in this chapter’s third section, as is the question of disposal of healthy embryos and different views of the moral status of the embryo. Interviewees who considered the embryo to have dignity and/or a right to life from conception and onwards were more positive towards GLGT than were the other interviewees.

Narratives of Life with Genetic Disease

Within narratives of life with genetic disease, interviewees told stories of patients they had encountered or of members of their own families. One interviewee told the story of his personal experience of disease. Some of these narratives contained words such as tragedy or similar value-laden notions. Professionally, at the PGD clinic, Andrew said, he met with tragedy. Personally, he wouldn’t want to have affected children, I certainly wouldn’t. I wouldn’t want to have a child who spends a great deal of its life, and it might be a shortened life or [a life] in contact with hospitals, always having uncomfortable or painful procedures, being unwell, being unable to

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keep up with the others at the same age, different schooling, anything like that. I couldn’t bear to watch my own child have to struggle the whole way through its life and then probably lose it. (8.24)

Andrew had relatives who had lost their child at an early age. Losing one’s child, he said, was ‘just the worst scenario’ (8.24). Living with a severe genetic disease was sometimes described as a ‘suffering’ and living with a child with a severe genetic disease was sometimes described as ‘distressing’; the death of a loved one was described as devastating (7, 8).

Interviewees also articulated frustration and the wish to alter the situation for the couples concerned in a slightly different story-line of life with genetic disease. These were stories that indicated that life with genetic disease could be or was painful, but the stories ended with descriptions of a situation where some diseases could be avoided or were avoided. The potential tragedy and pain was spoken of as being able to be minimised through use of assisted reproductive technologies and PGD, for those to whom they were available, and who wanted them. They could choose to try to avoid a(nother) child with a genetic disease. Descriptions of the possible value of disease prevention through selection of embryos were always conditioned: emphasis was put on the value of being able to prevent disease if the couple concerned so wished, and not disease prevention as such.

Some interviewees also explained that it was understandable if certain couples wanted to avoid the birth of a child with a particular disease. ‘Naturally’ we want our future children to be healthy. Who would not want that, Simonetta remarked (4.26). One interviewee, Jörgen, also said that though one should have respect for those who were handicapped in different ways, being handicapped ‘was no merit’ (18.18). Statements such as these reflected the view that it was understandable and legitimate if women and men wanted to avoid the birth of a(nother) child with a particular genetic disease: life with genetic disease was sometimes tragic, it could be avoided, who would not like a healthy child anyway since having a genetic disease was not better than not having it, other things being equal.
Simonetta did not only explain that it was natural to want healthy children, she also described healthy children as normal children. This was the case when she commented on the hypothetical story of a mother with two previous children with fragile-X who wanted to use PGD for a third child, wondering whether though it was ‘ugly’ to say so, there was not a ‘right to a small slice of normality?’ (4.14). In this context, the normal thing is to have children without the genetic disease. Her statement that it was ugly to say so indicated an awareness that this view might be controversial.

Finally, Angelo told a narrative of life with genetic disease that neither focused on tragedy nor on hope in terms of the possibility of avoiding genetic disease. Angelo had embodied experience of a disease, i.e. experience of a particular disease in his own body, and he emphasised how grateful he was to be alive.

As a general tendency in the data, interviewees told stories of couples who lived with a genetic disease or with a child with a genetic disease and who wanted to use or had used PGD. More seldom, they told stories of couples who lived with a genetic disease or had a child with such a disease but who did not want to use PGD.

Used For Genetic Diseases Only?

Interviewees discussed what genetic conditions PGD was used for. They also emphasised that they did not want to define serious or severe genetic diseases.

As a general tendency, interviewees described the possibility of searching for a certain severe genetic disease in embryos and the subsequent selective transfer and implantation of an embryo or embryos in the woman’s uterus as positive. Some interviewees described uses of PGD for what they described as less severe genetic diseases that were not lethal at an early age. Some also stated that PGD should be limited to lethal diseases, even if this was not always the case. As an example, Andrew recalled a situation in which a couple wanted to use PGD for an X-linked, non-lethal genetic disease that resulted in hypospadia. The couple had two boys who had had severe hypospadia and who had
undergone five to ten operations each in order to correct it. The woman, Andrew explained, wanted to use PGD for sexing for a girl. He described the enthusiasm at the clinic as a reason why this couple were offered PGD for this genetic disease. In his view, ‘there was really no reason why she [the woman] had to continue having children and yet we seemed to find that that was acceptable’ (8.6).

I don’t think we would now; I don’t think we would do it. I think being caught up in the enthusiasm of PGD actually working, because we had a lot of pregnancies at that time, we got caught up and said that seemed fine because it’s what she wanted, but I didn’t think it was fine, really. I don’t think that that’s necessary. I think PGD should be limited to really lethal conditions in families who have lost children and don’t have a family. (8.6)

Later on in the interview, I asked Andrew if there were any moral dilemmas with the use of PGD as he saw it. He explained that the ‘biggest’ dilemma to him was whether ‘to perform treatment where that family doesn’t need it, rather than [to treat a more or less serious] condition.’ However, he said he experienced slight moral problems when PGD was used for non-lethal genetic conditions (8.12).

Many interviewees had a similar approach to the issue of what genetic diseases should be searched for. The seriousness or severity of the disease was seldom discussed as the decisive factor, the important thing being the particular experiences of a couple ‘at risk,’ the life history and experiences of the couple or family. This view harmonises well with the UK Human Fertilisation and Embryology Authority (HFEA) guidelines for the use of PGD (HFEA 2003c:123-124). According to HFEA, the severity of the disease matters but it is not the decisive factor; the couple’s experience of the particular disease should also be taken into account, as well as other factors. It seems to harmonise less well with the Swedish guidelines (Bet 1994/1995:SoU18), according to which PGD should only be used for couples at high risk for a specific severe progressive genetic disease that involves a high risk of having a child with the disease. However, even though most interviewees explained that they did not want to define serious or severe genetic diseases,
Duchenne’s muscular dystrophy, SMA and cystic fibrosis were put forward as examples of such diseases.12

Only a few interviewees described a morally relevant difference between medical reasons, such as the use of PGD for genetic diseases, and non-medical reasons for the use of PGD. Instead, several interviewees referred to laws or policies or to practical differences when they made a distinction between these two kinds of reasons for the use of PGD. As one example of the former kind of reasoning, Joyce told the story of a Sikh couple who had had two children who had died from a recessive bone disease. The woman and man, Joyce said, were ‘desperate’ to have another baby boy and the woman ‘was so desperate that she wanted to have pre-implantation genetic diagnosis for sexing […] because she felt that to go through another pregnancy for a female was going to be impossible for her.’ The reason Joyce put forward for not referring the woman was that ‘it wouldn’t have been a legal thing to do’ (9.4). Whereas Joyce referred to laws and policies, Ned referred to practical difficulties. Ned explained that he had no moral objection or problem regarding the selection of embryos for genetic conditions, nor regarding the selection of embryos by height or weight. It would be practically inappropriate, but it would not be a moral problem for him. In his words:

For Duchenne’s, I’ve got no problem with that. If you’re selecting embryos for other factors, non-medically important factors, height, weight, all these sorts of stuff, potential malignancy risk, hearth disease risk, these things in the future. I’ve not got an ethical problem with that. It’s not appropriate. It’s not practically appropriate. (10.20)

To some interviewees, the question of what genetic conditions PGD was or should be used for also led to the question of what reproduction meant. Such was the case when Elisabetta explained that to use reproduction technologies was a matter of deciding what reproduction meant. She exemplified her view with the stories of women who had passed the menopause but who had used IVF in order to become pregnant. In her view, it was not a ‘scandal’ that women at the age of sixty wanted to have a child, it was a ‘sign that our society is using reproduction for other, private needs.’ She continued:
So, you feel alone, you’re sad, you’re depressed, and instead of eating […] or buying a dog, you want to have a child at sixty. It’s at the same level and so it’s not immoral, it’s something very sad in my opinion, something that has shamed and deformed the meaning of reproduction, of what it is being a father, being a mother. (5.20)\textsuperscript{13}

A distinction can be made among medical reasons, such as between diseases that are lethal at an early age and those that are not (though it can also be questioned how clear such distinctions are in practice). A distinction can be made between selections for medical versus non-medical reasons. A distinction can also be made between selections made in order to give birth to a healthy child for couples at risk for a particular genetic disease and a general testing for chromosomal aneuploidy, i.e. screening. The latter would be the case if a couple did not need to be at risk for a particular disease in order to use a diagnostic method. This was also how one of the Swedish interviewees, Jörgen, described the possible uses of pre-implantation genetic screening (18.2). Whereas PGD was performed in order to try to avoid a particular serious disease in the embryo, pre-implantation genetic screening was different since it implied ‘screening for health’ (18.2, 56).

Descriptions of pre-implantation genetic screening as implying or leading to a screening for health can also be compared to the descriptions of PGD in the other interviews. Many interviewees emphasised that PGD was not a means to enhance health (though it, hopefully, led to the birth of healthy children), nor was it a matter of screening (and it should not become so, either). It was not a general search for a number of genetic diseases, nor was it offered to couples who were not at high risk for a particular disease. In Jögen’s description, pre-implantation genetic screening could be used in the search for chromosomal aneuploidy and offered to others than those at high risk for a particular disease (18.2).

Finally, some interviewees emphasised that PGD was not a matter of treatment of disease and that this made the technology problematic. Such was the case in the interview with Angelo, who stated that PGD was not a method that treated disease in an embryo. It was a ‘selection against affected embryos,’ nothing else (1.36). Angelo explained that we unfortunately live in a ‘diagnostic era,’ not in a ‘therapeutic era,’ as regards PGD.
It is also noteworthy that Angelo was positive in his descriptions of GLGT, provided that technical safety and accuracy was maintained. GLGT would imply therapy and not the selection of embryos.

The Special Case of Infertility: A Disease?

As a tangent, interviewees did not only discuss genetic diseases that PGD could be used to search for, but some of them also described infertility as a disease and Andrew described PGD as ‘willing infertility in some couples’ (8.62). Some couples who were not infertile may, because of the risk of a certain genetic disease, choose not to have children. If so, the result will be the same as if they were infertile. In Andrew’s words:

I view infertility as not so different from PGD because it’s willing infertility in some couples. I think infertility is probably the worst disease that couples can go through in many ways. It doesn’t alter as a serious illness would what they can do, whether they can live or not, but they can have infertility and have [it] the whole of the rest of their life, which is not the way they choose it to be. They’re stuck with it and [unable to exercise] control and very disappointed. (8.62)

Infertility was not only a disease, but the ‘worst disease.’ It did not alter the ability to live but the possibility of choosing to live as one might want. Andrew concluded this reflection by saying that he thought the morbidity for infertility and genetic diseases has been ‘grossly underestimated’ (8.62). Reflections such as these also resulted in the description of assisted reproductive technologies as important for some women and men. They wanted such technologies.

A few of the interviewees also contrasted infertile couples with the ‘normal’ population. As an example, Jörgen explained that ‘we’ have understood ‘IVF [couples] as infertile, as a handicapped group of people that we help’ and he contrasted this group of people with the ‘normal’ population (18.48). Thus, infertility was described as a deviation from the normal and the response to this deviation was therapeutic: these women and men could be offered assisted reproductive technology treatment.
First Narrative of Concern

Descriptions of pain and tragedy in narratives of life with genetic disease correspond to certain other studies of views of medical professionals on genetic diseases or disorders (Shakespeare 1999, Kerr et al 1998). In contrast to these studies, interviews analysed in this book also contained four different kinds of narratives of concern, i.e. narratives that highlighted concerns or worries of different kinds, on the part of the interviewees. The first of these kinds of narratives focused on interviewees’ uncertainties as regards how to interpret others’ experiences of life with genetic disease. This was also described as a reason not to define serious or severe genetic diseases. As an example, Hilda explained that what she may not experience as painful, someone else may and ‘you see everything in a different light, I think, when you’re affected yourself’ (15.20).15

Interviewees also underlined the importance of couples’ self-estimated quality of life in assessments of life with genetic disease and the emphasis on the perspective and experiences of the person living with the disease was present in two slightly different versions. Sometimes, interviewees emphasised the importance of what I label lived experiences. Such experiences included personal experiences of close relatives with a genetic disease as well as personal experiences of having a particular genetic disease. Sometimes, interviewees only referred to the latter sub-category of lived experiences, which I label the embodied experiences, i.e. personal experiences of a genetic disease that someone has in her or his own body. As an example of the importance of embodied experiences, articulated through the use a narrative, Simonetta told the life story of Michel Petrucciani.

Michel Petrucciani was a jazz musician with a rare genetic disease that made his bones break continually, with resulting malformations. Petrucciani, Simonetta said, was not more than one metre tall and he had serious health problems. He died because of a respiration crisis. Still, she said, he had chosen to father a male child, and the child was affected by the same disease. ‘I don’t want a child with his disease,’ Simonetta stated, ‘I don’t, but he existed and he has done great things.’ I wonder, she concluded, if it does not all depend on whether you know the person (4.8).
Quality of Life
Simonetta used this narrative in order to clarify difficulties in judging someone else's quality of life (4.8). When applied to the PGD context, this meant that future others had better to assess their own lives. Though empirically impossible, this would mean that the future child's self-estimated quality of life and embodied experience needed to be taken into account in the PGD situation. Simonetta also described discussions of the quality of life of future others as something that scared her, particularly if such discussions were framed in the language of which lives were worth living (4.22). A similar view was also articulated by other interviewees.

As another example of the emphasis on personal experiences in assessments of quality of life and life with genetic disease, Angelo chose to tell his personal story of life with a heart malformation. He contrasted his perspective as a medical professional with his perspective as a person with experience of a severe disease. I, he said, have the ‘feeling in my skin and bones of the truth of this statement. Life for me was a gift, personally’ (1.89). That experience affected his understanding of the use of PGD. Angelo did not refer only to his personal experience, but also to his previous work with children with severe mental diseases. As long as we are ‘not in the head of those people,’ he said, it is ‘very hard to judge for someone else:

I had occasion to meet several of those kids and sometimes they are using a kind of facilitated communication, which is a kind of way [...] [to] type, or you are helped to type. [...] They generally come out with incredible things. Some people had doubts about this because they thought ‘well, the person helping is more or less directing what is being typed,’ but some of the answers are really too personal to be directed by someone who doesn’t know. I think that in those heads there is a kind of treasure hidden that cannot get out, so it is a terrible responsibility to choose for them. (1.8)

This narrative underpinned Angelo’s view that PGD may be an option for some but that it is difficult (and a ‘terrible responsibility’) to judge how life with a certain disease may be for future children.

Genetic Disease, Quality of Life and Health
The Vagueness of the Concept of Health

Whereas some interviewees discussed the notion of quality of life in detail, this was not the case when it came to issues of health. I did ask interviewees about their understanding of health, but most of them answered in sweeping terms and their answers were short. Even so, a few interviewees, such as Elisabetta, stated that the meaning of quality of life as well as of health and of normality was crucial in discussions of PGD. In her words, ‘this is the core of the problem in my opinion, what is health, what is normality, what is the best quality of life’ (5.14).16

PGD, Andrew remarked, was a ‘healthier option in the holistic sense than going through prenatal diagnosis and termination’ (8.44). Other interviewees referred to the WHO definition of health as physical, psychological, social and spiritual well-being. Some, such as Nils and Björn, said it was a utopian definition and that no one was ever healthy in this sense (14.67-69, 17.129). Some interviewees also said that the precise meaning of health (as of disease and quality of life) was difficult if not impossible to describe. This was the view of Simonetta, who stated that for her, a healthy person was able to interact, to discuss and to joke. For someone else, health may mean that you are able to run or it may mean having a certain level of intelligence (4.26). Health was a difficult concept, filled with meaning dependent on our personal experiences and convictions, and its personal character complicated the discussion of what diseases to search for. However, most interviewees used the notion of health as absence of disease or genes for disease in their discussions of PGD and of children born after its use: healthy children were children without a particular genetic disease.

Embryos

There was one noteworthy exception to the general tendency not to discuss health in detail in the data. Particularly some of the Italian interviewees did discuss disposal of healthy embryos as problematic; Giovanna said that it was her major objection to the use of PGD.17 Some of the interviewees also described the deliberate implantation of affected embryos as
problematic. Furthermore, some described their understanding of the moral status of the embryo as what made a certain technology or use of a technology morally acceptable to them. The topic of embryos recurred in most interviews, and interviewees introduced it themselves with one exception. The issues of the moral status of the embryo, examined embryos and healthy embryos, and implantation of affected embryos will be explored in the following three subsections.

The Moral Status of the Embryo
Most of the interviewees described the embryo as one of the issues that needed to be discussed in the clinical encounter, even though they also stated that they themselves had little or no moral difficulty with embryo disposal. Ian articulated this view particularly clearly. When I asked him how he would describe the PGD situation for the couples concerned, he responded that they needed to think through their understanding of the embryo. This was ‘the most important’ moral question to address in the clinical context, since those of his patients who considered the embryos to be a ‘person in its own right’ would probably consider ‘the wastage of embryos [to be] just the same as termination of pregnancy’ (12.10). Further on in the interview, I asked him how he viewed the embryo and he explained that embryo disposal was nothing he did ‘lightly, but you know, I wouldn’t be upset and I wouldn’t lose sleep and feel uncomfortable if somebody embarked on PGD and affected embryos were allowed to perish’ (12.16).

Ian also explained that he saw a moral difference between an unimplanted and an implanted embryo. The latter had the potential to become an individual, not the former. Other interviewees made slightly different distinctions, as did Nils, for example, when he suggested that there was a morally relevant difference between fertilisation of an egg in vitro without the aim of implantation and fertilisation with this aim (14.53). These interviewees expressed a graded view of the moral status of the embryo. Life did not have moral significance from the first development of the embryo, but such significance developed gradually. This view was combined with the view that all embryos should be treated with respect.

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A few of the interviewees described embryos as having moral significance from conception and onwards. Vittorio was one of them and he described embryo disposal as morally illicit. He also explained that he disliked the concept of ‘pre-embryo’ that had been coined in the Anglo-Saxon literature. Immediately after fusion of egg and sperm, Vittorio said, the embryo was not a ‘passive embryo’ and not a pre-embryo. It chose its own place for implantation in communication with its mother through the hormonal system (2.27). Vittorio also referred to the official views of the Roman-Catholic Church and its discussions of assisted reproductive technology (2.14). Expressing a slight variation on the view of Vittorio, Björn stated that he considered embryos as being ‘unique individuals’ from conception and onwards, with a ‘constitutive value’ involving the right to life. He combined this view with the view that the ‘fundamental ethical problem’ with assisted reproductive technologies and PGD was that embryos were created, and in a later step, sorted out (17.52-54, 62). In Vittorio’s and Björn’s examples, the embryo was described as at the heart of the matter in a sense that was not present in most other interviews. Embryos had dignity and should be protected.

Differences in their views on the embryo had consequences for how interviewees viewed the use of PGD as well as germ-line gene therapy. Interviewees who described major difficulties with the use of PGD due to the disposal of embryos described fewer difficulties with the use of germ-line gene therapy than did other interviewees. According to Vittorio, germ-line gene therapy was ‘dangerous’ (2.36). Still, he believed that it could in principle be morally acceptable, for him, provided that there was no other embryo disposal, no separation of procreation and the conjugal act, and lower risks for women involved in the procedure (2.38). Angelo, who shared some of Vittorio’s hesitancy about the use of IVF and PGD, explained that he did not ‘find any ethical objections to germ-line [gene] therapy as long as it is therapy’ (1.77). Likewise Björn explained that, as he had understood germ-line gene therapy, it would not be in conflict with ‘fundamental values,’ such as the right to life. Björn also commented on his view in relation to the view of ‘society,’ where, as he put it, the opposite seemed to be how things were understood (17.99-101).
Other interviewees who articulated a graded understanding of the embryo saw little use for germ-line gene therapy. Steven described it as ‘a non-starter, really’ (7.55). Why treat a sperm or an embryo with germ-line gene therapy when one can just choose another one, he and Jörgen asked. Why give a single cell the ‘status of a patient’ and why develop technologies for interventions in germ cells when PGD is available and when the result would be the same on one level, namely the birth of healthy children?

The status of the embryo may be understood as one of the moral dividing-lines between those who considered the use of PGD to be morally acceptable and those who did not. However, there were also other moral dividing-lines, some of which will be explored now.

**Examined Embryos and Healthy Embryos**

Alva did not describe the selection and disposal of embryos as morally problematic as such, but she did have a problem with disposal of embryos on the basis of genetic information. She contrasted her view of PGD with what she chose to label a ‘practical view.’

From a practical point of view it was best to select healthy embryos out of the embryos obtained through IVF. However, she explained, the practical view was not sustainable. The selection of embryos in the PGD situation was based on some knowledge of their genetic status and this made a difference. Embryos were genetically examined, they were ‘seen,’ and the seen selection was based on the principle of avoiding embryos with genetic diseases. Such was never the case in unseen selections, in which no genetic knowledge was obtained and in which selection was based on other criteria. ‘Ethically,’ Alva said, these two selections were ‘worlds apart’ (13.22). Alva also compared prenatal diagnosis and abortion with IVF and PGD, and explained that if you test a child for a known disease and choose abortion afterwards, then indirectly you say that children with this deficiency have not the same right to live [...] In my view, it is a question of giving humans, foetuses, different human worth, and that is upsetting and wrong. In fact, this goes for the fertilised egg as well. (13.22)
Chapter 4

According to Alva, selections based on genetic knowledge implied an undesirable grading of the worth of embryos as well as foetuses; such selections also implied negative attitudes towards human beings with genetic disease. This was her personal view and, Alva added, she would of course refer a woman and man who had a severe genetic disease and who so wished to a PGD clinic.

Steven described another scenario where some embryo selections, as opposed to embryo selection in general, could be understood as morally complicated: the scenario of PGD HLA typing.21 At the time of this interview, HFEA had not yet granted a licence for PGD HLA typing, and Steven recalled an American situation where a couple wanted to use PGD to select an unaffected child that would also be an HLA compatible bone marrow donor for the previously existing sibling. However, he, personally, did not consider tissue typing to be so ‘terribly wicked’ as it was sometimes pictured. There will be ‘ten or a dozen embryos anyway,’ he said, so why not choose one which is compatible? (7.4).22 Though he did not describe which the possible moral questions were, one such question could concern the extent to which the embryo chosen for implantation is treated as a means to an end and whether and if so in what sense this is morally problematic.

Finally, some interviewees were concerned about disposal of healthy embryos when sex selection was done for medical reasons. Giovanna labelled such sex-selection as a technically ‘easy’ testing, but problematic for other reasons. Testing was performed on sex instead of the more complex genetic testing. This being the case, and if the genetic disease was recessive and x-linked, all male embryos would be allowed to perish in order to avoid boys in general – affected and unaffected embryos alike (3.4).21 This was a major problem in her view and she described it as ‘particularly so’ from a genetical point of view. The gene for Duchenne’s muscular dystrophy would augment in the gene pool, since testing would result in the possible birth of unaffected girls or carrier girls (3.4). Within this criticism, two different and distinct arguments were combined. In part, the reason why sex-selection for medical reasons should not be done was framed in genetical terms (the gene would augment in the gene pool). In part, the reason was that healthy embryos were disposed of and that this was undesirable.
The Case of Affected Embryos

Some interviewees discussed implantation of affected embryos. As an example, Ned explained that he saw no moral difficulties with the selection of embryos and disposal of affected embryos. Instead, he said he would have a moral problem if embryos with a known genetic disease were deliberately implanted. In Ned’s view, it would be morally worse to implant an embryo with a genetic disease, when this knowledge had been obtained, than to select and implant embryos for non-medical reasons. This was the case for one moral and one practical reason. Embryos, Ned stated, could not give informed consent to being implanted. In his reasoning, it was implicit that lack of such consent was problematic if affected embryos should be implanted, but not if unaffected embryos should be implanted. The likelihood that the embryo would be successfully implanted into the woman’s uterus also decreased, which made implantation of affected embryos ‘inappropriate’ (10.20-22).

Within the British context, the discussion of implantation of affected embryos was not an altogether hypothetical reasoning. Other British interviewees did describe actual scenarios in which embryos with a known genetic disease were discussed for implantation. Such was the case when Andrew told the story of a couple who used PGD for sex selection for medical reasons. He explained that this particular woman and man wanted to use PGD in order to avoid incontinentia pigmentosa, a ‘non-lethal’ condition as he put it.24

The woman was very mildly affected, Andrew said, and women or girls tend to be so, apart from the five per cent who have ‘quite severe mental retardation.’ Boys born would not be affected. If affected, male embryos would abort spontaneously. ‘What we would do,’ Andrew said, was to ‘replace male embryos knowing that either the male would be affected [and be spontaneously] aborted or [the male embryo] would be unaffected’ (8.6). However, IVF and PGD showed that there were only female embryos. Realising this, the couple insisted on having some of them put back since ‘it was better than nothing.’ In the end, the PGD team did not replace the female embryos, nor did they dispose them. The embryos were frozen, Andrew said, partly because the PGD
clinic only had a licence to replace male embryos and partly because they felt it was a wrong timing for the woman. When the woman had her embryos in a dish in front of her and wanted to have a family, it was ‘too difficult a choice’ to have them disposed of.25

A somewhat similar story, in the Italian context, was put forward by Elisabetta. In this story, the woman did not change her mind during treatment, but afterwards, and implantation of affected embryos did take place.

When Elisabetta was asked to develop her view of the embryo, she explained that ‘it’s not so important that you believe that the embryo has a soul. In any case, the embryo is a problem’ (5.10). Embryos, she explained, ‘should be respected [...] so of course a technique that selects embryos and that accepts and chooses some embryos and eliminates other embryos is problematic’ (5.60). Elisabetta clarified her view with a story of a couple who wanted PGD for an X-linked recessive genetic disease. The woman received treatment, only female embryos were implanted, but implantation failed. The woman could not ‘stand the idea of abandoning’ the male embryos, as Elisabetta put it, and later ‘she decided to transfer also the male embryos’ (5.58).26 The story began with the conclusion: the main difficulty with PGD was to select some embryos and dispose of others.

The main dilemma, the main problem, is to choose the best and most appropriate embryos and to leave the other embryos. I think this is always a problem for couples. They can be more or less conscious [about it], but this is a problem. (5.58)

In Elisabetta’s view, embryo disposal was complicated since some couples, even though they had agreed to the disposal of embryos, found themselves not wanting it.27

These examples are also interesting when set in relation to the discussion by Heather Draper and Ruth Chadwick (1999) of possible new moral questions when PGD is used. Draper and Chadwick describe hypothetical scenarios, one of which concerns a couple who know that they are at risk for cystic fibrosis (Draper and Chadwick 1999:114-120). The woman and man use PGD and they are told that they have six viable
embryos. One of them is affected with Down’s syndrome. Since the couple are not concerned about Down’s syndrome, they explain that they want two of the embryos to be implanted, without discrimination and at random. When Draper and Chadwick discuss this scenario, they argue that if the woman and man are trying to make a decision about the quality of life of the possible future child and if they consider Down’s syndrome to be compatible with ‘a quality of life worth having,’ they are making a responsible parental decision. When this is the case, the woman and man have a right to decide about the use of PGD.

Draper and Chadwick also describe another scenario, in which a deaf couple who undergo IVF for infertility difficulties explain that out of the nine viable embryos they want the one embryo with congenital deafness to be implanted first. The woman and man, Draper and Chadwick say, hold that this future child will have the best quality of life, since any hearing child would neither be part of the hearing nor of the deaf community for the first five years of her or his life. This was also a hypothetical scenario discussed in some of the interviews. When this was done, many of the interviewees were hesitant regarding the implantation of affected embryos. As one example, Evelyn explained that she appreciated the viewpoint of the deaf community, but that she had ‘difficulty with the concept of specifically excluding embryos that you know are likely to be phenotypically normal’ (11.30).28 As another example, Alva explained that she did not want to participate in such a use of PGD and that it would be difficult to make a distinction between such use and uses for other reasons, such as if a homosexual couple would want a homosexual child. Her reasoning implied that such a distinction and differentiation was needed: a use of PGD for deafness meant that one ‘went too far’ and ‘crossed the boundary’ that distinguished acceptable uses from unacceptable ones (13.46). It can also be noted that in the USA a deaf child has been deliberately conceived using donor insemination by a man with five generations of deafness in his family. This was done so that the child would be deaf like its lesbian parents (Savulescu 2002).

One of the interviewees who considered the embryo to be a person in it own right from conception and onwards was more positive to-
wards implantation of affected embryos. If we respect the choice to use PGD in order to avoid implantation of embryos with a particular genetic disease, Angelo said, we should also respect the choice to implant embryos with disease. In both cases, ‘it’s their [the couple’s] responsibility, it’s their choice’ (1.34). This line of reasoning can also be supported by the view that if embryos have dignity and should be protected from conception and onwards, the important thing is to implant them, independently of whether they are affected, carriers or unaffected. This seems also to be the reasoning in the Italian law on assisted reproductive technologies (Legge 19 Febbraio 2004, n. 40, Norme in Materia di Procreazione Medicalmente Assistita). At maximum, three embryos are allowed to be created and all of them must be implanted in the woman’s uterus.

I consider Draper and Chadwick’s examples to be interesting, and the examples enable their discussion of possible new difficulties with PGD. When these examples are compared with the examples that the interviewees put forward, a difference also emerges. Whereas Draper and Chadwick’s couples seem to know what they want and are vocal about it from the start, the interviewees describe scenarios in which couples were possibly less certain of what they wanted (from the start) or they changed their minds during treatment. This also leads to the issues to be discussed in the next chapter: conditions for choice in reproductive genetics. If being vocal about one’s wishes and wants becomes a prerequisite for being offered PGD in the first place, this may be morally problematic.

Summary and Concluding Remarks

Summary
Some interviewees told narratives of life with genetic disease that indicated that life with genetic disease could be and sometimes was tragic and painful. Some of these narratives also contained descriptions of hope in the sense that some women and men had the possibility of trying PGD. Interviewees also described and discussed different uses of
Almost all of them explained that PGD should only or primarily be used for medical reasons, but they did not describe the severity of the genetic condition as the primary factor in clinical discussions about whether to offer and use PGD. Instead, they underlined the importance of the experience of the particular couple. A few interviewees described scenarios in which PGD had been offered and used for non-medical reasons, which was described as undesirable or problematic, though not always morally problematic. One interviewee also articulated concern about a screening for health. Interviewees did not discuss potential conditions that germ-line gene therapy could or should be used for.

Interviewees also told narratives of concern that highlighted their perceived difficulty in defining genetic disease and quality of life in any objective manner; this was the first kind of narratives of concern and three more will be presented in the following chapters. The difficulty made some of the interviewees ambivalent in terms of how to describe and evaluate the uses of the new technologies.

I distinguished between lived experiences and the sub-category of embodied experiences. Lived experiences were personal experiences of close relatives with a genetic disease and personal experiences of having a particular genetic disease. The sub-category of embodied experiences contained only personal experiences of having a particular genetic disease. Some interviewees explained that lived experience was crucial in any effort to decide whether a disease was serious or not.

Finally, most interviewees articulated graded views regarding the status of the embryos; a few articulated the view that the embryo had dignity and should be protected from conception and onwards. The latter interviewees were more positive towards GLGT than the former. Some interviewees also explained that disposal of healthy embryos was problematic in general, and some described disposal of embryos on the basis of obtained genetic knowledge to be morally problematic. The issue of whether to implant affected embryos, deliberately, was also discussed. This is one of the new moral issues evoked by the possibility of using PGD.
Concluding Remarks

In a discussion of prenatal genetic diagnosis in 1998, the sociologist Abby Lippman stated that stories about disease and health were increasingly told in ‘the language of genetics.’ Genetics was to a growing extent identified as the mode in which health and disease were explained (Lippman 1998:144). Lippman also described how prenatal testing had been presented as a response to the needs of pregnant women. She asked what it meant to need such testing, she stated that pregnant women were ‘bombarded with behavioural directives’ that were likely to create a feeling of incompetence and that the search for testing, translated into the language of a need, could well be a search for proof of competence as well as the result of descriptions of women above 35 years old as belonging to a high-risk group. She was critical of what she labelled the ‘construction’ of needs for prenatal testing and she argued that it seemed as if women came to need prenatal testing only when the test for some diseases had been developed (Lippman 1998:149-152, 1994).

If Lippman’s discussion is applied to the results in this chapter, some similarities and differences emerge. The interviewees did use genetic explanations in the discussion of various diseases as well as, sometimes, in the discussion of characteristics such as sexual orientation or intelligence. In their discussion of PGD, they also described healthy children as children without a particular genetic disease. Some of the interviewees also framed the use of PGD in the language of needs, present among some women and men at risk for a genetic disease. This was particularly the case in descriptions of women and men who had not accepted prenatal testing and selective termination of pregnancy but who wanted PGD. However, in contrast to the need for prenatal testing as described by Lippman, the need for PGD may be less a search for proof of competence translated into a need since the ‘users’ of these two technologies differ. In the case of PGD, most women and men have previous lived or embodied experiences of the particular disease. Though this can be the case in prenatal testing as well, being at risk for a particular genetic disease is not a necessary criteria for using it – as it is for PGD in Sweden and the UK. Furthermore, even if interviewees described healthy children as children without a particular genetic dis-
ease, they also, in discussing the meaning of health in general, described health in terms of certain abilities or in holistic ways.

Still, Lippman's statement that the identification of oneself as part of a risk group can influence the acceptability of genetic testing (Lippman 1998:150, see also Ettorre 2000:409) does apply to PGD and to pre-implantation genetic screening if offered to all couples who undergo an ex-corporeal assisted reproductive technology. Such risk group descriptions were present in narratives of life with genetic disease when these narratives were told about women and men who were described as 'high-risk' couples with regard to a particular genetic disease.

Most of the narratives of life with genetic disease indicated that such life could be tragic and painful (compare Shakespeare 1999:672-675, Kerr et al 1998:180-181). There were also narratives of life with genetic disease that indicated that, for some of the couples at risk for a particular genetic disease, there was hope. Some couples could be given the possibility of trying to avoid the birth of a(nother) child with a genetic disease. In such descriptions, choice provision was referred to as important and valuable, not disease avoidance as such. Still, these descriptions harmonise with certain aspects of what some call 'the medical model' in disability theory: the tragedy of the individual was emphasised (as opposed to an emphasis on the failure of a society that disables some people) (Reindal 2000:89).32

This emphasis on tragedy and pain also sometimes resulted in two different uses of normality. First, the notion of normal was used to make a certain wish legitimate: it was nothing strange to want to avoid genetic disease in future children. It was a normal/natural wish that most of us would share. Second, healthy children were also sometimes described as the normal ones. In the latter descriptions, some interviewees expressed what has been labelled a 'non-scientific usage' of the notion of normality in medicine: health was associated with normality and health meant absence of disease (Hoedemaekers and ten Have 1999:539-540). Though this understanding of normality can be used in order to indicate that normality – i.e. health – is desirable, it is important to note that it is not necessarily so.
Most interviewees described the use of PGD for medical reasons as acceptable. Acceptance varied depending on, among other things, how severe the diseases were perceived as being. However, most interviewees also emphasised that severity or seriousness in any objective sense, if there was such a sense, of the disease was not the decisive factor. It is to be noted that the hesitance towards using the concepts of severe or serious genetic diseases, and the criticism on the basis that what is a severe or serious genetic disease is a subjective matter, is also found in certain handicap movements (DHR 2001). It is also worth noting that PGD was described as being used for non-lethal genetic diseases and that some interviewees, when they reflected on these uses, said that such uses should not have been considered acceptable.

The use of PGD sharpens some ‘old’ questions such as the question of how to define disease and health (Zeiler 2003). If PGD should be available for the diagnosis of certain severe genetic diseases as in the Swedish guidelines, there is a need for at least distinct criteria for such diseases (or the guidelines should be changed, as has been suggested by a non-parliamentary discussion group, see Wahlström et al 2002). In a similar way a definition of genetic disease is needed if PGD is to be used for genetic diseases. As an example, it can be discussed whether and, if so, in what sense XYY syndrome and oculocutaneous albinism are diseases (Caplan 2002). The use of PGD also raises certain ‘new’ questions. One such question has been addressed in this chapter. According to the Human Fertilisation and Embryology Act (1990), when IVF and PGD are used, the welfare of the child shall always be considered (and, presumably, provide a basis for any action undertaken). Is such welfare considered, and promoted, only when unaffected embryos are implanted? Arguably, there is a difference between the situation when a deaf couple want to implant an embryo with congenital deafness and the situation when a couple want to implant affected embryos since there are no unaffected. One such difference concerns whether a decision to implant affected embryos is based on what is considered best for the future child.

For the deaf couple, discussed by Draper and Chadwick (1999), implantation of affected embryos was their first option and they considered
it best for the child. Their decision was based on the understanding that deafness was not a condition that should be eliminated. Instead, it could be argued that children whose parents are deaf and who are active members of the deaf culture, not being deaf may result in their growing up in between two worlds, the hearing world and the deaf world. This could be negative (Chadwick and Levitt 1998). For the other couple, discussed by one of the interviewees, implantation of affected embryos was the second-best. The reason why they underwent PGD in the first place was to avoid implantation of affected embryos. As the interviewee described it, the decision to implant the affected embryos seemed not – at least primarily not – to be based on what was best for the children. Instead, it seemed to be the case that this was best for the couple who wanted children. An affected child was better than no child.36

The statement that treatments in the context of assisted reproductive technologies should only be given when accounts have been taken of the welfare of the child born after such treatment re-opens the ‘old’ questions of what welfare means and how it can be taken into account. It can also lead to other ‘old’ questions, such as whether – and, if so to what extent – a particular disease or disability is disabling, whether it is disabling to the extent that the child’s welfare is hampered and whether it is wrong to ‘bring avoidable suffering into the world’ (Harris 2000:96, 2001, 2002, Glover 2001, Reindal 2000, Lebacqz 1999).37 The language of disability is contested ground.

In this context it should be noted that if PGD is used and if a particular child is born as a result of its use, this child has not been wronged in the sense that it could have been, but was not, born without the disease. Instead, in the context of PGD, another child would have been born. In the context of GLGT, the issue of whether such therapy result in a changed identity need to addressed. If it is claimed that its identity is not changed, it needs still to be asked whether the child has been wronged (Chadwick and Levitt 1998:212-213). These issues are further discussed in chapter nine.

The third section of this chapter focused on different understandings of embryos and it showed that interviewees who considered that the embryo had dignity and should be protected from conception and onwards were also the most positive towards GLGT. GLGT, these in-
terviewees said, meant treatment of embryos, not just selection and disposal of some embryos. In this sense, these interviewees concurred with the view offered in the literature – that GLGT is positive since it has the benefit of actually treating a disease (Walters and Palmer 1997). Provided that safety could be guaranteed in the future, and that as little experimentation on embryos as possible took place as steps in the development of the technology, these interviewees explained, there were few other moral difficulties. A comparison of this result and the different kinds of objections to GLGT (see Ch. 1) highlights the fact that no interviewee articulated the objection that future persons had a right to ‘unmodified’ genetic inheritance (European Parliamentary Assembly 1982). Likewise, no interviewee addressed the issue of ignoring the right to bodily integrity of future others since no informed consent of the future generations on whom GLGT would be performed could be obtained (Sutton 1997:68). No interviewee articulated the objection that the use of GLGT implies a change in the prerequisites of the future person concerned, which will undermine our moral community (Habermas 2003:95). However, interviewees who held a graded view of the embryo did explain that they saw little use for GLGT. In this sense, they concurred with the view that the availability of PGD provides an argument against GLGT, except in rare cases when all potential children have a high risk of being affected with the particular genetic disease (Richter and Bacchetta 1998). Why use GLGT when one can select embryos with PGD?

The Italian interviewees who considered that the embryo should be protected from conception and onwards also referred to the official views of the Roman-Catholic Church on the issue. Furthermore, four out of the six Italian interviewees referred to official views of the Roman-Catholic Church somewhere in the interview (even where they explicitly declared that they did not share these views). Keeping this characteristic of the Italian interviews in mind as well as the fact that Pope John Paul II has declared disposal of embryos to be immoral, it is important to note that some Roman-Catholic moral theologians have elaborated other understandings of the embryo. As early as in 1972, Karl Rahner stated that new embryological knowl-
edge (such as twinning or spontaneous wastage of embryos that fail to implant) exposed the above view of the status of the embryo to doubt (Rahner 1972:226, 236), and others have followed (McCormick 1994, Cahill 1993, Farley 2001). It has been argued that the human embryo, before development of the primitive streak, need not constitute ‘an individualized human entity with the settled inherent potential to become a human being,’ since fertilisation is itself a process and since individuation has not yet become irreversible. This knowledge, it has been claimed, provides a basis for the argument that some individualisation is necessary if the embryo is to be understood as having the status of a person and/or human dignity (Cahill 1993:129-130). This reasoning can also be compared with the ‘centuries-old’ Catholic position that if a conceptus should warrant personal status, a certain development is necessary (Cahill 1993:124, Farley 2001:115).

To conclude, interviewees’ reflections contained values such as the value of having the possibility of avoiding genetic disease in one’s children, for those who so wanted. Some of the interviewees’ discussions of implantation of affected embryos also indicated that whereas they were concerned about the difficulty in defining, discussing and evaluating life with genetic disease without lived or embodied experience of that disease, they also considered implantation of affected embryos as problematic. In this sense, genetic disease was sometimes described as a negative value, i.e. as something that could be good not to have, and sometimes as impossible or most difficult to evaluate. Interviewees’ reflections also contained the norm of having children or wanting to have children and their reflections contained morally relevant life interpretations, most clearly articulated in discussions of embryos. Interviewees’ understanding of the moral status of the embryos mattered to their discussion on the uses of PGD as well as GLGT. Finally, interviewees described a number of moral experiences such as the experience of approving or disapproving of different uses of PGD or when one interviewee told his personal experience of life with disease, which made him conclude that it was a terrible responsibility to judge how life with a particular disease could be (and to decide whether to use PGD or not).
CHAPTER 5

Conditions of Choice

Discussions of choice and its conditions formed the third core theme. In contrast to the previous core themes of medical progress and genetic disease, quality of life and health, the core theme of conditions of choice was discussed in detail and at length by almost all interviewees. The core themes of medical progress and genetic disease, quality of life and health were also discussed by almost all interviewees but not in such detail or at such length by so many of the interviewees as was conditions of choice.

This chapter’s first section presents and discusses interviewees’ descriptions of the ideal practice and the ideal clinical encounter. The second section presents and discusses descriptions of the actual practice and actual clinical encounters, when this practice and these encounters harmonised with ideal descriptions. The third section contains descriptions of the actual practice and actual clinical encounters when these did not harmonise with ideal descriptions. Such was the case when interviewees described scenarios where ideals were not reached, when they explained that they doubted that ideals could be reached or when they said that there were certain complicating aspects that needed to be thought-through and that these were not always clarified. They then told two kinds of narratives of concern. They told stories that indicated their concern that certain risks were not clarified to the extent that they should have been. They also told stories of actual complicating circumstances that were not a matter of risk but which made them concerned about the actual practice. Often, such narratives also indicated interviewees’ ambivalence regarding how to describe and evaluate PGD.

Interviewees’ discussions of choice and its conditions also focused on who should, ideally, set the agenda in the clinical professional-patient encounter as well as in national policy-discussions of what conditions to
search for, and they reflected on who did set the agenda in the actual encounter. When such was the case, interviewees described a number of pressures on patients and on themselves of relevance to choices. These topics are discussed in the fourth section of this chapter. As a final aspect of conditions for choice, a few interviewees commented on the possible right to use reproductive technologies. These discussions are presented in the fifth section of the chapter.

Again, germ-line gene therapy was less discussed than was PGD. Germ-line gene therapy was discussed in relation to different kinds of risks.

The Ideal Practice and Ideal Clinical Encounter

Most interviewees described and discussed the ideal clinical practice and the ideal clinical encounter. As a first general tendency in these discussions, the explicit or implicit assumption was that PGD should be used in a responsible and morally thought-through manner and that practice should be carefully regulated. As an example, when asked whether there were any non-medical difficulties with PGD, Giovanna explained that the major moral problem as she saw it in her Italian context was that diagnosis was done for a number of reasons, not all medically motivated, in order to make money. She stated that she and her colleagues had to make sure that control was maintained. ‘We, as geneticists,’ Giovanna said, ‘need to proceed very slowly’ (3.6). A high level of control, of each PGD centre and every use of the diagnostic method, needed to be obtained instead of what was now, according to Giovanna, often the case (3.6).

Giovanna’s reflections were general in the sense that she did not enter into details of how control should be obtained. Other interviewees gave more detailed descriptions of the characteristics of a responsible and morally thought-through practice. This was particularly the case in the interview with Evelyn, who explained that she felt a particular responsibility to make sure that parents were aware of the effects and the risks of IVF and PGD, such as the risk of error in testing, and that she was answerable for how PGD was and would be used (11.4, 12).

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The Cornerstone of Correct Information

As a second general tendency in the interviewees’ discussions of ideal practice and ideal clinical encounters, interviewees emphasised the importance of giving correct information. Such information should be given, all interviewees stated, but there was no consensus as to what correct information meant. The view of counselling as a matter of providing women and men concerned with as neutral information as possible, as a means to minimise professionals’ undue influence on patients’ decisions, has been described as the preferable view in certain literature (World Medical Association 1987). A ‘non-directive ethos’ combined with a ‘principled stance of value-neutrality’ has also been described as contributing to the ‘work-place ideology of genetic counseling’ (Bosk 1993:27). The possibility of neutral information has also been questioned (Clarke 1991, 1997), as has the view that value neutrality is necessarily desirable (Caplan 1993). All these views were present in the interviews as well.

According to a first view, labelled information as pure as possible, medical professionals should only provide women and men with information in terms of what knowledge exists, of facts, of statistics and of possibilities of tracing genes for different diseases. This view could both be an ideal and a description of what actually took place. Such was the case when I asked Nils if he experienced any new difficulties, as a researcher, once PGD was available. ‘No, not really,’ he answered, but he explained that he did get a lot of questions when he was lecturing in public. He recalled one such question, concerning what he would do if he knew that a family had a certain predisposition for a specific genetic disease. What he would do, Nils said, was discuss ‘the probable or theoretical risk’ that a child will have a certain disease. He would never give advice or impose his own views and values on the woman and man (14.20).

The implicit assumption in this view is that advice biases choices and that giving information regarding facts and risks – though it may still bias to some extent – is the best alternative. Information, as pure and as cleansed from values as possible, was an ideal to be striven for. This version of pure information should be distinguished from what may be called a naive version of it, i.e. the view that information can be given without any bias.
Nils did not enter into the discussion of whether information as such was problematic, but other interviewees remarked that even if advice and personal views were not expressed, information as such was problematic. Information was impelling and restrictive. This view was articulated by Alva, for instance, when she remarked that information was not ‘innocent.’ I asked her how she would describe the situation for couples once PGD was available for certain diseases, and Alva answered that couples ‘must choose.’ They could not ‘choose not to choose.’ ‘It sounds as if we inform very innocently and most people ask for information,’ she reflected, ‘but there are people who wished that they had not needed to choose’ (13.24). In her view, information given precluded the possibility of choosing not to know and not to choose; it conveyed certain restrictions on what couples could and would choose.

Furthermore, one interviewee explicitly questioned neutral information in the sense of non-advice discussion as an ideal in the genetic counselling. The situation in which couples considered using PGD was so specific, Andrew stated, and so many moral questions were evoked that advice might need to be given. Medical professionals should be allowed to advise in the genetic counselling (8.40) since PGD evoked so many difficult questions. Andrew exemplified such difficulties with a story of a couple that he had encountered:

I remember one couple very clearly. They said, you know, they never wanted to know about this kind of thing, but it’s not choice, there’s not a choice […] Couples come to see me who might have no educational background, you know, he might be a window cleaner and she might be a housewife. Suddenly, they have to think about numbers of embryos […] morphology of embryos that was way beyond what they normally expected to confront in their lives, and they’re faced with ethical questions that in many ways they’re really unprepared to face. I think they become swamped by it sometimes. Suddenly they have to think within a very short time-scale as well. (8.16)

In Andrew’s view, PGD evoked more moral questions than most people met during a lifetime, and this during a restricted period. The risk of information overload was present, in the sense that too much informa-
tion was given and that this information also meant that a number of complex moral issues had to be addressed. Hence, advice should not be prohibited – it needed to be given. This is the second view that could also both be an ideal and a description of what actually took place (as was the case with the view of information as pure as possible) and I label it information in need of being supplemented. It was present in two versions.

First, as we have seen, Andrew held that information needed, at least sometimes, to be supplemented with advice as to what to do. Second, other interviewees explained that information needed to be supplemented with a discussion of moral questions and that correct information should include a discussion of such questions. When Björn described changes for him as a professional once PGD was available, he said that he would inform couples of this possibility. However, he added, when certain uses of PGD had been accepted in national policies, this might result in some people not thinking through all the moral aspects themselves. They ‘trusted’ that a moral assessment had been done and that PGD would not be offered if such an assessment had not been done (17.22). If so, the question was to what extent couples attention should be directed to possible moral issues.

The Actual Practice and the Actual Encounter: Harmonising with the Ideal

In some of the interviewees’ descriptions, ideal and actual practice coincided. This was the case in certain of the British and Swedish interviews and particularly so in the interview with Evelyn. Evelyn explained that she was committed to her present responsibility. Such a responsibility meant that she was answerable for what took place in the everyday work at the clinic. As an example of how she would make sure that a responsible practice was maintained, she described how she would reason in a hypothetical scenario if, as she said, she was counselling a couple who were not only concerned about a specific genetic disease. If they told her that
they’re worried that all sorts of other things could happen as well, “could we while we’re there also test for a whole range of other conditions,” from a practical point of view we will need to sit down and explain to them, we’ll try and reassure them that the risk of the other things happening is very small. [We will] explain to them that you can’t just test for all these other things. (11.28)

Evelyn said that certain uses were acceptable and others were not and that they, at the clinic, would and should explain this to couples. As can be seen in the excerpt, such explanation was described as needed from a practical point of view. In this particular sense, Evelyn’s reasoning resembled that of Ned when he explained that certain uses of PGD were not ‘practically appropriate’ (Ch. 4, sect. Used for Genetic Diseases Only?).

Later on in the interview, Evelyn also explained that she and her colleagues worked together, ‘as part of a very closely integrated, very experienced, very thoughtful team’ (11.67). If faced with difficult questions they should not be, and were not, afraid to consult whoever they thought appropriate. Evelyn described this as a way of making as sure as possible that the clinical practice was responsible:

At all times, all the members of the team must be involved and must feel comfortable with what we’re doing, because that’s the way you build in as many internal checks as possible, to make sure that what you’re doing is reasonable and responsible and safe and appropriate for the couple. The couples are part of that team. If we’re ever not sure or we’re asked difficult questions, we mustn’t be afraid to consult, to consult very widely, to consult with ethicists, to consult with lawyers, social workers, the Human Fertilisation Embryology Authority, whoever. (11.67)

Practice should be carefully regulated and moral questions should be dealt with. In Evelyn’s descriptions, this was also what happened in the actual practice. She described a carefully regulated and responsible practice through the use of examples of how everybody took part in discussions (which resulted in ‘internal checks’) and she stated that ‘we spend a considerable amount of time considering the ethical dimension
of every single request that comes to us’ (11.4). The regulated practice, she said, helped ‘to preserve the respect that the service is likely to have’ and it was a way to reassure people that PGD was not used for ‘trivial reasons,’ nor was it ‘a pass to eugenics’ (11.69). She and her colleagues had, Evelyn said,

a responsibility to make sure that PGD is only ever offered in a very protected and carefully licensed way, so that we can try and reassure the public that we will not let it be ethically abused, because if we do the whole service comes into disrepute. That would jeopardise the possibility of us being able to offer this service to people who have a very genuine need for it. (11.4)

Here, then, the medical professionals’ responsibility was twofold. It was a responsibility to supply people with PGD, for the sake of their genuine needs, and it was a responsibility not to let the service come into disrepute. The medical profession and its desire to keep PGD centres open was described as a guarantee against moral abuse. Thus arose the image of the responsible doctor and researcher who acted in accordance with the will of and on behalf of the patient groups and who guarded the practice against abuses. Evelyn described a situation where there should be no gap between ideal and actual practice. It was her responsibility to make sure that there was no gap.

Evelyn articulated a present responsibility as well as what I label a prospective responsibility, a responsibility to anticipate and envision future moral issues and scenarios in need of reflection. Such a prospective responsibility can be part of the present responsibility – to account for a responsible, morally thought-through practice at present also involves reflecting on future scenarios. This was the case when she explained that her and her colleagues’ responsibility was ‘particularly not only to think about the ethical issues of the moment, but also to anticipate what could happen ten, twenty, thirty years down the line.’ Sometimes, she continued, she felt that they were ‘in a better position to look far ahead to the future than perhaps other people involved, who may be concentrating more on what is happening now’ (11.12).
The described need for PGD, of some couples, can also be related to other interviewees’ descriptions in narratives of progress and narratives of life with genetic disease. If so, life with genetic disease could be tragic and painful, someone had a need for PGD, professionals could offer it, but when so doing they had a responsibility to make sure that technologies were only used in accurate and morally acceptable ways.

The Actual Practice and the Actual Encounter: Complicating Aspects

The analysis also highlighted reflections about what happened in the actual encounter that did not harmonise with the ideal descriptions of conditions of choice, which point to a gap between ideal and actual situations. Such reflections were often described through the use of narratives of concern, i.e. narratives that indicated interviewees’ concern that certain risks were not clarified and narratives of actual, complicating circumstances that made interviewees concerned about the actual practice.

Five areas of caution with regard to counselling in the clinical encounter, to the use of PGD and sometimes to future use of GLGT recurred in the interviews. Interviewees were concerned as to whether correct information about alternatives to IVF/PGD was given. Interviewees were concerned as to whether correct information about medical risks of IVF/PGD was given, and medical risks were described as a reason not to allow GLGT. They were concerned as to whether the limits of information available were clarified in respect of PGD and as to the level and status of knowledge of GLGT. A few of them were concerned about the character of PGD and whether it would complicate counselling. They were concerned about the low success-rate of PGD. These concerns are presented in the following five sub-sections.
Was Correct Information About Alternatives to IVF and PGD Given?

Vittorio was one of the interviewees who said he doubted that correct information about alternatives to IVF and PGD was always given. Vittorio explained that his clinic had specialised in neonatal surgery and he held that such surgery might be an alternative to PGD in certain conditions. However, Vittorio said, few clinics had specialised in neonatal surgery and few professionals knew about the recent developments in the field (2.10). Hence, counselling did not achieve its purpose of providing all relevant information.7

Was Correct Information About Medical Risks Available and Given?

Other interviewees were also critical of information given by colleagues and of pictures given in and through the media, as was the case when Joyce explained that she was worried about ‘one-sided pictures.’ She was concerned about alternatives as well as IVF/PGD not being spelled out correctly. As was said earlier, Joyce was one of the interviewees who had personal experience of assisted reproductive technologies. She was concerned about how PGD was presented in the media:

I just sort of compare what I know about that situation with the desperate disappointment of having gone through all of the tests [of IVF] and the stimulation and everything like that and only a twenty per cent chance of having a healthy baby. I think what happens is that people have been sold the good news stories. There have been a lot of television programmes on this, and it’s often been wrongly portrayed as the only way that a couple can have a healthy baby when faced with a genetic risk. (9.12)

Joyce stated that the positive sides of IVF/PGD were exaggerated. She also said that PGD was portrayed as ‘the only’ way for couples faced with a genetic risk to have a healthy child. ‘It affects me,’ she explained, because she wondered whether doctors ‘had explained to them the other option’ of prenatal diagnosis and an early termination of preg-
nancy, and ‘whether both options were spelled out to them in an equal way’ (9.12). Joyce also explained that she was ‘not anti PGD,’ but that she just felt that ‘there’s quite a lot of zealots around who are so pro it, that they sometimes minimise the down-side of it and ignore other options’ (9.26).

The ‘arduous’ IVF procedure, which involved medical risks and which was necessary if PGD was to be used, was described as a major disadvantage in all interviews, and most interviewees evaluated the use of PGD on the basis of consequences for women who underwent IVF and PGD procedures. As an example, Joyce explained that she wondered if PGD centres did not have a ‘vested interest in encouraging people to enter into that process’ (9.12). She also stated that the whole IVF procedure, she said, was ‘enormously stressful’ (9.8). In her words:

the sort of taking your temperature and waiting for ovulation and then seeing whether you’ve conceived and whether … I mean, it’s just, it’s terr … it’s very, very stressful. (9.18)

In Joyce’s view, IVF also imposed traumas on people through ‘the sort of involvement of medics at every sort of stage of a conception’ (9.46).

One interviewee, Giovanna, also described IVF as a tiring and risky measure to take but for her the tiring IVF procedure was a reason why PGD should be allowed. On the one hand, Giovanna compared PGD with prenatal diagnosis and described PGD as ‘much, much, much less tiring’ from a psychological point of view since it involved no termination of a pregnancy (3.10). On the other hand, she compared the use of IVF with someone ‘playing with’ her life or ‘interrupting one life for the sake of another.’ In her view, women who used IVF and PGD ‘interrupted’ their own life during all the medical check-ups, hormonal treatment etc. for the sake of the potential future child (3.12). However, since the women had to undergo so much treatment, it was ‘just’ from a moral point of view that couples could use PGD in order to make as sure as possible that the pregnancy proceeded in a good manner (3.6). They had put up with the painful IVF treatment and this was described as morally relevant to their use of PGD.
The physical pressure on women who underwent IVF was described as an important facet of IVF that needed to be carefully thought through. It was discussed in all interviews and it was sometimes emphasised through the use of such terms as ‘the most,’ ‘huge’ or ‘big.’ Other pressures were described as emotional. Steven focused on the latter in his reflections on the difficulties present when IVF and PGD were used:

I think the emotional sort of process of getting wound up, ready for conception and maybe it not working out that time or not happening to schedule or whatever. There are lots of ups and downs emotionally […] You’ve got very understandable emotions anyway, but then with these sorts of levels of hormones being wound up, it makes it even harder on the woman. (7.8)

The risk of emotional stress was also described as present if technologies failed, and particularly so if it failed several times. Some couples went through ‘enormous amounts of treatment,’ Andrew explained. Each time they tried PGD, they went ‘through all the psychological processes again, of what’s happened to them in their obstetric careers if you like, the children they’ve lost, the pregnancies they’ve terminated’ (8.10). Andrew recalled one situation in particular, when he was counselling a woman who had lost a previous child through SMA. The woman didn’t respond well to PGD, and according to Andrew she was still grieving for the lost child.

She only had two or three oocytes each time but she went through, she insisted on going through PGD three times. Each time was more and more damaging to her. It was like, you know, we had embryo biopsies and a lot of the embryos were affected by SMA, the majority were. Each embryo that was thrown away was like her daughter’s death again. It was very damaging. We stopped carrying out the treatment any more. (8.10)

The story indicated the risk of repeated severe emotional distress (i.e. a psychological risk) as a consequence of previous failures. Physical risks and most psychological risks were described as present for women.
Only one male interviewee brought up the issue of men’s experiences. When Angelo did so, he discussed the situation for men and commented that ‘also the father’ was ‘stressed by the whole thing, if he cares for his wife of course’ (1.10).9

Finally, some of the interviewees spoke of possible physical risks for the unborn child. Such was the case when Evelyn described aspects of IVF and PGD that were of ‘some concern.’ When asked if there were any new difficulties that couples who wanted to use IVF and PGD would face, Evelyn explained that risk of embryo ‘damage’ through the use of these technologies might be present even though no international studies had indicated that this was the case. Though IVF and PGD had been performed for some time, Evelyn said, the number of children born was still low and a lot remained to be learnt. In her words:

> Although there’s no evidence that biopsying the embryo causes any significant damage, internationally not that many cases have been done. So there must still be some concern that there could be some damage done. (11.20)

Whereas most interviewees discussed risks of physical and psychological pressure for women and a few of them spoke of physical risk regarding the embryo, the opposite was the case when it came to germ-line gene therapy. The risks for the future child and future generations were discussed, not those for the women and men concerned. As an example, Steven said that ‘the potential hazards of germ-line manipulation’ could not be ignored and that ‘it’d be grossly irresponsible for someone to go down that road and leave this to potentially re-emerge in the future’ (7.53). Other views were present as well. In Ned’s view, germ-line gene therapy would only involve ‘anecdotal, hypothetical’ medical risks (10.55).

The different kinds of risks presented in this section will be labelled medical risks. Medical risks are understood as a direct consequence of a certain intervention and they can be physical as well as psychological.
Were the Limits of the Information Available Clarified?

Most of the interviewees who discussed correct information stated that it meant, among other things, that the limits of available knowledge should be clarified and that women and men should be told about what genetic information could be given. Some interviewees questioned whether and to what extent limits of knowledge and genetic information were accurately conveyed to couples.

When commenting on the conditions under which he would find PGD acceptable, Angelo explained that medical professionals should ensure ‘that parents at least are informed of the amount of risk of having a mal-diagnosis, that you could make an error’ and that there may be other diseases that you have not tested for (1.28). Angelo used an analogy in order to explain the limit of the knowledge obtained, even if IVF and PGD had been done successfully:

It’s like you have checked the map of the world and checked whether the continents were there. They were there, and you didn’t know that there was a small mistake in your city on Fifth Avenue. (1.26)

Not only could there be mistakes during testing, but mosaicisms, though frequent at that stage of development of embryos, could not be seen, nor could new structural rearrangements that occurred after implantation. Such Fifth Avenue information, as I label it, information about what kind of information the woman and man would not get, needed to be given. Some interviewees doubted that this was always done. A few of them also told stories of what happened when such information was not clarified or when couples did not hear or understand it, as did for example Joyce.

Joyce explained that she had referred a couple at her clinic to an IVF/PGD unit, where a certain trisomi was tested for. The family had the test and an ‘apparently normal embryo’ was re-implanted. However, the pregnancy didn’t go well, Joyce said, and ‘an amniocentesis was done and the baby had a different trisomi, one that hadn’t been tested for, but another, lethal one.’ As a result, the family had a termi-
nation later than would have been the case with ordinary prenatal diagnosis (9.4). Joyce concluded that ‘the unexpected can happen.’ In this particular narrative, pregnancy ‘didn’t go well’ and a late abortion was done. This was failure in terms of communication: correct information concerning exactly what PGD was used for was not given, or the couple did not hear or understand it.

Interviewees explained difficulties in conveying correct information concerning what kind of knowledge was obtainable as being a result of medical professionals not being explicit enough. They also explained that ‘people’ overestimated genetic testing. ‘People,’ Joyce said, ‘need to know that it’s not available just as much as they need to know if it is available’ (9.14). She explained that people tend to think, you know, if you’ve had one gene looked at, you’ve had all your genes looked at. Of course, it is important that people realise that you’re testing just for one thing. Particularly with preimplantation diagnosis you really are testing for just one thing at the present time. (9.14)

Interviewees also described difficulties in predicting what kind of genetic testing might be possible in the future. Again, the limited knowledge needed to be conveyed but in this case it was difficult to say what might become possible. Andrew recalled stories of couples where either one or both parents knew that they were ‘at risk’ for Huntington’s disease. He described these couples as living in a constant pause, a stage of waiting, which might become a way of living. They put their ‘lives on hold’ until testing was available, and no one knew when this would be. In lives-on-hold situations, there was a risk that false hopes would be raised, in the sense that couples were told ‘we’re nearly there’ even if this turned out, later, not to be the case.

We’ve had couples wanting Huntington’s testing for five years and we keep saying we’re nearly there, we’re nearly there, and we’re not there yet. I think they’ve put their lives on hold until it’s available, so I think that the prospect that PGD might be there is more harmful for those couples because they can’t get on and decide to have a family or do prenatal diagnosis and termination. They can’t move because PGD’s not there for them yet. (8.14)
Lives-on-hold situations complicated couples’ choices since there was lack of knowledge of future developments.

I label risks that information given is not correct, risks that couples are not told about what kind of information can be obtained and risks that no or not enough information can be given about future developments or consequences, but where couples nevertheless need to make a decision, epistemological risks. Such risks have to do with a lack or low level of knowledge or information, or difficulties in the evaluation of knowledge and information. A useful distinction can be made between the risk of something (risk that X) and the reasons for such a risk. The epistemological risk is the risk that no accurate knowledge can be given or that information, upon which couples base their choices, is not correct – as opposed to the medical risk that someone may be physically or psychologically hurt. The reason why medical risks are present can, obviously, be that we have too little knowledge about how to avoid these risks.

Epistemological risks were also present in interviewees’ discussions of possible future harm for children born after IVF and PGD. As an example, when asked if there were any more moral questions she would like to comment on, or if she wanted to comment further on previous ones that she had already touched upon, Åsa explained that the oldest children born after PGD were about ten years old today. Little knowledge was available concerning long-term consequences, she said, and couples needed to decide whether that was enough information for them (16.107).

Difficulties due to lack of knowledge were also described as a major reason for not using germ-line gene therapy. Such was the case when Steven explained that he did not think anyone ‘can come up and say “there is a ten percent chance within five generations of,” you know, “whatever,” but there must be potential hazards to it’ (7.53). Such lack of information made it difficult to assess future consequences. If GLGT was to be used, even if no accurate information about future consequences could be given, epistemological risks (such as the risk that couples had to make decisions without accurate information) as well as medical risks (such as the risk that the future child would be hurt) could be present.
**Did the Character of PGD Complicate the Discussion?**

One interviewee, Simonetta, declared that some of the Italian (private) PGD units made couples believe that PGD was an easy technology to use. This, she said, was dangerous and untrue (4.2). She also said that as a professional and *because* of the abstract character of PGD, it may be described as morally easier than prenatal testing and termination (4.2). Other interviewees, such as Nils, also described difficulties in conveying correct information as due to the character of the testing. The abstract and technological character of PGD complicated it.

When asked to compare the present situation with pre-PGD situations, Nils described IVF and PGD as

> more technified in some way. You do this fertilisation in vitro. You control. You do not implant before you know that, believe that you know that, the embryo that will develop is healthy. With this technology, things have changed, you can push these decisions away from you a little bit more. It becomes something you manipulate in the laboratory. It does not happen in my body. (14.16)

In these lines of reasoning, interviewees were concerned about PGD since it was a *debodified* technology in that it was used outside the body, in a laboratory. This characteristic made discussion of moral questions easier in a negative way: decisions could be ‘pushed away.’ Possibly, according to Nils, this made it more likely that PGD would not only be used for a particular genetic disease but as a tool in a general ‘quality control’ of embryos. If this happened, it would mean a ‘scary future’ in Nils’ view (14.16). A similar concern was articulated by Giovanna when she reflected on difficulties regarding the choice to use PGD. Giovanna compared PGD with prenatal diagnosis and she explained that the problem was different, because when you chose prenatal diagnosis, the foetus was already a part of you. With PGD, the embryo was not part of the woman’s body, which resulted in a greater ‘distance’ to what was happening. The distance was also enhanced by the fact that the concrete choice of the exact embryo was sometimes performed by the geneticist alone (3.10).
In a comparison with the previous discussions of different ways in which PGD was better than prenatal diagnosis and selective termination of abortion, it is to be noted that these interviewees described PGD as having negative consequences for the same reason as has previously been described as a positive aspect of PGD (see Ch. 3, sect. A Psychologically and/or Morally Easier Means). PGD and selective transfer of embryos was debodified, which made it psychologically easier than prenatal diagnosis and selective termination of abortion.

**Was the ‘Low’ Success Rate and ‘Confusion’ in Testing Clarified?**

Finally, many of the interviewees discussed the risk that IVF and PGD would fail. Chiara also stated that since success rates were low, it became a question of intellectual honesty ‘not to love technology’ too much (6.14). Failures were described as possibly due to inaccurate/imprecise technologies or inaccurate/imprecise uses of technologies, including difficulties in interpreting the obtained genetic information, or as due to genetic characteristics of the patient group. These patients may have had chromosomal changes that hampered normal cell divisions, Hilda explained (15.8), and this could partly explain the low success rate. I will label risks that technologies are inaccurate or imprecise or that they are inaccurately used as technology-derived risks. These risks are distinct and different from the previously described medical risks as well as the epistemological risks. Obviously, if technologies are inaccurate or imprecise or inaccurately used and if this results in failures as above, failures may result in (as an example) psychological pain, but this is not the issue here.

When asked if there were any new difficulties for him as a professional in his encounter with couples who wanted to use PGD, Andrew explained that PGD opened up a wide range of possibilities when it came to what genetic structures might be sought for and seen. The process of identifying the correct mutation that caused a specific disease was difficult and the risk of failure to find correct information was present. He explained that it was
easy to get confused by not looking at the actual translocation, which one it is. For example, we have some couples with a 13/14 translocation who have a current miscarriage, but maybe nothing to do with the translocation, because it’s such a common one. You can get too muddled in it. You can be offering a panacea that doesn’t exist. (8.20)

In Andrew’s view, making sure that the knowledge obtained was correct knowledge was sometimes difficult. Maybe a certain translocation really resulted in miscarriage, but it might also be due to other translocations, or to something else. Such a difficulty is a difficulty of seeing, obtaining and evaluating relevant information. As a medical professional, he could have difficulty in discerning what information was relevant.

The limited reliability and the low success rate were major concerns for most of the interviewees but they were discussed to a larger extent and in more detail in some of the Italian interviews than in the others. Use of PGD may, Giovanna said in a reflection on possible difficulties, involve a ‘huge risk of failure’ in the test (3.6). This view was echoed in all of the Italian interviews, such as was the case when Vittorio stated that on average, 20% of the women who went through IVF carried a healthy child to term (2.22). The risk of failure was, in his words, ‘very, very high’ (2.14). The low success rate raised questions. When should a technology be considered too risky and too unsuccessful?

Technology-derived risks were also discussed in relation to germ-line gene therapy. Some of the interviewees used analogies in order to argue that germ-line gene therapy was not more dangerous than other, more common interventions, given that technology-derived risks were minimised or absent and technological safety was obtained. One of them, Angelo, said that at an experimental stage certain moral dilemmas might be present. Once this stage was passed and provided that technical safety was obtained, he didn’t ‘see why we should be more scared about impacting on DNA than just cutting up and stitching the bowel or taking a pill’ (1.83). Hilda used a similar analogy between germ-line gene therapy and common forms of medical treatment. In the future, she said, using germ-line gene therapy need not be stranger
than it was to use penicillin to cure pneumonia today (15.22).

Not all interviewees shared this positive view. Joyce articulated a more sceptical view of germ-line gene therapy and she used the pejorative term of ‘messing around’ with genes in order to make her point. ‘If you,’ she said, ‘start messing around and sticking genes in various places, how does it affect the action of other genes?’ (9.38) She also stated that the potential of germ-line gene therapy was ‘overestimated’ in her view. The technological problems were much bigger than the potential moral problems. She explained:

I think there’s an overestimation of the power of genetic technology actually, particularly when it comes to situations [that involve] not diseases, you know. You might talk about behaviour, you might talk about normal, physical attributes as well as diseases. The genetic control of those situations is probably going to be complex and not modifiable by just tinkering about with a particular gene or even two or three genes. It’s likely to be highly complex and involve many different sorts of pathways. (9.38)

In Joyce’s view, ‘messing around with it [the genome of an embryo] is not going to be very easy’ (9.40).

Who Decides and Who Sets the Agenda: Ideals and Constraints

Many of the interviewees discussed the ideal decision-making at the level of the clinical encounter as well as at the level of public, national policy-making. Who should, ideally, take part in discussions, who should make decisions and who should set the agenda?

Ideally, all interviewees agreed, women and men at risk for a genetic disease should be ‘free’ to choose in the clinical encounter in the sense that the decision as to whether to use PGD was theirs to make. At the same time, a larger part of the interviews contained interviewees’ descriptions of situations in which they said they doubted the extent to which choices were free. Through these descriptions of perceived pres-
sures on couples, the presence and realism of couples’ choices can be problematised. Interviewees also described pressures on the choices of medical professionals.

Ideal Decision-Making

Most of the interviewees presented views that came close to a dialogical ideal. The couples concerned should make the ultimate decision as to whether to use PGD or not, but in the decision-making process the woman and man concerned and the medical team should engage in an on-going dialogue. Hilda, for example, explained that as long as PGD was discussed for different severe genetic diseases, she thought couples should be allowed to take part in discussions of what to test for alongside medical professionals. She also explained that this was not only an ideal description of how she would like encounters to be when she was the professional, but also how she believed that she would want things to be if she was a patient. If she was at risk for something that was not yet technically possible to search for, she would want to influence the discussion in such a way that the development of tests for the particular disease was at least further discussed (15.16).

Some interviewees also expressed a strong desire not to hinder couples if they wanted PGD for a certain disease, given that it was within the law. As seen before, this was the view of Joyce (the important thing was that couples were given a choice, provided that what they wanted was within the law, as discussed in Ch. 3, sect. One More Choice). Such was also the case when Hilda explained that for some couples, PGD was ‘their last possibility.’ If they were willing to take the risks associated with IVF and PGD, Hilda said, she could not be the one to stop them. If ‘they are willing to take this risk and go through this, then, I mean, I cannot be the one who says “no, I don’t want to do this’” (15.62).

None of these interviewees clarified how far they would go in meeting couples’ wishes, but Åsa gave one example of when she felt that it ‘ethically speaking, almost is wrong to deny’ someone the use of PGD if it should be asked for. She recalled a meeting with a woman who had two children with Down’s syndrome. The woman lived in a small vil-
lage in the northern part of Sweden, where ‘everyone knew everything about everyone else’ as Åsa put it. The woman, Åsa explained, ‘just couldn’t become pregnant. I felt that it was ethically wrong to deny her this [PGD]’ (16.66).

Sometimes, the emphasis on couples’ free choice was also combined with the emphasis on lived or embodied experience of life with a particular genetic disease and with reluctance towards strict national policy-making. Such was the case when Elisabetta explained that she did not like legal restrictions in general (5.56). Chiara also explained that it was not evident what diseases it should be permissible to search for in PGD, nor was it evident who should decide what conditions to search for. Furthermore, no medical professional or political authority in any country could decide ‘if cystic fibrosis is more serious than Down’s syndrome, or something else’ (6.10).

The verbal dissociation from power, where medical professionals stated that neither they nor politicians should decide about uses of PGD, raises the question of who should decide, ideally. Several interviewees emphasised a line of thinking that could be designated power to the people. However, ‘people’ was not understood as meaning lay-people in general, but couples at risk of having children with genetic diseases, who wanted to use IVF and PGD. Andrew explicitly articulated this view:

If the couple felt that it was a serious problem [...] I would say “well, that’s your choice,” you know, “that’s your experience of it and if that is a very serious thing to you then nothing else really matters,” I still feel that it’s the individual’s choice rather than the public’s. [...] I don’t think it’s the public’s business what the individual does, and I don’t care if the majority in the UK don’t feel that PGD is acceptable for cystic fibrosis or Huntington’s, if it’s important to the family. They should be allowed treatment. (8.28)

Scepticism was not only directed at the idea that medical professionals or politicians should decide what should be allowed, but also at the idea of the ‘public’ as a decision-maker. Instead, many interviewees supported the idea that those who had experience and who wanted to use PGD for a certain condition should be the ones whose voices were
heard and whose wishes should, provided that what they wished was not illegal, guide medicine.

It is also noteworthy that the scepticism towards regulations was only articulated in discussions of PGD and not in discussions of germ-line gene therapy. As an example, though Elisabetta explained that she was ‘against restrictions in general’ some restrictions were necessary in the case of germ-line gene therapy. Otherwise, ‘we’ were at risk of ‘doing things that go beyond […] reproduction’ (5.56).

Pressures on the Woman and Man
Press from Medical Professionals and from Health Care Structures
The ideal of free choice was not always met. Most interviewees gave examples of how women’s and men’s decision-making was negatively influenced by others. They described pressures and demands on women and men at risk for genetic diseases as imposed by medical professionals and by health-care structures. As one such example, Andrew described the views of couples who had experience of life with a disease as crucial. But, he added,

I’ve become more and more worried that, if a couple want treatment, we feel obliged to offer it to them [and it is] not always in their best interest, but simply because they want it and we can do it. Then, we are almost supporting them, pushing them towards it. Of course, they’re going to be, if they want something they’re going to be very vocal about it, because they have to have been quite vocal and persistent to have got as far as us. So they’re never going to say to the doctor “I think I want to have this.” You know, they might not turn up for treatment, but they are going to have to say “We really want this, we must have it now,” and so then we end up saying “Yes, you must have it now.” Before you know it, we’ve done the treatment. We’ll, we never stepped back to say, you know, “just because they wanted it, was it the right thing to do for that individual?” (8.28)

Here, Andrew described himself as contributing to the pressure on the couples concerned. Pressure on couples was partly due to health-care
structures – there were few PGD clinics and in order to be sent to such a clinic couples needed to sound convinced. Thus there was a structural directiveness that made couples likely to act in a certain way in order to get what they wanted. There is also the idea of a vicious circle, where medical professionals pushed couples, couples needed to be persistent, the more persistent they sounded, the more professionals felt that couples should use the technology, etc. Andrew expressed concern about the consequences of this vicious circle. Little space was left to encourage reflection, articulations of doubt and hesitancy. If present, he continued, such reflection was seldom articulated but shown through absences during treatment. Couples did not show up when expected.

Andrew’s reflection indicated a possible communicative failure in the sense that what interviewees said it should be possible to articulate in the clinical encounter did not coincide with what was in fact articulated – if the reason was that couples dared not articulate their worries.

Ideals of free choice and free participation in discussions can also be discussed from the angle of couples who were described as not wanting to participate in the ‘actual choice’ of their future children, but where professionals were eager to have them engaging in these discussions. Though this is not an example of an explicit demand, it is an example of complicating aspects of so-called free choice. Such was the case when Andrew told the story of couples who did not want to take part in the discussion of exactly what embryo to implant, but who were ‘drawn’ into that discussion against their will. This, he reflected, was an intrusion ‘in the bedroom’ and medical professionals were ‘invading’ couples’ ‘personal space’ at conception, even though such invasion was welcomed.

In Andrew’s experience, couples did not want to know or feel that they contributed to the exact choice of their future children, but one of his colleagues wanted the couples to take an active part in the decision as to which embryo to implant. Andrew said that his colleague

gets very involved in, you know, discussing the merits of each of the embryos, and you can often see the patients not wanting it. It’s almost as if when they get to that end stage, they want to know that

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these are the embryos to put back and have them back, end of dis-
cussion. They don’t want to get involved in all this choosing, they
almost don’t want to feel that they’re choosing their children. (8.42)

Andrew explained that he could see that couples did not want to par-
ticipate in this kind of discussion and he reflected on what made the
couples not want to participate:

I don’t think many people do want to get involved with actually
choosing their individual embryos. They just want [us] to say
they’re affected or not, because it’s undignified in some way. You
know, that’s your last bastion of maintaining some personal life,
you know, and you don’t want to invade it too far. (8.42)

Two aspects of the narrative are to be noted. The use of the metaphor
of a bastion of personal life implies the idea of a border that keeps in-
truders on one side of its walls. In this example, the bastion is described
as something that medical professionals necessarily invade and it calls
for caution. A distinction is also made between the explicit choice of
actual embryos and the choice to use PGD but not to take an active part
in the discussion of concrete choice of embryos. Whereas the former
choice is described as being ‘undignified in some way’ to some couples,
the latter is not.

Pressure Due to the Existence of Technology – The Technological
Imperative

Interviewees also described pressures and demands on couples as a
consequence of the very existence of the technology. Again, an excerpt
from the interview with Andrew can exemplify this view. Andrew ex-
plained that some couples seemed to feel that they should use IVF and
PGD since this was possible. Probably, he said, some couples could
have accepted not having more children or having gamete donation or
adopting if their condition allowed them to adopt, but ‘because a tech-
ology is offered to couples, and there is support of the doctors offer-
ing it, then couples start to choose options that they might never have
wanted’ (8.10). He continued:
simply because this technology is there, many couples seem to feel that they must take it, that they are denying their future children [something] if they don’t take it. (8.10)

The view that a certain technology should be used since it is available is commonly labelled the technological imperative: what can be done, technologically, should be done. Andrew described it as a part of the high-risk couples’ reflections that he met with in the clinic. In his description, the value of technology seemed to have been internalised by some of the couples and it had received a normative dimension. It was not only an option, but something that should be used. If not, PGD might even be guilt-engendering: couples might feel that they are denying their future children something.

Though PGD may have these undesirable consequences, Andrew also described it as therapeutic. This could be the case, he said, even if its use did not result in the birth of a healthy child. Andrew explained that ‘they’ve done everything. They can’t say they didn’t try’ (8.10). For these couples, such a conclusion was described as a relief. They could go on with their lives. It is noteworthy that the use of PGD as such was not questioned because of this consequence but – instead – PGD was considered positive since it was the last resort, a final end to the process of trying.

Pressure from Society and Groups in Society
Pressure and demands were also described as coming from ‘society.’ Such was the case when Alva elaborated her view that ‘the problem’ of choosing PGD was ‘that you do not choose information.’ I asked her what she meant and she explained that information ‘does not come when people ask for it’ (13.34-36). Furthermore, Alva said, people knew that PGD was possible and this knowledge had consequences for those who chose not to use PGD and who gave birth to children with a genetic disease. Alva used the example of prenatal diagnosis, when it revealed that the foetus had a certain genetic disease, to make her point. She said that it was only people with a strong faith that could handle that pressure of not aborting it, whose beliefs forbid them to
abort. In her view, very few of the women she had met at the clinic and who had given birth to children with genetic diseases or impairments managed the feeling of guilt, of having done something that ‘society’ did not approve of (13.36).

Andrew also described pressures on women and men at risk for a particular disease, who did not want to use PGD, from those who were at risk for the same disease and who had used PGD. This was also one of the few detailed reflections on the situation for couples who do not want to use PGD in the data. Andrew described support networks for families with a certain genetic disease and he described some of the members of such networks as

definitely a tight clique of patients who are coming to us and having treatment for PGD. They all know each other, they all keep in touch with each other about how the treatment’s going […] There must be some people that choose not to do that [use PGD]. I think the majority of those couples are probably having prenatal diagnosis and termination, but some of them are probably going ahead and having the child born and the child will die. I wonder how couples who have only had unaffected children because they’ve terminated the affected or only have unaffected children because they’ve had a successful PGD view those families. I suspect they probably think that those couples have no right to have an affected child. (8.30)

For such couples, who chose neither PGD nor prenatal diagnosis and termination, Andrew said, he wondered what it was like (8.30).

Pressure from the Partner

Finally, interviewees also stated that pressure and demands might come from one of the partners in a relationship, or at least one of the partners may be more convinced that PGD is the right option than the other partner. Alva emphasised the risk of discussing the ‘couple’ as one entity, as two persons with one and the same understanding of what they want. She drew a parallel to the situation of abortion, where the choice made by the woman need not be her actual wish (13.113).
Pressures on Medical Professionals

The possibility of pressures on couples’ free choice with regard to prenatal diagnosis or genetic counselling in general has been discussed in other studies (Hildt 2002, Wyatt 2005, Lippman 1998). Less commonly, studies analyse possible pressures directed at medical professionals. Medical professionals are, typically, ‘in power’ at the clinic. However, interviewees did not always perceive this power, experience it as real, or describe it as real.

When Andrew described himself and his colleagues as ‘pushing’ couples, he also described this pushing as resulting in a state where little or no reflection was encouraged. He said that he never stepped back and asked whether a certain procedure was good for a specific couple. Given the ideal described earlier, such a vacuum can also be understood as constraining the professionals’ desired, ideal encounter. Interviewees also described what they understood as demands on them made by women and men who desired to use PGD in ways and to extents that professionals did not agree to.

Such was the case when Andrew explained that he sometimes doubted that a certain couple needed to use PGD. Andrew explained that in his view, ‘we shouldn’t feel as doctors that we have to provide it because someone wants it and couples shouldn’t feel they have to do it because it exists’ (8.12). As we have seen, Andrew also explained that he had become ‘more and more worried’ about situations where couples wanted treatment and where he and his colleagues felt ‘obliged to offer it to them [and it is] not always in their best interest but simply because they want it and we can do it’ (8.28). In such cases, the technological imperative seemed also to be influencing professionals. Andrew described himself as feeling obliged to offer the technology – because it was possible. Elisabetta articulated a similar concern about demands on medical professionals and she described a situation she experienced some years ago. A couple wanted to use PGD for a specific genetic disease in which the probability of having an affected child was about thirty per cent if female and ten per cent if male. The couple wanted to use PGD to select a male embryo, and thus to reduce the possibility of the disease, but to combine it with amniocentesis. Elisabetta consid-
ered this to be an exaggeration in terms of diagnosis, and in her view an ‘unethical’ request. She asked the woman if she considered the combination of several tests to be ‘really fair,’ and the woman responded that she had the right to decide, and that the interviewee was the clinician. The woman, Elisabetta reflected, thought that this ‘was not a matter that should involve myself. I don’t agree, because I think that the clinician cannot be just a sort of automatic distributor of embryos, you are involved in the decision’ (5.6).

The examples could be read as indicating a pressure and a demand on professionals to perform diagnosis for conditions that they considered to be morally questionable. They could also be read as an indication of what is sometimes labelled ‘patient empowerment’ when the women and men concerned get more and more to say (as described by Ned, 10.12). In any case, it can be noted that (some, not all) medical professionals, who could be described as being in power as a group, were hesitant with regard to who should decide what genetic conditions to search for and said they experienced demands put forward by couples as problematic and undesirable.

The question of being in power is related to responsibility and as such to uses of PGD in morally acceptable ways. When Andrew told the story of him and his colleagues sometimes ‘pushing’ couples, he chose to open the door to the difficulty of the power position. He described the complex relations, but seemed not to be quite sure how to improve them.

Right to Reproductive Choice – Realism and/or Rhetoric?

The interview guide contained questions regarding whether rights were relevant to the discussion of PGD and germ-line gene therapy. The possible right to reproductive choice and to certain reproductive alternatives was one of the few areas where the topic was interviewer-introduced and not first commented upon by the interviewee, and interviewees’ responses were short. In this sense, rights seemed not to be
a topic that interviewees had experienced as relevant, important, worrying or an interesting part of their present situation – or at least not to the same extent as other topics. This is interesting, since reproductive rights occupy a central place in some bioethical discussions. In these discussions, reproductive rights are sometimes discussed as a matter of freedom of choice and autonomy (Robertson 1994, Buchanan et al 2000, Harris 2000b). Reproduction technologies are also discussed in the context of human rights, as in some European policy documents (European Parliamentary Assembly 1982, Council of Europe 1997). Within the bioethical literature, the discourse on reproductive rights is also criticised for hiding important gender inequalities and for falsely implying that rights are gender-neutrally used (Raymond 1995).19

Within several of the interviews, the practical realism of rights was questioned and often so on the basis of economic constraints on medicine. There was no freedom, one interviewee commented, or at least only a restricted freedom. Rights might exist hypothetically, but in the concrete health-care system they lost their impetus. However, as some interviewees such as Evelyn and Ned stated, things may change in the future. ‘Interestingly,’ Evelyn commented on the issue of rights, ‘the new human rights legislation might be the area that throws up the biggest challenges for us in the next few years’ (11.48). Couples, she explained, who have been refused the use of PGD for social sex selection may challenge it in the courts. Likewise, even if he did not use the notion of right in that section, Ned said that as a consequence of patient empowerment, people may demand PGD for a variety of reasons (10.12).

There were two exceptions to the general tendency not to discuss rights if interviewees were not explicitly asked whether rights were relevant to the discussion of uses of PGD and germ-line gene therapy. The first exception concerned couples’ right to choose to implant affected embryos – one of the new moral questions with regard to PGD. The second exception concerned the right of professionals to refuse to give treatment for conditions where they did not consider such treatment to be morally right. This has also a bearing on what has been described as a second new moral question with regard to PGD, at least in the UK: the possible enforcement of the professionals’ obligation to take the
welfare of the child into account, as opposed to the couples’ right to decide about treatments. As has already been said, according to the HFE Act (1990), the welfare of the child needs to be considered if assisted reproductive technology is to be used. If no agreement is found as regards what is the best for the future child, it has also been said, the final decision as to whether to use PGD seems to reside with the clinician and not the woman (Draper and Chadwick 1999). Andrew commented on both of these possible rights. He considered the first to be wrong and the latter to be important.

In Andrew’s view, parents could not have a right to decide to implant affected embryos, and he referred to the future child’s autonomy as a reason for this view:

> It’s something to do with choosing an affected child above [an] unaffected. I think it is quite wrong. If you don’t have a choice, then you might have an affected child and cope with it and it’s right that the parents have the freedom to do that, but I don’t think it’s right for the parents to have the freedom to actively choose for a child to be affected because the autonomy of their child is more important [than the parents’ freedom]. (8.34)

The meaning of the notion of ‘autonomy of the child,’ used by Andrew, was not altogether clear. It may be understood as implying that the future child should have as much possibility of acting autonomously in its life as possible. Such reasoning presupposes that possibility of acting autonomously is diminished with genetic disease or impairment.

When discussing the second right, professionals’ right to refuse to give a certain treatment, Andrew recalled a situation where a couple had received a negative answer from the clinic regarding their request to use PGD. The man in the couple had a compound heterozygote carriage of cystic fibrosis and only one mutation was detectable, which meant that it would be difficult to say whether the embryo would be a carrier of only the known mutation or of the known mutation as well as the other, undiagnosed allele. The PGD team said they would only put back homozygous unaffected embryos. If so, in the worst scenario, the implanted embryo would have a carrier status as regards the un-
known mutation. However, the couple wanted the team to put back carrier as well as non-carrier embryos, and they responded with anger when the team refused to do so on the grounds that embryos may be carriers of both alleles and that, if such was the case, the future child could have the same health problems as the man had. Andrew explained that

the husband was very well with it, and the spectrum of illness was such that the child could have clinical cystic fibrosis. We felt that that was unreasonable and we felt that it was our right to say so and that we didn’t have to treat. (8.40)

However, the couple claimed that the clinic had no right to deny them treatment. Andrew continued:

The patients didn’t feel that at all, they didn’t feel that we had a right as doctors to decide whether or not to do treatment, but I think doctors do and I think doctors should. […] I feel that doctors should have a right, but we clearly don’t […] Although we all have a right to say whether we will or will not perform terminations, I do [perform terminations] because I don’t have a particular moral problem with it, you don’t seem to have a right to be able to say to the patient that you’re counselling “I don’t think you should have a termination, I don’t think it’s in your interest.” (8.40)

In this sense, whereas constraints may be present, medical professionals were in power, but such power could be questioned by patient groups.

When rights were discussed by interviewees in response to my questions, they commented on distributive as well as substantive rights. According to one view, once PGD existed as a medical option and once testing was allowed for specific diseases, it should be available for everyone. The need for such a distributive justice was expressed in several interviews, whereby it was said that correspondingly, there should be a distributive right to use PGD. In terms of the substance or content of rights, Giovanna explained that everything that had life had the potential of procreation. In her view, procreation was a specific sort of creativity and an important part of human life. She said that once there was

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a right to life, there was also a right to procreation, and a right to use reproduction technologies once they existed (3.35). Some interviewees also chose to comment on the possible right to parenthood, and most of them were hesitant regarding such an idea.

Several interviewees were concerned about the rhetoric of rights, and stated that such rhetoric was dubious. As an example, though Angelo, who had personal experience of severe diseases, held that there was a right ‘to be respected in your life,’ he found it ‘annoying’ that there should be a list of individual rights, starting with a right to ‘family and a right to children and a right to work and a right to strike and a right to rest and a right to a pension and all those kind of things’ (1.71). He explained that he preferred to talk of freedom to act according to what was given to each individual. Life was a gift, he stated, and not a right. ‘I was given life. It was a gift, I didn’t make myself (mm) so I have to accept it’ (1.71).

No interviewee described a right to ‘inherit a genetic pattern which has not been artificially changed,’ as put by the European Parliamentary Assembly (1982:4.a). Such a right would have implications for the use of germ-line gene therapy.

**Summary and Concluding Remarks**

**Summary**

Interviewees emphasised that choice/free choice/autonomous choice should be present in reproductive medicine. Correct information should also be given, which implied that a certain amount of information and a certain kind of information was given. According to some interviewees, correct information meant that no advice should be given, as in the assumption of information as pure as possible. Other interviewees explained that advice needed to be given or that moral questions, maybe, should be brought up for discussion by the professionals; these interviewees spoke of what I have labelled information in need of supplementation.

Interviewees also described the actual encounter. Sometimes ideal and actual practices were in harmony. One interviewee described
medical professionals as having a present responsibility that meant that they were answerable for what took place in the everyday work at the clinic. Professionals also had a prospective responsibility, a responsibility to anticipate and envision future moral issues and scenarios in need of moral reflection, which could also be understood as included in the present responsibility.

Interviewees also described scenarios where ideals were not reached. They sometimes explained that they doubted that ideals could be reached. They said that there were complicating aspects that needed to be thought through and that these were not always clarified. They then told two kinds of narratives of concern. There were stories that indicated interviewees’ concern that certain risks were not clarified to the extent that should be done. There were also stories of actual, complicating circumstances (that were not a matter of risks) that made the interviewees concerned about the practice.

The comparison between the ideal and the actual revealed a gap between the ideal and the actual encounter, and interviewees’ examples of actual clinical encounters highlighted different kinds of risks that needed to be explained. Medical risks were risks of physical and/or psychological harm, as a direct consequence of a certain intervention. They may be present for women, men and future children. Epistemological risks were risks that no accurate knowledge could be given or that the information upon which couples based their choices was not correct. Technology-derived risks were risks that technologies were inaccurate or imprecise or that they were inaccurately or imprecisely used. Furthermore, some interviewees stated that the debodified character of IVF/PGD could be negative for couples in their decision-making process and for counselling.

Interviewees also discussed who should participate in decision-making and make the final decision as to what to search for and whether to do so, at the clinic. They discussed ideal decision-making. Ideally, all interviewees agreed, women and men at high risk for genetic diseases should be ‘free’ to choose. Some interviewees also articulated a dialogical ideal, where future parents and medical professionals (of different kinds) were engaged in the discussion of what to search for together.
Furthermore, interviewees described what happened when ideals with regard to decision-making were not met. They described situations in which they doubted the extent to which choices were free. They gave examples of perceived pressure on patients or on themselves that complicated free choice. Constraints on couples were described as due to healthcare structures, to medical professionals, to society, to differences in views within the couple or to the very existence of PGD. Such was the case if a structural directiveness made couples likely to act in a certain way in order to get what they wanted. Once at the PGD clinic, one interviewee said, couples needed to be persistent: the more persistent they were, the more professionals felt that couples should use the technology (we, one interviewee said, ‘push’ them), which resulted in a silencing of questions. Little or no space was left to encourage reflection, articulations of doubt and hesitancy. Such was also the case when some women and men were described as compelled to make a certain kind of choice. They could not choose not to choose. Scenarios were also described that resulted in pressures on professionals owing to couples’ demanding certain uses.

As a final aspect of choice, interviewees were asked about the right to choose to use a certain technology. Whereas interviewees often reflected in detail and at length on other issues in the interviews, they rarely engaged in such reflection when I brought up the issue of rights. However, there were two exceptions to this tendency: couples’ right to choose to implant affected embryos and the right of professionals to refuse to give treatment for conditions where they did not consider such treatment to be morally right.

Three major reasons not to use germ-line gene therapy at present were also articulated. The medical risks, technology-derived risks and epistemological risks made such uses inappropriate at present according to all interviewees. A few of the interviewees were also positive towards GLGT provided, as they put it, that technical safety could be maintained at the same level as with other new technological developments.
Concluding Remarks

Descriptions of couples’ wishes and needs in respect of IVF and PGD have been present in narratives of progress and narratives of life with genetic disease. What is different in this chapter is the explicit emphasis on medical professionals’ responsibility to make sure that couples who had a ‘genuine need’ for PGD could be given it, now and in the future, and to anticipate and discuss moral questions that may emerge. Professionals had a responsibility to make sure that such needs were met in a morally thought-through manner.

It is noteworthy that interviewees did not make distinctions between the concepts of choice, free choice and autonomous choice. As regards the information which is crucial if women and men concerned should have a choice, the issue of what non-directive genetic counselling meant was a major one in the data. This is also the case in the literature. The non-directive view of counselling has been criticised as difficult (Clarke 1991, 1997) and described as undesirable if meaning that professionals refuse to answer questions such as ‘what would you do?’ (Baylis and Downie 2001). Obviously, this question need not imply that the patient want the professional to decide for her or him. It has been claimed, as did also a few of the interviewees, that non-directive genetic counselling in the sense that only information is given do not meet the needs of the women and men concerned (White 1998) and that failure to offer professional recommendations of treatment alternatives could be seen as negligence (Caplan 1993). It has also been suggested that non-directiveness in counselling may seem straightforward as a means to enhance free choice, but that this is not necessarily the case (Koch and Nordahl-Svendsen 2005:825).

Whereas interviewees rejected the paternalism of the past, some of them described situations that resembled a ‘client-technician model of professional relationships,’ in which they should provide genetic information and technologies in non-directive ways and perform any medical procedures that women and men requested (Wyatt 2005:ii19). This was described as negative to medical professionals themselves, who disapproved of being ‘automatic distributors of embryos’ as one inte-
viewee put it. It was also described as negative to couples who asked for and needed not only support in whatever decision they made but sometimes also advice. 

This chapter brings up a ‘new’ moral question in respect of PGD, apart from the question of the right to implant affected embryos: the question of whether there is a new power shift at stake, from women to professionals. This is also suggested by Draper and Chadwick (1999), when they compare the previous prenatal diagnosis situation with the PGD situation.

Once pregnant, Draper and Chadwick explain, a woman can decide whether or not to use prenatal testing and to determine whether she wants to carry the child to term. In the PGD situation, once embryos are fertilised, and if there are only affected embryos, a woman may ‘lose control’ over the next measures taken. This is so if the PGD team decides that implanting a particular embryo, even if they have been given a licence to do so, is not for the best of the future child. Though such a situation can primarily come about in the UK, because of the amendment that professionals who participate in fertility treatments have a statutory obligation to consider the future child’s interest, it raises important questions. A certain woman who wants to have also affected embryos implanted cannot make the PGD team do it, even though some of the interviewees in this book sometimes felt pressured to act in accordance with some women’s wishes. But, if affected embryos are not implanted and if the woman does not want them disposed of, what will happen to them?

As Draper and Chadwick (1999) point out, if embryos exist, and if the professionals consider implantation of any of these embryos to be against the future child’s welfare, they are obliged not to implant it. Should they freeze the embryos and let the woman and man try find someone else who would find it acceptable to implant them? Such an approach is questionable, since what is at stake is not only the particular professionals’ conscience as in any area where a professional, for personal moral reasons, refuses to carry on or interrupt a certain treatment, or abort a pregnancy. It can also be asked whether the profes-
sionals should dispose of embryos against the will of the couple. This is likewise problematic since, after all, and as also suggested by Draper and Chadwick (1999) the embryos belong to the couple, if to anyone.

Interviewees’ descriptions indicated a gap between ideal and actual clinical practice. Such a gap can be understood as an argument for trying to improve the conditions for choice in reproductive genetics. If this argument is accepted, efforts need to be made to change practice and to make it resemble the ideal. However, it is to be noted that increased choice in terms of the further possibility of choosing to use IVF and PGD sometimes hampered certain choices. Though positive at first sight, this increase in choice may be psychologically stressful for the couples concerned, choices may as such be morally difficult, and choices may be illusory in the sense that choices presented are not real choices since structures hampered choice. Such was described as the case when interviewees discussed the phenomenon of structural directiveness and the compulsion to make certain choices. These phenomena will be further discussed in Ch. 7. There are, to say the least, many complexities of choice in medicine (Lupton 1997).

To conclude, the value of free choice was the overarching value in this chapter. Such was the case when interviewees worried that couples were not given correct information of different kinds and when they worried about pressures on couples as well as on themselves. Such was also the case when interviewees explained their concern that some couples could not choose not to choose. Interviewees also articulated the value of dialogue between the women and men concerned and the medical team. This particular dialogue at the PGD clinic was also described as a norm (in the sense of a prescribed guide to conduct), as was choice provision. The latter norm was present in almost all interviews. Couples should be given a choice, within certain limits. The norm of responsibility for uses of PGD, though not always explicit, was also present in almost all interviews and it was particularly clear in some of the interviews with persons who worked at PGD clinics. Most interviewees’ also described moral experiences of relevance to their discussion of conditions of choice, and such experiences were often told in the form of narratives of concern. Fi-
nally, interviewees articulated morally relevant life interpretations, as
did for example the interviewee who had embodied experience of se-
vere disease, who stated that life for him was a gift and that this in-
fluenced his understanding of the technologies.
CHAPTER 6

Uses Beyond the Boundary?

The last core theme was formed by interviewees’ descriptions and discussions of uses of PGD and germ-line gene therapy that were, possibly, beyond the boundary of the acceptable or the desirable. Such was the case when some of the interviewees told narratives of concern that focused on present or future exaggerated use or misuse of the technologies. This last kind of narratives of concern is presented and discussed in the first section of this chapter.

The boundary that separated desirable or acceptable technologies or uses of the technologies from undesirable or unacceptable ones was sometimes legally or practically motivated. In some cases, interviewees also referred to or constructed a morally motivated boundary. Different boundaries are presented and discussed in the second section of the chapter, as are interviewees’ discussions of who may breach the boundary. This section also highlights the issue of ambivalence in trust in the particular sense that some interviewees articulated ambivalence regarding whether to trust that others would keep within the boundaries. Who the others were varied.

The third section presents and discusses two possible negative long-term consequences of exaggerated use and misuse: a tendency towards perfection and the marginalisation of certain groups of people. It also presents and discusses three uses of the notions of the natural and the use of playing God and of hubris, as present in the interviews. Interviewees’ uses of these notions clarified why certain actions and practices were described as ‘beyond’ the boundary or potentially so – as well as why certain practices were described as acceptable. Finally, some interviewees wondered if the development and use of new technologies, germ-line gene therapy included, was not ‘just evolution.’
All narratives and all core themes are now presented, and two general tendencies are noteworthy. If the narratives are seen as a whole, a phenomenon that was present in interviewees’ discussion of PGD becomes particularly clear: their ambivalence regarding how to describe and evaluate certain uses of the technologies. Ambivalence was also, sometimes, articulated in on-the-one-hand/on-the-other-hand kind of reasoning without the use of narratives. Some interviewees commented explicitly on this phenomenon in their own reasoning. Such was the case when Jørgen stated that ‘as you can see, I vacillate back and forth in my approach’ as regards use of PGD for some genetic diseases (18.46). Nils also explained that PGD evoked many difficult questions and that he had no clear-cut answers to them (his reflections, Nils commented, sometimes got a bit ‘woolly’). However, he added, one should be suspicious of clear-cut answers since those who gave such answers could not really have thought the issues through (14.40). A few interviewees articulated ambivalence also with regard to germ-line gene therapy, but this was not as usual as with PGD and, if present, it was not discussed in as much detail. As one exception, Andrew explained that what worried him with germ-line gene therapy was ‘that you’re breaching the boundary of actually interfering with the genetic code’ (8.50). Andrew explained his ambivalence with regard to such breaching of boundaries. He described breaching as worrying and he questioned the basis for this worry. Did it really matter if boundaries were breached?

The previous chapters have primarily contained discussions of PGD and to a much lesser extent germ-line gene therapy. This chapter discusses germ-line gene therapy almost as much as PGD.

The Last Kind of Narratives of Concern

The last kind of narratives of concern focused on examples of exaggerated uses and misuses. These were either described as happening now, but not in the interviewees’ own country, or as likely to happen in the future. There was one exception to this general tendency: the Italian
interviewees gave examples of exaggerated uses or misuses that took place in their own country, now and not only in the future (to be explored in sect. *Who Breaches the Boundary?*). Most Swedish and British interviewees who told stories of exaggerated uses and misuses told stories of what took place elsewhere, for instance in Italy or the USA. Such was the case when Nils explained that he had been to the USA some years ago and that he, while there, had read an article in which some researchers had stated that they were working for the ‘improvement of human beings’ and for ‘higher intelligence’ in human beings (14.14). Nils remarked that higher intelligence would not necessarily be an improvement or lead to ‘better’ human beings. He also explained that he considered such work ‘creepy’ and a misuse of knowledge and technology (14.14). Such was also the case when Jörgen explained that he thought PGD should be allowed for genetic diseases but that its use for social sex selection was ‘quite horrid’ (18.4). Such selection, Jörgen said, was done openly in Jordan. Though not legally permitted, social sex selection was also performed in Spain, according to Jörgen, and the legislators seemed to ‘turn a blind eye.’

While these stories focused on uses that interviewees described as undesirable, they also explicitly or implicitly made clear that such uses did not take place in Sweden and Britain. However, one British interviewee did tell a story of what had taken place but should not have taken place in the UK. This story has been briefly described in the discussion of what to use PGD for (Ch.4, sect. *Used for Genetic Diseases Only*?). It can now be presented in some detail:

Andrew told the story of a couple who wanted to use PGD in order to avoid an X-linked, non-lethal genetic disease that resulted in hypospadia. Or, Andrew said, one of the partner’s ‘probably’ had an X-linked genetic disease. The actual gene had not been found. In any case, the couples had two boys who had had severe hypospadia, they had undergone five to ten operations each in order to correct it and this had had, as Andrew described the woman and man saying, a very significant psychological effect on the boys. The woman wanted to use PGD for sexing for a girl. Andrew explained that he and his colleagues didn’t
know if there was any possibility that females would have genital problems as well – though, he added, it didn’t seem likely. He and his colleagues also asked what the woman and man would do if they were not offered PGD. In that case, Andrew recalled the woman saying, she ‘simply wouldn’t extend her family. She wouldn’t under any circumstances consider [using prenatal diagnosis and selective] termination for a boy’ (8.6). However, she very much wanted a girl. Eventually, she had PGD and got twin girls.

Andrew described the enthusiasm at the clinic as a reason why this couple were offered PGD for this genetic disease. In his view, ‘there was really no reason why she [the woman in the couple] had to continue having children and yet we seemed to find that that was acceptable’ (8.6).

I don’t think we would now, I don’t think we would do it, but I think being caught up in the enthusiasm of PGD actually working, because we had a lot of pregnancies at that time. We got caught up and said that seemed fine because it’s what she wanted, but I didn’t think it was fine, really. I don’t think that that’s necessary. I think PGD should be limited to really lethal conditions in families who have lost children and don’t have a family. (8.6)

In this narrative, PGD had been used for what this interviewee said it should not have been used for, in the UK. Italian interviewees told stories of exaggerated uses and misuses, in Italy, in the USA and in the Netherlands. No such stories were told about germ-line gene therapy.

Boundaries and the Breaching of Them

The assumption that certain uses of a technology implied the breaching of a boundary was implicit or explicit in the stories of exaggerated uses and misuses. Such a boundary was sometimes legally, sometimes practically and sometimes morally motivated. Most interviewees also described boundaries as constructed, they were drawn and re-drawn, though it was not always clear by whom. Many of them used the no-
tions of boundaries, limits and border-lines in metaphorical senses: these notions were seldom used in a neutral manner as a matter of description of two different uses.

Interviewees articulated concern that established boundaries might be breached. They discussed whether such breaching took place and whether it, if it took place, was or should be troubling. Some interviewees also stated that they thought boundaries had already been breached and that this was unfortunate. Four kinds of boundaries were present in the interviews.

First, some interviewees described a boundary between uses of PGD for severe genetic diseases, often described as lethal at an early age, and less severe genetic diseases, or between genetic diseases and other characteristics such as height, colour of eyes or sex. Medically relevant differences were used to separate the acceptable from the non-acceptable. As an example, Ian explained that it was ‘easy’ to draw the line in discussion of ‘seriously handicapping conditions,’ i.e. uses that he did consider acceptable. However, line drawing was not always that clear (12.36). The boundary based on medically relevant differences was sometimes legally motivated, as was the case when Joyce explained that she would not have referred the Sikh couple to a PGD unit since it was illegal to use PGD for social sex selection (Ch. 4). It was also, sometimes, practically motivated. Such was the case when Ned made a distinction between implantation of affected embryos and implantation of unaffected embryos and when he argued for the acceptability of only the latter. The ‘implantation ability’ of the embryo should guide the selection of embryos, Ned said, and implantation of affected embryos would probably decrease the implantation success rate (10.24-26). Ned also explained that he considered social sex selection ‘impractical and stupid’ from a medical point of view, but not ‘unethical per se’ (10.69).

Second, some interviewees discussed boundaries that separated the technologically safe intervention from the technologically dangerous or unsafe intervention. Typically, this was the case when interviewees contrasted PGD with germ-line gene therapy. Though many interviewees emphasised that the technologies for PGD needed to be improved,
uses of PGD were never described as a matter of ‘messing around’ as were uses of germ-line gene therapy (9.38). This second boundary between desirable and non-desirable was based on technical differences relevant to safety and accuracy. The implicit and sometimes explicit premise was that it would not be morally acceptable to use certain technologies if at least a minimum of safety could not be guaranteed: germ-line gene therapy was described as unsafe and this was a reason not to allow it. Such being the case, this boundary was morally motivated. Difficulty in obtaining safety and the ‘tinkering about’ with genes were also sometimes described as making the future use of GLGT an illogical choice when one could just implant healthy embryos, as Joyce put it (9.38).

Third, some interviewees described boundaries between acceptable uses of technologies and unacceptable uses as being drawn at different places depending on how they understood the moral status of the embryo. Such was the case when Ian explained that since he did not consider the embryo to be a person in its own right from conception and onwards, PGD was an acceptable technology for him (12.65). This morally motivated boundary was drawn at different places by different interviewees, owing to differences in understandings of the moral status of the embryo. As has been seen, interviewees who considered embryo disposal to be morally problematic were also more positive towards GLGT than were the others.

Finally, a few interviewees described what resembled slippery slope reasoning. They explained that the allowance of one technology may lead to a more liberal understanding with regard to that particular technology as well as with regard to related technologies. This was described as undesirable. One interviewee, Björn, explained that once one had got on to the slippery slope, it was difficult to motivate where a certain line should be drawn. In his view, Sweden had already got on to a slippery slope (17.44). In this kind of reasoning, strict boundaries were described as important but difficult to maintain in order to avoid a future blindness to morally relevant differences. The future blindness made it important to respect boundaries, here and now.
Who Breaches the Boundary?

Anne-Sofie Bakshi's study of texts in Läkartidningen (the Swedish Medical Journal) and in Swedish newspapers indicated that in the context of prenatal diagnosis certain groups of people were described as interested in re-defining or being at risk of extending the boundary between what should be allowed and what should not be allowed (Bakshi 2000). Such was also the case in the present study. Interviewees' descriptions sometimes had a stereotyped character, as when some doctors were described as so eager to gain new knowledge that risky technologies were offered to women and men, even if the women and men concerned voluntarily agreed to undergo treatment. These descriptions also sometimes counteracted stereotyped pictures of the doctor, performing technologies for the sake of curiosity, and the patient as victim. Such was the case when patients were described as those who wanted to breach a certain boundary.

Some of the interviewees used the notion of society in their discussion of boundaries and the breaching or undesirable re-definition of them. These interviewees were concerned with the question of whether present-day society was ‘mature’ enough to construct and/or keep boundaries where they needed to be constructed and maintained. As an example, Alva said that one could argue that a mature society should be capable of analysing values and of constructing and sustaining moral boundaries. It should constantly decide ‘what is right’ (13.22). However, she questioned the maturity of her society since society pushed couples into decisions that they may not have wanted to make. Alva exemplified her concern with stories of women who, when giving birth to children with severe genetic diseases, felt that they had done something society did not accept. These women, Alva said, felt that ‘society’ was saying to ‘the sick child that will be born, “you should not have existed, we have means for such as you today”’ (13.36). In such excerpts, Alva personified society. Alva was also one of the interviewees who, in these discussions, referred to the historical lessons to be drawn from eugenic societal interventions in the 1930's (13.22).
Elisabetta also described the uncertainty as to whether society was a mature setter of boundaries. In her view, present-day society had a low level of ‘consciousness’ in combination with a lack of a ‘well-developed sense of [the meaning of] reproduction,’ which made it necessary to prohibit certain technologies (5.56). Whereas these interviewees were concerned about society’s lack of maturity or its low level of consciousness, one interviewee explained that society needed to be given time. Whereas the other interviewees’ were concerned about society’s poor ability to draw and keep the necessary boundaries, this interviewee, Jörgen, articulated no such worry. Jörgen explained that as a specialist in the field, he had to be patient. Any specialist needed to count on being five to ten years ‘ahead’ of society, since society had to take a stand on so many different issues. This could be annoying, but a good relationship with society and a positive attitude among the public towards new developments was important (18.8).

The collective society was sometimes described as an agent and as a potential transgressor of boundaries, but more often, the potential transgressor was an individual or groups of individuals. The latter was the case when interviewees described situations in which couples wanted to use PGD for conditions that the interviewees considered undesirable or unacceptable. As was shown in the previous chapter, some interviewees described situations in which they felt ‘pushed’ by couples to offer PGD for conditions that they did not want to offer it for. One interviewee, Jörgen again, also said that today it was generally easy to fulfil couples’ wishes, since couples could become ‘reproductive tourists’ (18.8). Reproductive tourism is the phenomenon that some women and men who wanted to use technologies in ways or for conditions that were illegal or not in accordance with national policies, chose to travel abroad to get what they wanted. They travelled to a country in which the particular use of the technology was either not illegal or not regulated. In Jörgen’s description, this was not a scenario that made him feel ‘pushed’ by couples. Instead, he explained that he supported such tourism, as long as he considered a certain couple’s wishes as what was best for them (18.8).
Two more groups were described as possibly breaching boundaries: certain philosophers and medical colleagues abroad. One interviewee, Nils, was particularly concerned about the views of philosophers with a utilitarian perspective. He described such philosophers as arguing for the allowance of uses of medical technologies that he described as misuses. Nils explained that these philosophers argued for an allowance of an advanced quality control of embryos and if such philosophy gained wider acceptance, the future would be quite ‘creepy’ (14.4, 16). As a tangent, another interviewee contrasted philosophers’ reasoning with her own reasoning and she explained that clinical practice influenced her reasoning and made her less certain in her evaluations. Alva explained that if she had been a philosopher and if she had been philosophising in her room, maybe she would have been pretty clear about what she thought. Maybe, she said, she would have been able to say that she couldn’t accept certain uses, but she was not a philosopher and she had also to consider that she would meet the patient or the couple (13.22). In Alva’s description, the philosopher philosophising in her or his own room was not an ideal.

Some interviewees also described colleagues as those who might redraw lines and who might misuse technologies. Such was the case when Joyce questioned whether certain professionals had a ‘vested interest in encouraging people’ into PGD (9.12) and when Alva explained that some medical professionals were ‘driven by the desire to develop technology further’ and that they may be ‘seduced by the possibilities’ (13.112). However, when present in the Swedish and British interviews, the potential misuse by colleagues was described as real in certain other countries, but not in these interviewees’ own countries. Such was particularly clear when Evelyn described the British situation as a carefully regulated one. She contrasted this with the situation in Italy or in the USA. This, she said, worried her. A ‘liberal’ use of PGD in other countries may have an undesirable effect on people’s evaluation of PGD in the British, regulated context:

I do worry about how liberally PGD appears to be available elsewhere. I do worry that response to situations that occur in other countries may have an adverse effect on the way people value PGD
here. It looks unlikely that other countries such as Italy or America will ever have the same sort of degree of control and regulation as we have. I think that’s unfortunate. (11.69)

No statistically generalisable statements about differences can be made because of the small sample of interviewees, but it is to be noted that all of the Italian interviewees questioned certain uses of PGD that they described as taking place in Italy. PGD, the Italian interviewee Simonetta explained, had been advertised ‘as a major success,’ and she said that she feared what she saw as an inclination among colleagues to take advantage of the novelty of the technology (4.2). According to Angelo, PGD (in the cases of X-linked genetic diseases) was

an easy game technically speaking and it’s making a big business. I don’t want to say that all gynaecologists are making money out of it, but it is big business. (1.10)

Criticism was also directed at the general self-understanding of doctors. Angelo, though he was a hospital doctor and medical geneticist himself, sometimes spoke of the ‘medics’ as ‘them.’ Sometimes, Angelo said, ‘it’s the medics themselves that do the harm to themselves, because they present themselves too triumphantly and it seems that everything is possible now’ (1.22).

Finally, a high level of self-criticism was present in some of the interviews. Such was the case when Andrew commented on his awareness of how his own perception was changing. As has been seen, Andrew commented upon the right of couples at risk for a certain genetic disease not to use PGD (or prenatal diagnosis and selective termination of pregnancy). He asked how these couples were approached by those who were at risk for the same disease but who had used PGD or prenatal diagnosis/selective termination of pregnancy. He also commented upon his own reactions, saying that it was ‘very insidious:’

It’s very insidious, I even find myself thinking now “they don’t have a right to have that” [deliberately give birth to a child who is likely to be affected] but, of course, they have a right to have an affected child. You know, there have always been children affected and dy-
ing of horrible conditions. I don’t think we should suddenly start being, what’s the word, the unborn child’s advocate, saying that “because this technology exists, parents have no right to have children like you who are going to die.” I think that it’s probably so insidious that these choices are starting to exist without anybody being able ... apart from people like yourselves probably, who see it from the outside. When you’re actually in PGD as a patient or a doctor you don’t even notice that your perceptions are changing. I know mine definitely are. I think that’s quite wrong. That shouldn’t have to be. (8.30)

It wasn’t altogether easy to evaluate PGD from inside the PGD clinic, Andrew said, neither as a doctor nor as a patient. He noticed that his own perceptions were changing, exemplified by his reaction that he found himself thinking that couples who knew they were at risk for a particular genetic disease had no right to become pregnant and give birth to a child who was likely to be affected. Of course, he added, they have a right to have an affected child. His perceptions were changing and, according to Andrew, this was unfortunate. It was ‘quite wrong’ and it ‘shouldn’t have to be.’

The analysis of who was described as breaching the boundary – as the potential transgressor of the boundary – indicated that the transgressor could be many of us: it could be society, patient groups, philosophers, interviewees themselves or their colleagues. The potential transgressor could not be altogether trusted. She, he or it may breach boundaries.

Beyond the Boundary?

Some of the interviewees’ descriptions and discussions of boundaries and the possible breaching of them took up two negative long-term consequences if boundaries were breached and if technologies, consequently, were used in undesirable ways: the tendency towards perfectionism and the marginalisation of certain groups of people. In discussions of uses of technologies that went ‘beyond the boundary,’ inter-
viewees also used the notion of the natural in three different ways. A few of them also used the notions of playing God and of hubris. One of them said that, maybe, breaching boundaries was not so bad – maybe it was ‘just evolution’ (8.50). These descriptions and discussions are presented in the following four subsections.

**Perfectionism and Marginalisation**

The phenomena of perfectionism and marginalisation of certain groups of people were sometimes described as two sides of the same coin. If we start to sort out embryos with less serious diseases or if we start to select embryos for non-medical reasons (more and more ‘perfect’ embryos in some sense), this may have consequences for those fewer children who will be born with genetic diseases. They may be marginalised.

Only a few interviewees described the phenomena of perfectionism and marginalisation as a threat and as a reason for concern at present. Vittorio did so when he described the perfect society as a grey, sterile sea that he contrasted with the non-perfect society, described as a sea filled with life. ‘A perfect society, sterile, neutral,’ Vittorio said, ‘I see it as a grey sea, empty, without life, not a blue sea full of light with lots of fishes seething life in it. I see it as a grey lake, dark, without any life’ (2.29). In his view, PGD was a means to perfection, and perfection was something negative. Vittorio described himself as a proponent of a colourful society, where differences were encouraged. Most other interviewees who commented on perfectionism and/or marginalisation described them mainly as future threats, if a certain genetic disposition was understood as likely to result in more happiness than other genetic dispositions or if people started to search for as ‘perfect’ genetic a disposition as possible (1.8, 14.71). In that case, the technologies would be misused.

A few interviewees also explained that perfection was used as a rhetorical concept by those who did not wish PGD to be further developed. Giovanna contrasted perfection with well-being and good health, goals
that she explains that she did work for. The important thing was to keep PGD under control, Giovanna said, and to use it for diseases only. Such use did not imply perfection. She explained, for instance, that ‘it will never happen that I contribute to the perfection of children’ (3.51).

No interviewee used perfection in a positive sense; perfection was always described as something that should be avoided, as was the marginalisation of certain groups of people. However, whereas perfection was questioned as a rhetorical tool, this was not the case with the marginalisation of certain groups of people. As an example, Elisabetta explained that this marginalisation was a possible future result of a selection not of embryos with a particular serious genetic disease, but of selection for ‘small problems.’ This selection was partly due to the gaining of terrain of a certain understanding of quality of life, as she saw it. In her words,

> there is an increasing trend to define quality of life as a very selected condition in which you have to be intelligent, beautiful [...] a trend towards higher selection of human beings and probably also children with just four fingers, with not such a high IQ, with other small problems. Probably in the future, [they] will be marginalised and will not have a place in our society. (5.14)

Others, such as Andrew, did not describe marginalisation as (primarily) their worry, but as something that others articulated and worried about. This example is to be noted since it was one of the few exceptions to the general tendency in the data of not giving examples of those who had experience of life with disease and who did not want to use PGD.

Andrew told the story of a former fellow-student who had a genetic disease. This man, Andrew explained, was involved in different handicap networks, he wrote in newspaper and spoke on TV, and he was ‘always speaking in favour of handicapped people’s rights, saying that they’re being weaned out of society and their stakes are being lessened because they don’t have to exist any more.’ Andrew disagreed with this former fellow-student, and he explained his reason for disagreeing:
I think it’s being done for the wrong reasons. It’s making people say PGD shouldn’t be done because, look, he wouldn’t exist, which it isn’t at all. It’s stopping children dying. (8.30)

Andrew also expressed doubts as to whether he or his fellow-student was right:

On the other hand, you know, he’s right. We are stopping children being born with things, because we don’t think it’s right for children to die, and that isn’t the public’s choice any more than saying it’s not right for a child to not to be born because it’s got a cleft palate. (8.30)

Though saying that PGD could mean that certain people with genetic diseases probably would not exist and that his former fellow student might be right, Andrew ended by explaining why he did not agree: ‘We don’t think it is right for children to die.’ Thereby, Andrew left the tension in the narrative – between the description of PGD as resulting in fewer children dying on the one hand and the marginalisation of certain groups of people on the other hand – unresolved.

Comparatively few interviewees commented on or chose to describe the concern of others as Andrew did. Even fewer described others’ perceived negative long-term consequences as unrealistic. One interviewee, Ned, did so. In a discussion of germ-line gene therapy, he described and questioned the view of ‘people.’ ‘People argue “well you’re narrowing the gene pool,”’ Ned explained, and he used this as a contrast to his own view. There were ‘anecdotal, hypothetical risks’ of GLGT, but

in reality, the benefits certainly way outweigh the risks. People are worried will this thing escalate to a ridiculous degree, where people are having genetic medication at an early stage, malignancy risks and increased heart disease risks, risks of depression, all these sorts of things. No way in reality that will ever happen. (10.55)

People’s worries would not prove warranted, as Ned saw it.

*Uses Beyond the Boundary*?
With Nature Or Against Nature?

Even though interviewees came to divergent conclusions regarding what was a desirable or acceptable use of a technology, many of them did use the natural or nature as a conceptual tool in their discussions. Some argued that uses of technologies could be equated with what happened in nature, and some described uses of technologies as natural in the sense of ordinary. Still others, who held that certain uses were beyond the boundary of the morally desirable, stated that certain uses were against nature. In all of these cases ideas of what was natural were used as underpinning of their reasoning about what was acceptable or desirable – or unacceptable or undesirable – uses of PGD.

Two Understandings of the Naturalness of the Technologies

In a first understanding, the natural was understood as what happened in nature. It was contrasted with what happened when human beings intervened (in so-called natural processes). In other words, nature is natural. Some interviewees who described the natural as what happened in nature also explained that because of the similar results of what happened in nature and human interventions, human interventions were just as natural as what happened in nature. As an example, Ned explained that there were no moral problems with selection of embryos, since embryo selection happened also in nature (10.18). Ned said that he ‘would have no objection to pre-implantation genetic diagnosis, yes, I would be happy to select embryos on that road,’ but that he would not terminate a pregnancy (10.16-18). I asked him if he could explain how he came to this conclusion.

I’ve got no objection to selecting embryos before carriage, I have objections about termination of pregnancy after carriage. [The] reason for that is, it’s physiologically acceptable to select embryos because that’s what happens in nature. Only 12% implant, so there is already a selection process underway. (10.18)

Two assumptions are implicit in this reasoning. First, what happened in nature was not morally problematic. Second, human intervention
could be equated with that which happened in nature if the result was the same. According to Ned, there was no morally relevant difference between selection in nature and selection after PGD.

The view that what happened in nature was natural and not morally problematic was also used as a point of reference in arguments against the use of PGD. Such was the case when Alva distinguished between a positive and a negative, exaggerated control. She stated that in certain situations, human beings needed to learn to ‘let go.’ They needed to ‘accept’ their ‘place in nature.’ Alva used an example from delivery care to explain her understanding of the experience of lack of control as ‘one of the core elements of existence:’

I think human beings must accept their place in nature. […] Modern delivery care gives the woman an illusion that she has a right not to feel pain, for example […] indirectly, that this is something that you should be able to control, it is one of your human rights, but the thing is that you do not have control. This is one of the few occasions in life where you experience that you do not have control over life and you do not know what will happen. Will the child be healthy or injured? How much will it hurt? You are at the mercy of a course of events in your body. I don’t think that it is meant that you should have it, have control. I think that the woman is facing, what can I call it, one of the core elements of existence. You don’t have control. You are not God. (13.78)

Humans needed to accept their place in nature. This implied that we should not know and control everything.

In Alva’s reasoning, humans could, but should not act ‘against nature,’ and the kind of embryo selection that took place after PGD was an example of such acts against nature. ‘Nature also selects, but in a different way,’ Alva said (13.58). The difference was one of why selection took place: selection in nature was not based on genetic knowledge. Therefore selection in nature and selection in PGD could not be equated (13.22). There was a morally relevant difference between them: embryo selection in PGD was based on genetic knowledge. To Alva, this meant that the element of human control was taken too far.
I consider Alva’s and Ned’s examples to be interesting since they indicate how medical language (such as ‘12 per cent of the embryos implant naturally’) and morally relevant life interpretations, in this case interpretations of how human life should be, were combined. This blend of medical language and life interpretations was used in order to articulate a view of the naturalness of a medical technology.

Ned’s use of the natural also clarified the idea that nothing qualitatively new took place in embryo selections through the use of PGD. This idea, that the use of a certain technology was nothing but an extension of ordinary medicine, was also present when Angelo compared future use of germ-line gene therapy with ‘taking a pill’ (described in Ch. 5, sect. *Was the Low Success Rate and Confusion in Testing Clarified?*). Similarly, Hilda stated that gene therapy may be an option in the future. ‘Eventually,’ she explained, ‘it won’t be stranger than giving antibiotics to someone who has pneumonia’ (15.22).17

Later on in the interview, I asked Hilda if there were any non-medical reasons why germ-line gene therapy should not be developed and used in the future. She used the notion of the natural in answering and she explained that whereas certain medical interventions may be seen as unnatural today, what is considered natural will change with time. In the future, she reflected, we might not need to fertilise an egg in order to get a new potential life. We may be able to treat germ cells with hormones to achieve the same purpose, or maybe, just any cell. On the one hand, she said, we can – of course – have objections to such an intervention and the ‘further away we get from the natural, the more difficult does it become to imagine the consequences’ (15.50). On the other hand, what we experience as frightening and far away from a natural situation may become self-evident for generations ahead of us. They may not see any ethical difficulties where we see them today (15.50-52).

The idea that what is perceived as natural will change with time and that the natural is what is frequently done (such as taking a pill and antibiotics) can be combined in the understanding of the natural as that which is common. This is a second understanding of the natural: the statistically normal is natural.
Mother Nature Knows Best
Some interviewees used nature as a metaphor that indicated the existence of something that human beings should not tamper with. Nature was also spoken of as an agent: it acted, it had its own rules. Such agency was attached to nature in Angelo’s expression ‘nature knows best.’ Angelo reflected on the ‘knowledge of nature’ in his discussion of assessments of risks in germ-line gene therapy. He stated that variations within human genes were important and not a thing we should tamper with or try to minimise. This was so since ‘mother nature’ knew the rules better than humankind (1.22). In his view,

for sure nature, mother nature, knows the rules much better than we do. [...] Medics and scientists in general think we can take our future into our hands and determine it, I think it’s extremely dangerous, because we’re just being too presumptuous. (1.22)

Whereas Angelo used the notion of ‘mother nature’ as part of his own reflection, Jörgen told a story in which others used this notion. Such was the case when Jörgen explained that he had sat next to a man who sold vacuum cleaners on a flight between the USA and Australia and the man had talked for an hour or so, about his own work. He then asked Jörgen what work he did. Jörgen said he explained that he worked with those who were not able to become pregnant. ‘Test-tube babies,’ the man replied. When Jörgen affirmed this, the man told him not to ‘fuss around with mother nature’ and he asked the steward if he could have another seat. He didn’t want to sit next to someone who ‘manipulated the world’ (18.14).

In all of these examples, nature or the natural was either described as something positive or as something neutral.

Is Playing God a Matter of Hubris?
Some interviewees also used the metaphor of playing God; those who did so mainly used it in reasoning against certain uses of technologies and it was sometimes combined with uses of nature or the natural. Alva used this vocabulary and she explained that she did not believe in mak-
ing ‘oneself a master of nature’ (13.58). If PGD was not used, she said, maybe a child would be born with a disease and maybe the child would die after some years or months, ‘but I have not made myself lord of the situation’ (13.24). She emphasised that she understood and would support those who did want to use PGD, but she returned to the issue of ‘me choosing what kind of children I want’ further on in the interview. In her view, this was a way ‘to put oneself above life’ (13.30). I asked Alva to explain a bit more what she meant by making oneself ‘lord,’ ‘playing God’ or ‘acting God.’ She explained that she used the notions in order to clarify what she considered a desirable range of human decisions and actions. In her words, she did not say it because I want to refer to a certain kind of theology. I think humankind must learn to accept its place in nature. I believe that we, today, preen ourselves too much [...] I think it is ] one of the core element of existence, that we do not have control. We are not God. (13.78)20

The level of control was paramount in this section: whereas some control was described as important, too much control, and a search for too much control in all areas of life, was described as problematic. In Alva’s description it would be hubris to try to control all aspects of life (13.78). Other interviewees, such as Steven, also stated that it would be hubris to believe that human beings could improve humankind through advanced forms of germ-line gene therapy (7.55). Some of the interviewees also asked why one should ‘tinker,’ ‘manipulate’ or ‘mess around’ with genes (9.42, 38, 14.52). These words were used in a pejorative sense, indicating that such interventions were something that human beings were not really capable of doing without ‘messing up.’

The metaphor of playing God was used in order to convey images of humankind transgressing its place in nature, as in the excerpt above. Humans tried to act like God and this was undesirable. Such was also the case when Simonetta explained that it was frightening to be able to make decisions regarding who should live, particularly so if humans tried to discuss what lives were worth living and what lives were not as a basis for the selection of embryos. It was a ‘delirium of omnipotence,’

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of ‘replacing a hypothetical God.’ Such reasoning scared her, Simonetta stated (4.22). In these examples, playing God was not described as forbidden or as something that should be banned. The metaphor was used in order to indicate that certain decisions and acts were undesirable and potentially dangerous. Humans were warned not to play God. I label this use of the playing God metaphor the playing God warning.

There was one exception to the tendency to refer to God only in discussions of what technologies should not be developed, offered or used. When asked if there was anything special in her way of looking at the world that she considered important for her understanding of gene technologies, Hilda laughed and said that she, a geneticist, should believe in Darwin. But, she added, she had ‘no problem in believing in God and Darwin’s teaching of the evolution [...] God was a skilled geneticist who gave us this ingenious system.’ It felt right, she also explained, to make use of the possibility of developing new knowledge and to utilise it for the good of other human beings (15.60).

No interviewee articulated the view that human beings are given the responsibility to participate in an on-going creation and that this responsibility is an imperative – something that we should do. Some version of this view, which I label God’s imperative of co-creation, is sometimes articulated by theologians engaged in bioethical issues (cf. Peters 1997) and it could be understood as a contrast to the playing God warning. If so, acting in ways that resemble God’s act need not be a matter of hubris, but a way to take care of and be responsible for one’s talents.

Finally, one interviewee referred to a phenomenon that he described in ways that resembled a belief in fate. Andrew laughed and said that he had a ‘superstitious’ conviction. He had the feeling that children who are born either as a result of complete natural conception pregnancy or some kind of intervention were always going to exist, if that makes sense. It’s very superstitious, but that child was always going to be and the pregnancies that are terminated for example before an SMA unaffected child is born through PGD ... it’s almost as if that was the child that was only going to be, anyway.
Those other children were never going to be, somehow. It was always the one that was born that was always going to be. (8.64)

Even if PGD was a complicated and technologically sophisticated intervention, even if the ultimate decision as to whether to implant a certain embryo was taken in discussion between parents and the team at the clinic, the child that was born after PGD was ‘always’ the child that should be born.

**Is This Just Evolution?**

Some interviewees articulated ambivalence regarding how to understand, describe and evaluate PGD. This was more seldom the case in discussions of germ-line gene therapy, which was often described as pointless or dangerous and, in any case, something that should not be allowed. As an exception to this tendency, Andrew did articulate ambivalence with regard to germ-line gene therapy. The character of germ-line gene therapy was a reason why Andrew was hesitant to ‘breach’ the boundary of interfering with the genetic code, as he put it, but he was hesitant with regard to whether interventions in germ cells were ‘disturbing’ or not, since they may be interpreted as ‘just evolution.’ Evolution, he explained, ‘just happens, or it’s probably got to a stage where people are going to be involved more, because scientists will help evolution along’ (8.50). Implicit in this reasoning is the idea that evolution and the principles that guide it are not disturbing. At the same time, Andrew said that there was ‘something a bit disturbing about starting to cross that boundary.’ When asked why, he answered:

I think it’s the last boundary that we know of as human beings, that you can interfere with. It’s the very last stage where you have never been able to alter how human beings are. You can alter their environment and their lifestyle and whether they have or have not certain things in life, but you can’t alter them. Even now in PGD you can only choose between one or the other, but once you start actually altering what human beings implicitly are then that must be the
very last boundary that exists that we know, that I can think of. I can’t think of anything beyond. It’s quite different from, you know, the last boundary of remaining on this planet or anything, you know, it is more genuine than that, it is just so specific to what we are that once you can start to cross it something about it just bothers me, personally. (8.50)

Thus germ-line gene therapy represented a special case in this interviewee’s view. There was nothing ‘beyond’ such an intervention and breaching the genetic code was transgressing a boundary different from others that human beings had transgressed. If germ-line gene therapy became a practical possibility, human beings were mouldable in a new sense. In Andrew’s words, interferences in germ cells made it possible to ‘alter what human beings implicitly are.’

Something about changing what human beings were bothered the interviewee, but he could not pinpoint what it was exactly, nor decide whether it was a serious worry or not.

Summary and Concluding Remarks

Summary

Four kinds of narratives of concern have been presented in the empirical chapters: narratives of concern regarding how to define and evaluate life with genetic disease, regarding different kinds of risks, regarding actual, complicating aspects of present uses of the technologies and regarding present or future exaggerated uses or misuse of the technologies. The last kind of narratives contained the assumption that certain uses of a technology implied or would imply the breaching of a boundary that separated desirable/acceptable uses from non-desirable/non-acceptable uses of technologies. Such a boundary was sometimes legally or practically motivated and sometimes morally.

One such boundary was described as being drawn on the basis of certain medically relevant differences. Another boundary was described as being drawn on the basis of technical differences relevant to safety and accuracy. A third boundary was described as being drawn in
different places depending on differences in views of the moral status of the embryo. A few interviewees also described what resembled slippery slope reasoning. The allowance of a technology might lead to a more liberal understanding with regard to that particular technology and/or to related technologies, which could imply a blindness to morally relevant differences.

Interviewees also told stories that indicated that others may develop, offer and use technologies in what they themselves considered undesirable or unacceptable ways: they described different potential transgressors of boundaries. Who the others were varied, from society as a collective to certain patient groups, philosophers, colleagues or the interviewees themselves.

Interviewees’ descriptions and discussions of uses that were potentially or, as was less common, definitely beyond the boundary took up two negative long-term consequences: a tendency towards perfectionism and the marginalisation of certain groups of people. Interviewees also used the notions of the natural/nature, hubris and playing God in order to indicate what they considered to be uses beyond the boundary or potentially so. In nature is natural reasoning, interviewees used the natural as a synonym for what happened in nature if humans did not intervene. The natural was also understood as the statistically normal. Some interviewees also described certain acts as against nature and others stated that nature knows best. In these cases, nature/the natural was either described as something positive or as neutral. Some of the interviewees’ reflections also contained a blend of medical notions and life interpretations in support of their taking up a position for or against the naturalness of a certain use of a technology.

The idea that certain acts were against nature was also present in the playing God warning. In this usage of the notion of playing God, to play God meant that humans did not accept their place in nature, as some put it. No interviewee articulated the idea of God’s imperative of co-creation, the view that human beings are given the responsibility to participate in an on-going creation and that this responsibility is an imperative. One interviewee said that God was a skilled geneticist and that it felt right to use genetic knowledge for the good of others. Finally,
one interviewee asked whether new technologies, GLGT included, were not just evolution. Having said that, this interviewee also explained that something about GLGT worried him. The use of GLGT implied the breaching of the boundary of interfering in human DNA. In this sense, GLGT was different from any other human activity.

**Concluding Remarks**

Studies of lay-people’s perception of non-medical applications of gene technology contain evidence of concern regarding misuse and exaggeration (Wibeck 2002), but this has been less common as regards medical applications of this technology (Kallenberg et al 1996, Fjaestad et al 2001). However, some such concern was present in this study. *Narratives of concern* that focused on present or future exaggerated uses or misuses in the interviewees’ own country were often told by Italian interviewees. When such narratives were told by the British and Swedish interviewees, they either referred to such uses abroad or in the future. There were two (one Swedish and one British) exceptions to this general tendency. The Swedish exception was the interviewee who explained that he considered all uses of PGD morally wrong. The British exception was the interviewee who told stories of uses that he had contributed to but that he now, when he looked back, said he thought shouldn’t have taken place. They were exaggerated uses. Apparently, such uses did take place – in the eyes of this interviewee – also in the regulated British context.

Some of the *narratives of concern* not only highlighted interviewees’ concern but also their ambivalence as regards how to describe and/or evaluate a certain technology or use of this technology. As described earlier, such ambivalence was also evident when *narratives of progress*, *narratives of life with genetic disease* and *narratives of concern* were taken together, as well as in on-the-one-hand-on-the-other-hand reasoning that was not articulated through the use of different narratives. Furthermore, medical professionals articulated an ambiguous outlook with regard to positive as well as negative aspects of PGD. Although the majority of them described PGD as positive for some couples, they...
did not do so unreservedly, and though the majority of them described scenarios that made them concerned about PGD, they also questioned the basis for this concern. An articulated ambivalence, this time on behalf of the women and men who had undergone PGD or would undergo it, was also a result of the qualitative ethnography by Franklin and Roberts (forthcoming). However, whereas medical professionals articulated ambivalence with regard to PGD, this was not as often the case with GLGT.

Furthermore, some have held that there is a ‘marked disparity’ between on the one hand the ‘confident rhetoric of the genetics establishment and its media apologists’ and on the other hand the ‘gloomy’ or ‘suspicious’ reactions of disabled people and their organisations, as well as environmentalists, religious figures, feminists and certain journalists (Shakespeare 1999:671). Such marked disparity was not present in discussions of PGD among the interviewees in this book. Instead, many medical professionals here articulated their, sometimes, acute awareness that new genetic knowledge and new technologies could be used by others for what they themselves considered to be morally questionable purposes and that they exercised little or no control over this by their own actions. Some of them also explained that there are historical lessons to be drawn from the past and that there is an ‘increased power’ of modern genetics, which called for caution, as also stated by the medical geneticist Peter S. Harper (1997:219). However, and as seen in chapter four, interviewees did describe life with genetic disease as tragic, and such a description may – indirectly – support a ‘back-door eugenics’ (Shakespeare 2003).

This indicates a complicated balancing act. Interviewees said they were concerned about exaggerated uses and misuses. They also said that PGD meant hope for some couples, that this was progress, that life with genetic disease could be and sometimes was tragic, and that couples should be given choice. Furthermore, they said that not all choices were acceptable, that implantation of affected embryos was morally problematic, that some groups in society might think that couples did not have a right to give birth to a child with a genetic disease if they knew that they were at risk for it. One interviewee said that he realised that he himself sometimes thought so.
Franklin and Roberts (forthcoming) state that depicting medicine as beyond, ahead of or outside society can be quite unhelpful. They explain that in opposition to the view that ‘society’ always finds itself ‘behind’ rapid technological innovation, their study shows that such innovation is a social activity ‘that is very much in our midst.’ Some medical professionals in the present study combined the latter two views: new technologies were a product of familiar desires, feelings and needs, such as the desire to avoid another child with a genetic disease in families where previous children had died of such a disease or the desire to help patients, but – still – new technologies were ahead of society.

Interviewees also discussed who was likely to breach the boundary. I consider it interesting that these pictures sometimes counteract the stereotyped characterisations of medical professionals as those who breach boundaries. I also consider this section interesting since it evokes, to my mind, interesting conceptual questions. Can interviewees’ descriptions of certain actors as potential transgressors of boundaries be understood as examples of trust in others that fade? Can it be understood as ambivalence in trust relations as regards particular others? Would it better be characterised as confidence that fades or reliance that fades – and what is the difference between these concepts? From my philosophical point of view, these are important issues to address, particularly at a time when there is a general discussion of whether the ‘public’ is loosing trust in medicine (Mechanic 1996, O’Neill 2002). What about medical professionals’ trust?

Furthermore, the descriptions of potential transgressors of boundaries highlight the complex interplay between different actors, be it society, individual medical professionals or philosophers, groups of patients or individuals at risk for a particular genetic disease. It can also be noted that no potential transgressor was described as being amoral. Instead, others were described as having either a different set of values and norms or a different hierarchy of values and norms, which was sometimes described as problematic.

In chapter four, two uses of the notions of natural/normal have been presented. It was nothing strange to want to avoid genetic disease in future children, and healthy children and fertile couples were described
as the normal ones. In this chapter, the selection of embryos in PGD was described as a natural selection, since selection also happened in nature. If combined with the previous uses of the natural/normal, IVF and PGD were incorporated into the natural order of reproduction. They were technical means to achieve what was natural and they were, in this sense, steps taken in harmony with nature. Other interviewees stated the reverse: that selection of embryos was against nature. If combined with the previous uses of the natural, these means of achieving the natural were questionable because they were against nature.

To conclude, within this chapter, interviewees’ reflections contained values, such as the value of not breaching certain boundaries. Interviewees’ reflections contained norms in the sense of prescribed guides for conduct, again in discussion of certain boundaries. Certain uses of technologies were described as beyond a particular boundary. This boundary, though it could be transgressed, should not be transgressed. Interviewees’ reflections contained the norm of the natural (as when one interviewee clarified that selection of embryos took place in nature and that it therefore also should be allowed in PGD), the norm of not playing God and not displaying hubris. Human beings should not mess around with genes, as was described as possibly the case with germ-line gene therapy. Interviewees also articulated moral experiences and often so on behalf of their patients. Such was the case when patients were described as feeling that if they refrained from using prenatal diagnosis or PGD they had done something society did not approve of. A few interviewees also articulated morally relevant life interpretations, such as did the interviewee who stated that human beings did not have and should not search for ‘too much’ control of their lives. Such was also the case when one interviewee explained that he thought that even if deliberate selection took place in PGD, the child born after its use was the child that was ‘always’ going to be born.
A Bridge Between the Empirically and the Philosophically Oriented Chapters

Four core themes have been identified. Each of these has been presented in a chapter of its own: a chapter on medical progress, a chapter on genetic disease, quality of life and health, a chapter on conditions of choice and a chapter on uses that interviewees discussed as possibly and in some cases definitely beyond the boundary of the acceptable or desirable. Patterns have been presented as well as what differentiates one interview or one section of an interview from others; so have also a number of analytic terms that have been used as tools in order to conceptualise certain aspects of the data. Some of these results of the analysis of the empirical data will be used in the coming philosophically oriented chapters and some will not.

The first of two following chapters discusses the concepts of choice and autonomous choice. The second chapter discusses ambivalence, trust and ambivalence in trust relations. The primary reason why these concepts are chosen for philosophical discussion is that they were discerned as central in the analysis of the empirical data. A second reason is that though they were central in the empirical data, they are either not yet very common in the bioethical literature, as is the case with ambivalence and ambivalence in trust (though trust is becoming a common concept for discussion: see for example Pellegrino 1991, Baier 1996, O’Neill 2002, McLeod 2002), or there are aspects of these concepts that were central in the empirical data that are not yet very common in the bioethical literature. The latter was the case with some of the pressures that interviewees described as present in the encounter with the couple and of relevance to decision-making, such as structural
directiveness and marginalisation of voices (see Ch. 5). Furthermore, as a third reason, these concepts were ‘thick’ and complex, which made them philosophically interesting.

Conditions for choice and autonomous choice
Choice was a common concept in the sense that interviewees often stated that couples and themselves as professionals should be given a choice. They also discussed whether couples and, less often, themselves had a choice in practice and whether – and if so, how – decision-making were hampered or constrained.

Qualitatively speaking, choice was central to their reasoning. Choice was a recurrent value and choice provision was described as most important. It was more important than for example the prevention of genetic disease as such. Choice provision was described as important for professionals themselves, as when one interviewee explained that it must have been difficult to work in the field before PGD was available – when, as he put it, there was little or nothing to offer to couples. It was described as important to couples, when it gave them the possibility to use PGD and try to avoid the birth of a child with a particular genetic disease. It was also described as important to couples independently of whether the actual use of PGD resulted in the birth of child without a particular genetic disease. Choice was also central in interviewees’ discussions of whether couples who wanted to implant affected embryos should be allowed to do so.

In these discussions, interviewees used the concepts of choice, free choice and autonomous choice without making distinctions between them. From a philosophical point of view, this evoked my interest. Are there any theoretical or practical reasons for making a distinction between these concepts? If so, what kind of distinction would be relevant?

Interviewees also discussed what information should be given in the clinical encounter and what information enabled choice. Some of them described encounters whereby gaps between ideal and actual practices were indicated. They told narratives of concern, some of which pointed to constraints on choice and on decision-making. They described situ-
ations of choice in which women and men could not discuss their questions, in their own time and at length, to the extent that interviewees thought should have been the case. They described situations in which they felt that others wanted to constrain their choices and to make them act in one way or the other. This evoked the question of how to conceptualise different kinds of constraints. It also evoked the question of which the conditions for choice are. Which conditions need to be fulfilled if we can be said to have choice? And, if there is a distinction to be made between choices in general and qualified choices such as autonomous choice, which conditions need to be fulfilled if we are not only to have choice, but also autonomous choice?

Interviewees gave several examples of constraints on conditions for choice. In the philosophical discussion, I will draw on these empirical examples. These empirical examples evoked the question of in what senses there were constraints on unqualified choice and/or on autonomous choice. They also evoked the question of how to understand the difference between the individual’s decision-making and shared decision-making, in which two partners are engaged, in the context of PGD.

Ambivalence, trust and ambivalence in trust relations
Ambivalence was also a common phenomenon in the data. On the one hand, there was progress and some women and men had a genuine need for technologies such as PGD. On the other hand, the same interviewees said, there were actual, complicating aspects and possible present and future exaggerated uses and misuses. Some of these were so negative as to render certain uses of PGD undesirable. Trust and/or ambivalence in trust relations were less common than ambivalence, but they still recurred in almost all the empirical chapters.

Qualitatively speaking, ambivalence, trust and ambivalence in trust relations were central to the interviewees’ reasoning. Interviewees articulated ambivalence concerning how to understand, describe and evaluate the use of a certain technology or a certain use of a technology. They also articulated ambivalence concerning whether there were morally motivated boundaries that should be maintained and whether it should be considered troubling if the boundaries were breached. As
regards trust, some of them explicitly emphasised that practice must be performed in a responsible and morally thought-through manner so that people would trust and support the PGD clinic. In other interviews, this was implicit. Some of the interviewees also worried that practice may not be responsible and morally thought-through. They then discussed whether there were morally motivated boundaries that would be breached. They discussed potential transgressors of boundaries who could not be altogether trusted in this regard. *These descriptions evoked conceptual questions: should the descriptions of certain actors as potential transgressors of boundaries be understood as examples of trust in others that fade or as ambivalence in trust relations as regards particular others, or as something else? What is trust?*

Precisely what the interviewees were concerned about as well as the reasons for their concern varied, but many of them articulated hesitancy, concern or worry with regard either to certain present or potential uses of the technologies and they expressed ambivalence concerning whether to trust that others would develop, offer or use technologies in morally acceptable/desirable ways or for morally acceptable/desirable purposes. Some interviewees said they doubted that others (or themselves) would remain within the boundaries that separated and/or should separate the desirable from the non-desirable or the acceptable form the non-acceptable. The ‘others’ included fellow-experts, society, some patients and some philosophers. *This evoked questions of whether these examples qualify as trust relations and as examples of ambivalence in trust relations. What distinguishes different trust relations? Are there any characteristics of trust relations that are common to all such relations?*

Ambivalence and trust were also central to those narratives of concern that highlighted interviewees’ hesitancy about describing and evaluating life with genetic disease without lived or embodied experience of that disease. Lack of such experience was described as making interviewees ambivalent as regards whether they could describe and evaluate life with genetic disease in an accurate manner. The assumption that we cannot understand what it means to have a particular genetic disease without having that disease, may also imply that we
should not trust our ability to make assessments of what is a more or a less serious disease. *This raises the question of what assessments we should reasonably consider ourselves as able to make in a certain area; this is of relevance for the discussion of self-trust. What are the conditions for self-trust? In what senses is self-trust different from other kinds of trust relations?*
In this chapter, I will distinguish between the \textit{general concept of choice} and the \textit{subcategory of autonomous choice}. I will argue that such a distinction has the theoretical benefit of allowing a more precise discussion of degrees in constraints on conditions of choices. Some constraints hamper choice in general and some hamper only autonomous choice. First, however, I will give a short overview of the theoretical bioethical discussion of autonomy. This is of importance as a background to my later discussion of different choices and for the understanding of in what respects my account of autonomous choice differs from certain other accounts.

The primary focus is on choice and autonomous choice, not on autonomy in general or on autonomous persons. My reason for this is that it is consistent with my empirical results. Conditions of choice were a core theme in the data, not autonomy in general. This, however, need not imply a narrow concern with what happens at the actual moment of decision-making. A situation of choice that I have pondered on for many years will be different from a situation of choice in which I have to come to a decision with little previous reflection and in the heat of the moment. The time factor is important, as is the context of choice, such as the structures in which we are given choice or give choice to others. Issues of choice also include questions of ‘the rules and procedures according to which decisions are made’ (Young 1990:22-23).

I will describe and discuss conditions that should be met if someone can be said to have choice in general as well as autonomous choice. Having done so, I will also discuss the empirical examples as presented
in the previous chapters. The focus will be on whether these examples can be understood as likely to hamper conditions for choice in general and/or autonomous choice, as these have been characterised.

Summary of the Bioethical Discussion of Autonomy with Regard to Choice

A first distinction needs to be made between autonomous persons and autonomous choices and acts. An autonomous person need not make autonomous choices in all domains or situations. Persons who are often non-autonomous can, on occasion, make autonomous choices. A second distinction needs to be made between formal, procedural and substantive accounts of autonomy.

Formal, Procedural and Substantive Accounts

Most accounts of autonomy hold the capacity for intentional acts and the absence of hampering influences to be crucial. With regard to hampering influences, a distinction can be made between external and internal influences (Nordenfelt 2000:130). In the former case, I may be hampered by others, by structures in society, by lack of certain institutions etc. In the latter case, the typical and often discussed example of an internal hampering influence is weakness of the will. Less often discussed, but just as important, are external constraints that have been internalised, such as may be the case if I have internalised my interpretation of the views of society to the extent that I am unable to choose contrary to these views.

In formal accounts of autonomy what matters is that we can decide and act. As an example, we are autonomous with respect to a certain act when we have the ability and the opportunity both to decide to perform that act and to execute the decision, given a specified set of circumstances (Nordenfelt 2000:131). No specific reflection is called for prior to the act and no substantive content of the act needs to be specified. Another example of a formal account of autonomy is the
well-known account by the philosophers Tom L. Beauchamp and James F. Childress, which focuses on ability or capacity to engage in autonomous decision-making. Autonomy, Beauchamp and Childress say, is self-rule, free from others’ controlling interference and from limitations that prevent ‘meaningful’ choice (Beauchamp and Childress 2001:58).1

If formal accounts are used, I may come to a decision that others find absurd, irresponsible, rushed-into or harmful to myself, but as long as I am able to engage in autonomous decision-making and not under hampering influences, I am autonomous with regard to my decision. This, other theorists hold, is an inadequate understanding. Too much qualifies as autonomous decision.

Formal accounts, critics argue, fail to clarify the difference between decisions made on the basis of instant desires and wants and decisions made after a certain kind of reflection on these desires and wants. They fail to account for the cases of what some call ‘Homerian compulsion’ (Dworkin 1996:15, Welin 2003:150), whereby I, as did Odysseus on his journey back to Ithaca, want to limit my opportunity to act on impulse.2 In this case, I have performed a certain kind of reflection on my desires and wants; this means that I have made an autonomous decision.

Some of the critics of the formal accounts of autonomy call for procedural accounts in which a certain kind of reflection or a capacity for a certain kind of reflection is a condition for autonomy. Some focus on the motivational structure of the person choosing. This being the case, in order to choose autonomously we need to have a ‘second-order capacity’ for a certain kind of reflection (Dworkin 1996:15) or we need to perform a ‘second-order’ level of reflection; we need to reflect on which first-order desires, beliefs, values etc. we want to identify with (Frankfurt 1971). In the latter case, the reflection on first-order desires needs also to be free from interferences (Dworkin 1976:26-28). Others suggest that in order to come to an autonomous decision we need to identify and reflect on what we ‘really want’ (Meyers 1989:43). We need to exercise a certain competency that involves a cluster of capacities or skills, such as skills of self-discovery, self-direction, and self-definition (Meyers 1989, Ch.2). Autonomy is the exercise of this competency (Meyers 1989:58).
In these cases, everyday trivial choices, such as whether to put on the coffee before making porridge for the children, can still be autonomous, as well as more complex and existential choices such as whether to use IVF and PGD.

Some writers call for a third kind of conception of autonomy. What, they ask, about people who have internalised oppressive norms? What if they act in ways that are harmful to them because they wish to conform to these norms? These critics hold that procedural accounts of autonomy need to be supplemented by substantive accounts of autonomy. The philosophers Catriona Mackenzie and Natalie Stoljar distinguish between weak substantive and strong substantive accounts; this distinction will also be used here (Mackenzie and Stoljar 2000:19-21). In weak substantive accounts, autonomous choices are only made by actors who meet certain substantive qualifications. In strong substantive accounts, the results of an autonomous choice need to have a certain content or substance.

As an example of a weak substantive account, it is argued that we need a certain sense of self-respect or self-trust in order to be autonomous. Self-trust, it is then held, is what makes us trust that we are able to remember alternatives and previous experiences and to reflect on them. Self-trust can be graded and domain-specific, but if we lack it, choices we make are not autonomous (Govier 1993:115). In strong substantive accounts, the content of the decision or act needs to be of a certain kind. Theorists who emphasise substantive independence and feminist theorists who suggest that the content of my preferences is not autonomous if influenced by oppressive norms of femininity to the extent that a ‘normative competence’ is no longer present (Benson 1990:57, see also Stoljar 2000) may seem to be odd bedfellows. However, in both cases the content of preferences, decisions or acts needs to be of a certain kind in order to qualify as autonomous. Some also suggest that in order to act autonomously we need to be able to distinguish between what is right and what is wrong (Wolf 1989).
Individualism and Interdependence

Many are those that have criticised common accounts of autonomy such as the one elaborated by Beauchamp and Childress for being underpinned by a too individualistic understanding of human beings (McLeod 2002, Donchin 2001, Sherwin 1998, 1992). Beauchamp and Childress argue that their conception is not ‘excessively individualistic’ and that it does not neglect the social nature of individuals or the effect of other persons on the individual’s choices (Beauchamp and Childress 2001:57). Critics disagree with them and hold that Beauchamp and Childress’ conception of autonomy does not clarify relational aspects to the extent that is needed. It ignores the ‘full extent’ to which autonomy can be undermined by power relations (McLeod 2002:106). However, particularly some of the substantive accounts of autonomy, such as the Ricoeur-inspired one elaborated by Gilles Voyer (1996:6) that implies a concern for oneself as well as others, meet this criticism. Such accounts do spell out, explicitly, relational aspects of autonomy.

In the discussion of relational aspects of autonomy, a useful distinction can also be made between ‘constitutively relational’ accounts of autonomy and ‘causally relational’ accounts (Mackenzie and Stoljar 2000:22). The former focus on the social constitution of the agent who chooses autonomously, the latter on the ways in which social relations enhance or hamper autonomy.

Situations of Choice and Autonomous Choice

Why Distinguish Between Choice and Autonomous Choice?

When autonomy is understood as a formal notion, no qualifications are made with regard to the kind of reflection – the procedure – that needs to take place, nor to the substantive content of autonomous choices or acts. What matters is that we can come to a decision and act on it. If so, we are autonomous with regard to choice.

I consider this to be an unfortunate characteristic since it allows little discussion of different kinds of choices. What if we live under op-
pressive structures through which we have been so socialised that we, when facing alternatives P and R, are only able to imagine ourselves choosing between P and non-P and not R or non-R? Or, what if our experiences in a particular field are relevant with regard to our choice of P or non-P, but these experiences are silenced in a number of different ways to the extent that we start doubting that they are relevant or, worse, that we did have these experiences? What if we, then, can come to a decision – need that decision not be differentiated from decisions made in contexts in which experiences are acknowledged and discussed? I believe so. I also believe that distinguishing between conditions that need to be met for someone to be in situations of non-choice, of choice in general and of autonomous choice is helpful in this differentiation. This distinction allows a more precise discussion of degrees in constraints on conditions of choices. If, as in formal accounts, autonomous choice is understood as present as long as we can decide and act on the decision and if no distinction between choice in general and autonomous choice is elaborated, choices made in oppressive or in some other sense hampering relations qualify as autonomous as long as we are not so oppressed that we can no longer choose. I take this to be too rough a definition. A choice may not be autonomous even if we can decide and act on the decision.

Compare also the situation in which a woman and man at risk for a particular genetic disease are not given as much time as they want to reflect on the alternatives PGD, PND and adoption if their condition allows them to adopt, the situation in which a woman had undergone several PGD treatments and each time 'experienced the death of her child' again, and the situation in which someone is under no psychological stress and can reflect on what she or he considers important in a particular area and then come to a decision. These situations are different, not only in terms of the possible degrees in constraints (or the presences of constraints in the first two examples and lack of constraints in the latter). They are also different in terms of what conditions of choice are constrained. Again, distinguishing between the general concept of choice and autonomous choice enables a precise discussion of constraints on conditions of choices.
In situations of non-choice, we have no choice at all. In situations of choice, we have choice but not necessarily autonomous choice. In order to have autonomous choice, something more is required than in situations of unqualified choice: I shall suggest that a certain kind of reflection is important. This will shortly be further discussed.

One remark on the term free choice, which I will not use. My reason for not using it is that I believe that a minimal freedom from constraint is necessary in all situations of choice. If we do not have a minimal freedom as regards the particular area of choice, we have no choice. Thus, we are in a situation of non-choice. Such is the case if we are coerced or forced, either physically or psychologically, to the extent that we cannot choose. Not only does all choice require a minimal freedom, all choices can also be either more or less free from hampering constraints of different kinds. Furthermore, all choices can be hampered by external or internal constraints and such constraints are graded. Constraints may either be more or less strong or subtle. They may be explicit or implicit. Absence of explicit constraints does not need to imply their non-existence.

As has been said, one of the controversies in the discussion of autonomy within bioethics has centred on the notions of individualism and relationality (Sherwin 1998, 1992, McLeod 2002). Distinguishing between different kinds of choice, discussing what abilities are crucial for these choices and under what conditions abilities for different kinds of choice can be enhanced, can, I suggest, contribute to the discussion of causal and constitutive relationality in situations of choice.

To Have A Choice

If someone has a choice, she or he needs to be in a situation of choice in which there are at least two alternatives that she or he perceives as alternatives. In order to have a choice, I shall suggest, this person must also have what is required to come to a decision. Furthermore, she or he must have what is required to execute the decision, i.e. act on it and/or have others act on it. A number of abilities, opportunities and certain intentions are important in this regard.
In the context of reproductive medicine, persons at risk for a genetic disease can be in a situation of choice with regard to whether they want to use a certain available technology in order to minimise the risk of their having a child with that disease; a number of choices can also be distinguished within this overarching choice. Professionals who work in this area also often find themselves in situations of choice. They have a choice in terms of what technologies to suggest to couples and what technologies to try to develop.

**Abilities, Opportunities and Intention to Come to a Decision**

If someone has a choice, she or he needs to have certain minimal abilities, opportunities and the intention to come to a decision. *Abilities to come to a decision* include abilities for minimal deliberation on alternatives and abilities to perform the mental act of deciding which alternative to go for. It includes an ability to understand that one is in a situation of choice, an ability to perceive at least two alternatives, an ability to understand basic differences between the alternatives, an ability to intend a certain outcome as well as an ability to decide. This is the case even if the person choosing decides that she or he does not wish to ponder on alternatives as soon as someone describes them. In the case of the shared decision-making that is crucial to many decisions in the field of reproductive medicine, we need also to be able to listen to our partner, to consider what he or she says, to communicate our own, basic deliberation and engage in a decision-making process that both of us find acceptable and, finally, to come to a decision that both find acceptable. Such a decision can be the result of compromises.

The importance of abilities such as these becomes particularly clear when they are lacking. If we have no ability to understand that we are in a situation of choice, we cannot choose and we have no choice. If certain alternatives are considered deeply undesirable in a particular society and if we have internalised this, we may be unable to imagine the said alternatives in a particular area. This means that we are unable to choose them and we have no choice regarding them.

In order to understand conditions for choice, we need also to ask how the crucial abilities come about. Probably, we are born with some
abilities and some are learnt and acquired. Minimal abilities for choice are, if not acquired in social relations, developed, shaped and possibly thwarted in such relations (Dodds 2000:226), and often so in close relation with those with whom we share our early years of childhood. In this sense, abilities for choice are causally relational. Minimal abilities for deliberation are also constitutively relational in the sense that they partly consist of traditions and norms, held by others in the context in which we live, which we have integrated into our thinking and which we cannot fully question without also questioning the necessary ability for minimal reflection. Abilities for deliberation are, in the words of the philosopher Marilyn Friedman, ‘always partly constituted by communal traditions and norms that we cannot put entirely into question without at the same time voiding our very capacities to reflect’ (Friedman 2000:41). The wider social context provides a necessary background against which choice in general becomes intelligible to the agent who chooses. We cannot do without it when choosing.

The question of how the crucial abilities for choice come about is important since much theoretical discussion of choice in the medical context has centred on possible ways for professionals to inform patients of their particular condition and of different treatment alternatives, to discuss the condition and the treatment alternatives, to propose a certain treatment and to receive the patient’s informed consent. Less often have ways to strengthen and support these abilities been topics for discussion (Dodds 2000).

In order to have a choice, we need also to have the opportunity to come to a decision. This involves the opportunity to deliberate and decide which alternative to go for. We need to have the opportunity to perceive at least two alternatives as alternatives, to see what the alternatives are and what the basic differences between them are. We need to have the opportunity to learn and acquire abilities as well as the opportunity to use them.

These opportunities can of course be unequally distributed among persons. A number of more or less subtle strategies can also be used in order to hamper such opportunities. If we do not have the opportunity to come to a decision, if we are given no time to reflect on a certain
matter or if there are no alternatives, the opportunity for choice is hampered, as it is if we do not have the opportunity to acquire the necessary abilities. What opportunities are available is also, often, dependent on what others have decided should be available.

Abilities and opportunities are graded concepts. We may have more or fewer abilities and more or fewer opportunities to choose. However, the third condition of *intentionality* is not graded. Intentionality distinguishes choices from mere accidental events. As an example, if I am not allergic to certain antibiotics, but when filling in a health form I accidently tick the box for allergy, I do not choose to misinform the medical staff nor to tick the box. I had no such intention – it was not a choice.

Intention, I suggest, is a mental state that precedes all acts. I take a decision to be one kind of mental act and, as such, it is preceded by *the intention to come to a decision*. Intention indicates the presence of volitional aspects crucial to its being possible to say that I have a choice; it can come about as a result of wants that I have. Furthermore, I understand intention as a dispositional concept. To intend to come to a decision in a particular situation implies that someone is so disposed that she or he will decide in one way or the other, when this is possible. This has bearings on the issue of self-trust.

When deciding in one way or the other, I suggest, I have a minimal self-trust in that I can make judgements about what is happening. Even if I only choose in a particular way as a matter of habit, I, at least, do not fully distrust my ability to decide. However, if I lack all trust in my ability to interpret information about alternatives, in my ability to remember alternatives, in my ability to deliberate on alternatives or in my ability come to a decision in a particular area, I will vacillate between different options. If so, my ability to choose fades. I am unable to choose.

The philosopher Trudy Govier suggests that minimal self-trust is present when we reflect on who we are and when we interpret and describe experiences that we have had. It is present when we remember years that have gone and when we make plans for the future. I concur with her; if we lack this minimal self-trust, if we distrust our ability to remember previous experiences or our ability to understand others’
gestures, to reflect and act, in areas that we consider important, it can be a handicap so serious that it threatens our agency (Govier 1993). Even in cases where I decide that I will ask others to decide for me, minimal self-trust is important if I am to come to my own initial decision. In this sense, this account of choice is weakly substantial.14

**Abilities, Opportunity and Intention to Act on the Decision**

Consider the following situation. Amanda and John know that they are at high risk for a particular genetic disease. They have been to genetic counselling and during that counselling they have discussed different reproductive alternatives. At this particular meeting with Susan, their genetic counsellor, Amanda and John explain that they do not want embryos to be disposed of as could be the case if they used PGD, but that they may, maybe, want germ-line gene therapy to be performed on one embryo. If so, no extra embryos would be needed, they argue, no embryos would be disposed of for the reason that they were not healthy; instead, they say, the embryo would be treated. Susan nods and agrees that given their hesitancy with regard to embryo disposal, germ-line gene therapy would be a good, though hypothetical, idea.

‘At present,’ she says, ‘we cannot perform germ-line gene therapy. It is not legal, but even if it was, we still have too little medical knowledge. I’m sorry. It’s not an option.’

Consider also a slightly different scenario, in which John wants to use homologous IVF (without donor) and PGD in order to have a biological child, without a particular genetic disease that he is a carrier of, together with Amanda. Amanda is hesitant as to whether she really wants to use these technologies. The more they discuss the matter, the more negative she becomes. In the end, she explains that she does not want to use them.

The first scenario raises the question, among other questions, of whether Amanda and John can be said to have a choice with regard to germ-line gene therapy. If GLGT is not available as a therapy, can they be said to have a choice in this regard? They can only act in one way with regard to GLGT in this situation – they cannot use it. The second scenario raises the question of what shared decision-making means.
Obviously, if Amanda and John are to use homologous IVF together, this presupposes that both of them agree to do so. If Amanda does not want to use IVF and PGD and if she shall not be coerced or forced into so doing, John has to accept this. He cannot use homologous IVF with Amanda without her. If so, can his acceptance of the only viable alternative qualify as a choice?

My point here is not that choice should necessarily be present, but that the discussion of choice can become an empty rhetoric. Alternatives need to be practically possible if choices are to be real and ‘choosing’ the only viable alternative is not a choice. However, accepting that there is only one alternative may be so, and we may also choose not to acknowledge that there is only one alternative. Also, the notion of acceptance can be used in situations where John accepts Amanda’s decision but where he has a negative attitude towards this decision, as well as in situations where he accepts and has a positive attitude towards Amanda’s decision. Regardless of John’s attitudes towards Amanda’s decision, if Amanda says that she does not want to use PGD, John may accept her decision. In this regard, he has a choice. He may also realise that without Amanda, he cannot act on his decision to use IVF and PGD with her. In this latter regard, he has no choice. He does not have the choice to use IVF and PGD as a shared action.

There is also a difference between situations in which we come to understand that something is impossible before we have even decided what to do, as did Amanda and John in the germ-line gene therapy scenario, and situations in which we come to a certain decision but then realise that we cannot act upon that decision. Had Amanda and John not been told that GLGT was no option, they could have decided that they wanted it. They could also have tried to find someone who would help them use such therapy. This leads to another aspect of the ability to act on a certain decision. Ability to act on a decision may, in some circumstances, imply that we need to have the ability to make others – in this case often medical professionals – realise the decision. If Amanda and John found no one who agreed to perform GLGT, GLGT was no option for them.

With regard to the intention to act on the decision, as has been said, intention precedes every act. It also precedes a decision (as a mental
Finally, opportunity to act on the decision implies, for instance, that if we want to stay within the realm of the law, what we have chosen is legal. If it is not, we have no opportunity to act on what we have decided.

A final clarification with regard to acting on decisions is called for. In situations of shared decision-making, the processes of deliberation may be complex, negotiations and compromises are often necessary; those involved in it may also change their minds during the process. However, even if a certain couple can choose to try IVF and PGD (they have the ability, intention and opportunity to come to this decision and act on it) this does not mean that what they wish – that IVF and PGD will result in the birth of a child without a particular genetic disease – is accomplished. Treatment may fail for a number of reasons. I take this scenario to be different from the previous ones. A certain couple can have a choice concerning whether to try to use IVF and PGD but in practice, what they hope for may not come true. Whether technologies and treatment would succeed was not a matter of choice; only whether the couple should try IVF and PGD.

**Shared Choices in Medicine**

The context of homologous IVF and PGD highlights the issue of shared decision-making and makes causally relational aspects of choice particularly evident. A comparison between situations of choice in medicine in general, with some exceptions, and situations of choice at the PGD clinic can clarify this point. In the case of medicine in general, there is most often one patient. Whereas this patient may choose to discuss her or his situation with others who s/he wants to discuss it with such as family, friends, other experts in the field, s/he need not do so. The patient can choose to keep the diagnosis to her- or himself. Even if the patient chooses to discuss what to do and whether to undergo treatment with others, these others are not involved in the same sense. Though the consequences of a patient’s choice can be very significant for some others, such as partner and/or children, these others will not necessarily undergo treatment themselves. If the patient chooses to
undergo surgery, the person treated for a disease is also the one who has the disease.

All of these aspects of medicine in general are either not as straightforward or different in the new reproductive genetics. In the latter, when IVF and PGD are used, the ‘patient’ is not one person, but at least two persons who cannot or dare not conceive a child together without technical and medical means. Neither of the so-called patients needs to have a manifest disease, but one or both of them need to be carriers of a disease. Also, if one or both of the patients have a manifest disease, and even though the disease is the reason why they approach the hospital, their disease will not be treated, nor necessarily will consequences of that disease be treated. Furthermore, both patients/partners need to be involved in the discussion of whether to undergo treatment, and if so which treatment. Knowledge obtained – genetic knowledge – is of relevance not only for the patients but also for siblings and other relatives. In situations in which PGD is offered and used, there is as yet no treatment of the disease for the future child. There is only selection of embryos on the basis of genetic information.

Whereas some of these conditions are common for the prenatal diagnosis situation as well, the choice in the PGD context has one obvious and special feature: when the discussion of whether to use PGD takes place there is no embryo, no pregnancy, no foetus. Conception, in vitro, has not yet taken place. Though choice in general and autonomous choice in traditional medicine have their complexities, some of these complexities are sharpened in the PGD context. Here, choices typically involve at least two persons. These persons are engaged in the shared decision-making in a way that is different from that which is most often found in medicine in general.

To Have Autonomous Choice
Whereas conditions for choice in general were formal, the following account of autonomous choice is procedural. As said before, I consider autonomous choice to be a special type of choice. Here I shall suggest that autonomous choice is present only when the conditions for choice
in general are met and we can perform a particular reflection on what really matters to us with regard to the area, can reflect on whether what really matters to us in this area is promoted in an acceptable way by the alternatives present, can decide on the basis of that reflection and act on the decision that reflection yielded. This procedural account is inspired by the procedural account of autonomy put forward by the philosopher Diana T. Meyers (1989, 1987). Meyers develops an account that attempts both to explain possible hampering influences of socialisation on autonomy and explain why socialisation need not hamper autonomy. Such can be the case if someone has been oppressively socialised, Meyers holds, if this person still has developed an ‘autonomy competence’ that involve a number of coordinated skills, such as skills of self-discovery, self-direction and self-definition, and exercises this competence (Meyers 1987:627). It is only, Meyers states, through the exercise of these skills that autonomy is achieved. However, skills for ‘autonomy competence’ may be more or less developed or be ill-coordinated; this being the case, autonomy may be partial.

What matters, in Meyers’ view, if we are to be said to choose autonomously, is that we are able to identify and reflect on what really matters to us with regard to the particular area of choice and do so (Meyers 1987, 1989). Hence what matters is not the substantial content of a particular decision, but the process through which someone reaches an autonomous decision. Though I consider her discussion very helpful, my account of autonomous choice is different from hers. I take autonomous choice to be present when I can reflect on what values, beliefs and norms I hold to be really important with regard to the particular area of choice and do so (Meyers 1987, 1989). Hence what matters is not the substantial content of a particular decision, but the process through which someone reaches an autonomous decision. Though I consider her discussion very helpful, my account of autonomous choice is different from hers. I take autonomous choice to be present when I can reflect on what values, beliefs and norms I hold to be really important with regard to the particular area of choice, when I can reflect on in what ways particular alternatives promote, hamper or hide these values, beliefs and norms and whether what really matters to me, in the particular area, is promoted in an acceptable way by the alternatives present. I need not do so. As long as there are no constraints on abilities and opportunities for autonomous choice, I have such a choice. This difference from Meyers’ account has the benefit of not making autonomous choice so unusual.

Meyers also distinguishes between ‘autonomous episodic’ and ‘autonomous programmatic’ decisions. The former decisions result from someone being in a situation of choice, in which the individual asks...
what she or he can do and really wants to do now with respect to the particular alternatives and executes the decision that the deliberation yields. Meyers’ ‘programmatic’ decisions, on the other hand, are taken after reflection of a broader sweep in which the question ‘How do I really want to live my life?’ is posed and answered (Meyers 2000:227). I discuss only what she labels ‘autonomous episodic decisions’ (ibid.), which imply that I need not be able and have the opportunity to reflect on my whole life plan. I need only be able and have the opportunity to reflect on what really matters to me, at this moment, with regard to a specific area of choice. This is important since my life plan, if I have one, need not be relevant to all my autonomous choices. Furthermore, the content of autonomous decisions made at different times may be contradictory. What I value etc. may have changed during the intervening period. Some may hold this to be unfortunate. Should not autonomous choices reflect stable values? To some extent, if I really value or believe something, such a value and belief may not be easily overturned, but I take it to be important that it can so be. If not, this would imply a too static understanding of the selves that make autonomous choices.

Abilities and Opportunities for Autonomous Choice

When choosing autonomously, I need to have the ability to identify what I value, believe, care about with regard to a particular area of choice. I need also the ability to reflect on whether these values etc. are what I really hold as important and whether they are promoted in an acceptable way by the alternatives present. I need have the ability to come to a decision on the basis of that reflection and to act on the decision that the reflection yielded. If any of these abilities required for autonomous choice are hampered, autonomous choice is hampered. As before, I take abilities such as these to be developed in social relations; as was the case with choice in general, abilities are both causally relational and constitutively relational. An array of opportunities for autonomous choice need also to be present, such as the opportunity to reflect on what we value with regard to the particular area of choice, to decide and act, and the opportunity to develop previous abilities.
In the medical setting, I have said, if a patient’s choice shall be supported, it is important to strengthen abilities necessary to the particular choice. If it is assumed that autonomous choice is desirable, and since the exercise of autonomous choice requires not only abilities for minimal deliberation on alternatives but also abilities for a certain reflection, it becomes important also to strengthen abilities for reflection on what matters to the individual.

A procedural conception such as this does not imply that the final decision need be of a certain kind. In the example of IVF and PGD, neither of the alternatives present may be understood as particularly desirable by those who engage in the choice as to whether to use the technologies. When reflecting on what matters to them with regard to each of the alternatives, a woman and a man at risk for a certain genetic disease may conclude that neither of the alternatives is desirable. They may conclude that neither alternative harmonises with values they hold to the extent that they wish it did. Still, under present conditions, one alternative is less bad – less undesirable – than the other. Though neither alternative harmonises with what they value etc., their final decision can be autonomous. This is so since choices are autonomous if the described reflection can take place.

Finally, this conception of autonomous choice is weakly substantive, as was the case with choice in general. In order to have an autonomous choice, I suggest, we need to have minimal self-trust. We need to trust that we are able to interpret alternatives. We need also, as was not the case in order to have choice in general, to trust that we are able to reflect on what matters to us with regard to the area of choice and to trust that we are able to decide on the basis of that reflection.21 We need not, of course, trust that we can reflect on all the values that we hold, but on the most relevant ones. In situations of shared decision-making, too much self-trust may, arguably, impact on the decision-making process to become less shared. This is so if we trust that our ability to reach the best conclusion is much better than others’ ability and if this results in an inability to listen to others and to reflect critically on our own views.

If two persons can be said to be involved in shared autonomous decision-making, it is crucial that both are able and have the opportu-
nity to reflect on what matters to themselves individually as well as what matters to the other person. Both of them need to be able to considered what really matters to the other person, without doing it for the other. If either of them has no ability or opportunity to do so, they cannot be said to be involved in shared autonomous decision-making. In situations of shared autonomous decision-making, the notion of compromise is important. Reaching a compromise does not imply that the final decision is also the decision that each of the partners would have come to, had she or he been alone in the process. It implies that a decision is reached that both partners find acceptable and that both found the decision-making process that resulted in the final choice acceptable. The partners involved in shared autonomous decision-making may disagree about goals and means, they may disagree about whether certain alternatives really promote what matters to them, they may have different understandings of what really matters in a particular area, and so forth. However, I shall suggest, as long as they can reflect on what matters to themselves individually as well as to the partner and as long as they are able and have the opportunity to ‘give and take’ in their reasoning and come to a decision that both of them find acceptable, they can be said to be engaged in shared autonomous decision-making. The issue of compromise underlines the intersubjective dimension of these choices.

Hampering Influences on Different Conditions of Choice

This section discusses different constraints on choice and/or autonomous choice, through the use of the examples in the previous empirically oriented chapters. It contains five sub-sections that focus, respectively, on complex, ambiguous, overwhelming or insufficient information, on psychological distress, on individual and structural directiveness, on marginalisation and cultural imperialism and on compulsion. The sixth sub-section focuses on the special case of shared choice and shared decision-making.
Chapter 7

Complex, Ambiguous, Overwhelming or Insufficient Information

We need to understand the meaning of alternatives in order to have a choice. In order to do so, it is crucial that we have, among other things, abilities to come to a decision. This includes the ability to perform a minimal deliberation on alternatives that, in turn, includes the ability to understand the basic differences between alternatives. It is also crucial that we receive basic information about alternatives. If we do not, no matter how able we are to come to a decision, we do not have the opportunity to do so. In order to have autonomous choice, I have suggested, we need also to be able and have the opportunity to reflect on what really matters and whether what really matters to us is promoted in an acceptable way by the alternatives present. Certain information about alternatives is important in this regard, as is the understanding of information. Some examples from the previous chapters are particularly interesting in this discussion.

Some interviewees explained that they were concerned and upset about one-sided pictures of IVF and PGD given in the media. One of them explained that she wondered if some colleagues did not have a ‘vested interest in encouraging people’ into PGD and she doubted that alternatives were described in equal ways. Another interviewee said that he doubted that colleagues knew about the latest developments with regard to alternatives to PGD. Still other interviewees explained that there was always a risk that the embryo had another disease than the one tested for, but that this risk was not always clarified so that women and men understood it.

Furthermore, some interviewees described the alternative of IVF and PGD as most stressful, terrible and as a way of ‘playing’ with your life. Whether IVF and PGD was, interviewees also remarked, perceived as an eligible alternative depended on, among other things, how the women concerned judged possible personal physical and mental traumas - when they tried to imagine what it would be like to undergo treatment. In this context, it is noteworthy that the interviewee who had personal experience of IVF was among the interviewees who emphasised the stress and pain in the procedure the most. It can also be
noted that other empirical research in which women with experience of IVF have been interviewed has also indicated the hormonal ups and downs and the psychological pressures on women. In this study, some women held that IVF ‘just takes over’ and that it became ‘a way of living’ (Franklin 1997:131-167).

These examples highlight questions of what information professionals give and discuss in counselling as well as what patients in fact hear. They also evoke questions of what information and what understanding of information is necessary if we can be said to have choices and autonomous choices. It can be asked whether it is, and if so to what extent it is, possible to understand what IVF really can mean before entering the programme – and in what sense possible difficulties in understanding matter in situations of choice and autonomous choice.

A minimal deliberation on basic differences between alternatives may be possible even if I am only given vague or little information and, be it noted, even if I am given false information. Such would be the case as long as I am able to understand the little information I may be given, am able to understand basic differences between alternatives, and have the opportunity to understand information and basic differences between alternatives. This being the case, and as an example, choice can be present even if a particular woman is not given the information that IVF can be experienced as most painful (or if she does not hear or understand this information). She may just be informed of some of the risks involved in treatment. If so, this woman may well have a choice. Such may also be the case even if she, once under treatment, regrets having chosen to undergo it.

Whereas being given basic information is enough for someone to be in a situation of choice, it need not be enough for someone to be in a situation of autonomous choice. Maybe IVF, as this woman experienced it, did not promote what really mattered to her in an acceptable way. Maybe, if she was not given enough information about how some women experienced the treatment, she did not have the opportunity to reflect on how the different alternatives promoted what really mattered to her – even if she had the ability to do so. If so, she did not have the opportunity for autonomous choice.

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A distinction needs to be made between the extent to which it is possible to understand what *in vitro* fertilisation and PGD mean, technically speaking, and the extent to which it is possible to grasp how I, as an individual, will experience them. If risks involved in IVF and PGD are not altogether clarified, if alternatives are not described in equal ways, this need not hamper the *ability* to come to a decision, nor the *opportunity* to do so. Such deliberation can be possible as long as someone is given basic information. However, if someone can be said to have the *opportunity for reflection* required for autonomous choice, this requires not only basic information. It requires also information that makes it possible to reflect on whether a certain course of action will promote, hamper or hide what really matters to this person. If not, opportunities for autonomous choice are hampered.

One interviewee also described lives-on-hold scenarios, i.e. scenarios in which little knowledge could be obtained about future developments but where couples nevertheless needed to decide whether to wait for the diagnostic method to be available to them or to abandon the idea and get on with their lives. Difficulties here concern the limits of knowledge, the present level of knowledge and uncertainty as to how to judge the latter. Lives-on-hold scenarios also evoke the question of what information we need in order to perform the minimal deliberation crucial to coming to a decision. On the one hand, we may hold that even the most basic information must be lacking if lack of information shall be a constraint on the *opportunity to come to a decision*. Being told that there is no certain information is also information, and couples could, at least, be told that no one knew for sure about future developments. On the other hand, being told that no one really knew, but also being told that ‘we’re nearly there,’ might be quite confusing. This interviewee described it as confusing to the extent that he chose to describe these couples as ‘putting their lives on hold’ and not able to ‘move.’ Whilst we may be given information, we may not be *able* to understand and evaluate it in the way crucial to autonomous choice; the information may make us too confused. We may also, if given information, experience what has been called information overload, i.e. so much information that we have difficulty handling it.
Whereas too little information can hamper the *opportunity* to perform the reflection crucial to autonomous choice, too much information can hamper the *ability* to perform this reflection. In lives-on-hold scenarios, being told that no one really knows about future developments but also being told that ‘we’re nearly there,’ can possibly be confusing to the extent that we are no longer able to reflect on how different alternatives promote values etc that we hold as important in the area in question. Similarly, a wide spectrum of alternatives may be confusing to the extent that we are *unable* to identify how alternatives promote values etc that we hold to be important, whereby autonomous choice is hampered. If it is confusing to the extent that we are unable to come to a decision, choice in general is hampered. Arguably, counselling that helps women and men to reflect on what matters to them (that enhances both their ability and their opportunity to do so) may promote autonomous choice more than a vast array of information. This, of course, would mean that the provision of genetic information is not the only or even the most important aspect of counselling.

**Psychological Distress**

Some interviewees also told stories of women and men who used IVF and PGD but where all the embryos were affected. One interviewee explained that when one such woman had her embryos in a dish in front of her and wanted to have a family, it was ‘too difficult a choice’ to have them disposed of. She wanted to have a family and seeing the embryos, she wanted them to be implanted even if they were affected by the disease. This interviewee also recalled a woman who had lost a previous child. This woman went through several IVFs and PGDs and for each try she, the interviewee said, experienced the death of the first child ‘again and again and again.’ The interviewee explained that the woman wanted to keep on trying but that it was ‘disastrous.’

Arguably, we may be more or less prepared for complex situations of choice. If we have to come to a decision in the middle of the psychological distress of losing our child again and again, such a situation probably will not enhance abilities involved if we are to come to a de-
cision. It need not, however, hamper such abilities either. Even if the choice is made under psychological distress, it is choice. However, if we can be said to have autonomous choice, this requires something more than choice in general. As a consequence, whereas even severe psychological distress need not hamper abilities to come to a decision, it is more likely to hamper the ability to reflection on how different courses of action promote what we really want.

The situation in which someone has the embryos in a dish in front of her and there are no unaffected embryos highlights the importance of the time factor. Limited time, as when someone has to make a choice in the heat of the moment can hamper the opportunity to make a choice at all, not just an autonomous one. Lack of as much time as desired, other empirical research indicates, is sometimes an issue in IVF situations (Price 1990).25

**Individual and Structural Directiveness**

Provision of value-neutral information, by the medical professionals in genetic counselling, and patients’ interpretation of such information have been described as crucial issues. The possibility of professionals’ provision of such information has also been questioned (Shiloh 1996, Clarke 1991). In my empirical data, some interviewees stated that information should be given about facts and statistics and nothing more. Others stated that value-neutral information could not be given and still others stated that sometimes advice needed to be given. In all cases, the idea was to promote the decision-making process.

These discussions are primarily relevant to the discussion of different senses of non-directiveness in the particular clinical encounter. They are examples of discussions of individual non-directiveness or individual directiveness. A certain individual genetic counsellor may be non-directive in her or his counselling; someone else may be more directive. Other examples highlighted the issue of structural directiveness. Structural directiveness can arise from the context in which genetic counselling takes place (Clarke 1997:181). As one example, it has been held that merely making certain genetic tests available can cause
some women and men at risk for genetic disease to feel that such tests are being promoted or, worse, lead to a certain outcome (Clarke 1997:181, Koch and Nordahl-Svendsen 2005). A similar view was put forward by the interviewee who explained that offering PGD might result in some people not thinking through the moral aspects themselves. They trusted that a moral assessment had already been done (and that this was enough).

The phenomenon of structural directiveness also focuses on organisational structures that can result in a systematic directiveness. Such was the case when one interviewee described the complexity of IVF/PGD and the organisational structures in which it was offered (only at four places in the UK, and you needed to sound convinced in order to get to one of these rare clinics) as a reason why medical professionals needed to be reassured that the woman and man concerned knew what they wanted. As a consequence, professionals at PGD units ‘pushed’ couples and this possibly made them sound more convinced than they in fact were.

Some kinds of structural directiveness can have an impact on couples’ time to reflect on alternatives. If they do, it can hamper opportunities for autonomous choice. Such opportunities can also be hampered if the women and men concerned do not feel free to express and discuss possible worries. Furthermore, if women and men have to behave in a certain way in order to get to IVF and PGD centres in the first place (be vocal and persistent, as described by one interviewee), those who are able to do so may possibly be privileged. Others may not be given the opportunity to choose PGD. As regards individual directiveness, it can also hamper opportunities for autonomous choice. Such could be the case if no time for reflection necessary for autonomous choice is given.

**Marginalisation and Cultural Imperialism**

When the philosopher Iris Marion Young (1990) discusses a number of forms of oppression, she also describes the phenomena of marginalisation and cultural imperialism. Marginalisation, Young explains, is the
phenomenon that results in certain people’s voices not being heard. Certain views are not brought up for discussion or are quickly dismissed, or certain people are hampered through processes that make them more or less invisible. Cultural imperialism involves the universalisation of a ‘dominant group’s experiences and culture, and its establishment as the norm’ (Young 1990:59). Perspectives and experiences within this dominant group are most often heard, and the members of the group have access to ‘the means of interpretation and communication’ in society (ibid.). I understand marginalisation and cultural imperialism as forms of constraint that are not very common in bioethical discussions of autonomy or autonomous choice, though it is important that they be discussed. They are particularly so in relation to the following empirical examples:

Some interviewees described couples’ decisions not to use PGD as psychologically difficult since they were at odds with perceived ‘attitudes in society.’ Few women who had given birth to children with genetic diseases or impairments could properly cope with the feeling of guilt, of having done something that ‘society does not approve of,’ one interviewee said. Psychologically, it was too difficult to act against the perceived norm of society. In such examples, if society is understood as an entity that is perceived as a ‘dominant group,’ this dominant group is also described as establishing the norm of not giving birth to children with genetic diseases. This is an example of ‘cultural imperialism.’ It is described by some of the interviewees, it is attributed to society, and it, according to these interviewees, has consequences for the choices of women and men at risk for a genetic disease.

In other examples, a technological imperative was described as being internalised by couples. One interviewee explained that some couples could have accepted not having more children or having gamete donation or adopting if their condition allowed them to adopt, but ‘because a technology is offered to couples, and there is support of the doctors offering it, couples start to choose options that they might never have wanted.’ ‘Because this technology is there,’ this interviewee continued, ‘many couples seem to feel that they must take it, that they are denying their future children [something] if they don’t take it.’
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technological imperative, i.e. the view that a certain technology should be used since it is available, was described as a part of couples’ reflections and as internalised.26 If such an internalisation takes place, use of technologies seems to have been understood as the norm.

If certain experiences and views are interpreted as the norm, other experiences and views may not be told or discussed; or if they do come up they may be dismissed as uninteresting or ungrounded. Thereby, marginalisation of some experiences and views may be a consequence of cultural imperialism. In this sense, both phenomena of marginalisation and cultural imperialism evoke the question of whose voices are being heard, listened to and regarded as important. As has been seen in the empirically oriented chapters, interviewees typically told stories of couples who had experience of life with genetic disease and who wanted to use IVF and PGD. The stories of those who had such experience but who did not want to use PGD were much more rare.

Marginalisation and cultural imperialism can hamper individuals’ abilities as well as opportunities for choice. If a certain woman and man feel that ‘the view of society’ is that they should use some kind of genetic diagnosis, either on embryos or on foetuses, and if they have internalised this view, they may be unable to come to a decision that opposes it. If so, they lack the ability to choose in this particular regard; they may be able to choose between PGD and prenatal diagnosis, but not between PGD and not PGD. Similarly, if we see a certain decision as being too difficult to live with in a certain society we may be unable to come to this decision, even if we are able and have the opportunity to reflect on what really matters to us.27

Finally, societal views can influence the legal system and become constraints on my opportunity to act on a decision. As we have seen, this was described as the case when a certain technology was available abroad but not in a patient’s or professional’s home-country. The woman and man would not have the opportunity to get the treatment unless they travelled abroad and became so-called ‘reproductive tourists.’
Compulsion

We may envision scenarios where a couple did not believe that a certain choice could be realised to the extent that such lack of belief resulted in their having no intention to choose. Thus, they would be in no situation of choice.28

The topic of intention was only indirectly present in the data, as in scenarios where interviewees stated that information as such led to unfreedom for those who did not want that information – as in the stories of couples who said that they wished there was no choice or that they never had wanted to know about the alternatives after having been told of the possibility of genetic testing. Such persons might not have had any intention to choose. They may have wished that there was no choice, but once informed, they had to choose and they did choose. As one interviewee put it, once couples were asked if they were interested in using the testing, they could not choose not to choose, even though they might wish to and even if they had had no intention to choose before being ‘informed.’ They had to decide what to do with this information. Some couples, another interviewee said, explicitly stated, after genetic counselling, that they did not want this choice. However, information forced them into a situation of choice in which they had to face questions such as should they listen to the information, how should they judge the information and should they base their decisions on it? Here, a distinction can be made between situations of choice that we consider psychologically and/or morally difficult and in which we wish choice had been psychologically and/or morally easier and situations of choice that we consider so psychologically and/or morally difficult that we wish that there was no choice. The couples above were described as saying that they wished there was no choice – not just that they wished choice had been psychologically and/or morally easier.29

Not wanting to take a stand, not wanting to say yes or no, can in itself be an autonomous choice. When informed about PGD, couples who do not want to take a stand must do what they do not want to: explicitly decide whether to use PGD. Not taking a stand is impossible, and information puts a restriction on what choices are possible.30
The Special Case of Shared Decision-Making in PGD

Two aspects of shared decision-making in PGD will be addressed. First, to what extent is decision-making shared? Second, is there a shift in terms of who has the final say in decisions as to what to use PGD for, to be compared with the decision as to what to use prenatal diagnosis for, as asked by Draper and Chadwick (1999).

Other studies have suggested that there may be a gender-bias of relevance to situations of choice. Women, as a group, some suggest, may be more responsive to unspoken needs or unexpressed discomfort than men, as a group (Donchin 2001). If accurate, this raises the question of whether and, if so, in what sense shared decision-making is shared. It also raises the question of what kind of counselling hampers or enables shared choice and shared autonomous choice.

As regards different kinds of genetic testing, it has been claimed that women have come to be seen as bearers of responsibility for genetic risks and such risks are not a matter of neutral probability (Steinberg 1996:267). A study on the experience of women who underwent genetic testing for breast cancer also showed that women perceived themselves as having a genetic responsibility to their kin: they underwent genetic testing for the sake of ‘doing the right thing’ for others, in order to determine risks and take steps to control them in some way (Hallowell 1999:605-613). It has also been shown that, in cases where predictive genetic testing of late onset disease was possible such as in the case of Huntington’s disease, more women sought genetic counselling than men and more women opted for genetic testing than men. Women ‘usually act as genetic housekeepers for the kinship,’ it has been claimed, in the sense that they take on the primary role in exchanging information about a genetic disease with relatives (Richards 1996:258).

A gender difference was also present in an empirical study of how women and men, in the case of couples where one partner was infertile, reasoned and evaluated reproductive alternatives such as adoption, IVF and intracytoplasmic sperm injection. Men were more hesitant than women when it came to the idea of adoption; women’s willingness to undergo treatment was often motivated by the wish to do this ‘for their husbands’ (Lasker and Borg 1987). Certainly, this can be a good,
and also rational reason, as was also the case when one of the interviewees described how she and her partner negotiated in the context of prenatal diagnosis. The husband explained that to him, genetic testing of the foetus was a condition if they should try for pregnancy in the first place, as was abortion if the foetus had a particular genetic disease. The interviewee stated that though this was not what she wanted, she accepted it for the sake of trying for pregnancy. In such a situation, reflection on what each of them holds to be really important may well take place, the woman and man may reason about goals as well as means of achieving certain goals. Both of them or one of them may also compromise on what is the acceptable or desirable goal as well as the acceptable or desirable means of achieving the agreed goal. Even if such situations do qualify as situations of shared autonomous choice as long as all persons involved consider the decision-making process and the final choice to be acceptable, this brings out the fact that if such choice has taken place it need not reflect all that mattered to those involved in the decision-making. It can also be both psychologically and morally complex. Furthermore, though being shared, the decision-making process and the final choice need not be shared in an equal manner.

Finally, a few interviewees explained, some couples said they had a right to use a certain technology. In some such situations, these interviewees also said, they did not consider the particular use to be for the best of the couple or for the best of the child or they considered the particular use to be a misuse for other reasons. Interviewees described these situations as worrying. ‘I am not an automatic distributor of embryos,’ one of them said. These are not examples that qualify as constraints on professionals’ choices or autonomous choices, as long as the conditions for these choices are met. However, they do highlight the possible tension between professionals’ expectations and understanding of their role as counsellors and the expectations of counsellees.

Tension between expectations is nothing new in genetic counselling, but counselling in PGD has an important twist to it, which – as has been seen – has been described as a new moral problem (Draper and Chadwick 1999). When a woman is pregnant, in the situation where no assisted reproductive technology has been used, the decision whether to
use prenatal testing as well as whether to carry the foetus to term is hers to make, irrespective of what others may say (before a certain week in the pregnancy). In the context of PGD, this is less straightforward, at least in the UK where physicians who participate in IVF and PGD have a statutory obligation to consider the interests of the future child. As a consequence, in situations where a certain couple want to implant an affected embryo, it seems as if the physician has the final say – and not the woman – though this is the other way round in other pregnancies. This means that there is a shift in ‘reproductive power’ from women to physicians (Draper and Chadwick 1999:119) that can hamper women’s possibility of having others act on their decision. In this respect, they would have neither choice, nor autonomous choice.33

What Choice and Why Choice

More alternatives increase choice. This can be positive. More alternatives can also be psychologically stressful, morally problematic, and choices may be illusory (in the sense that the choices presented are not real choices in that they are hampered by structures). Choice and autonomous choice can be hampered in many ways. The hampering influences described above were mainly of two kinds. Some of them had to do with situations where ideals succumbed owing to the concrete framework, such as lack of time for reflection. Couples had little opportunity to reflect. Such situations accentuate the gap between ideal and actual practice and the presence of a gap may raise important moral questions. Still, the gap may be bridged by more time, better structures, a heightened awareness of problems etc. Other situations were more problematic. The possibility of choosing to try PGD can sometimes transform itself into a constraint on certain choices. The possibility of PGD can be interpreted as an imperative to use it and, in any case, information compels us to choose in one way or the other even if we do not wish to choose.

In what I call a twofold empirical criticism in the discussion of autonomy in the literature, it is sometimes argued, on an empirical basis,
that not everyone wants to choose autonomously and that those who want to do so, do not always manage to do so. In my data, I take the presence of hampering influences on conditions for choice and autonomous choice to indicate that choice and autonomous choice within reproductive genetics were not always present (compare also Hildt 2002, Corrigan 2003). Furthermore, PGD cannot be understood as a means to increase the number of eligible alternatives for everyone. It may be understood as a means to increase the number of eligible alternatives for some, such as couples at high risk regarding a number of genetic diseases, who long for biological healthy children, who accept the idea of embryo disposal, and who consider the personal trauma as acceptable. There are also reservations to be made when it comes to PGD as a means to enhance reproductive choice in general. The empirical data indicated that not everyone who was informed of the possibility of choosing to use PGD wanted this particular kind of choice.

The described constraints highlight practical and moral limits of actual counselling. Practically, too little or too much information may not reliably meet the needs of the counsellees. Morally, if it is held that autonomous choices are morally desirable in the context of PGD, and if women and men are not given the opportunity to reflect both on what matters to them in the PGD context and on how different alternatives promote what matters to them, choices are not autonomous.

This has a bearing on the discussion of what information shall be given in clinical encounters in general and in genetic counselling in particular. It has been claimed that a strict non-directive genetic counselling, in which moral issues are not brought up unless by the women and men concerned, is justified on the basis that these women and men will face and answer the moral questions themselves. This view has also been criticised as irresponsible. How come we draw moral lines for social but not for medical terminations of pregnancy? Have ‘we fled so far from medical paternalism that we deny the ethical responsibility for our professional activities,’ medical geneticist Angus Clarke asks in a discussion of whether medical geneticists need not discuss which genetic diseases warrant the option of prenatal diagnosis and termination of pregnancy (Clarke 1991:998). Value neutrality is not
necessarily morality, others have claimed (Caplan 1993). Whereas these discussions focus on whether prenatal diagnosis and termination is not used for too mild genetic conditions, the discussion in the case of PGD often focuses on whether PGD should also be used for what is not a serious genetic disease and on difficulties in defining the seriousness of such a disease.

Though conditions for autonomous choices, as I have characterised them, need not be hampered by a strict non-directive genetic counseling, they need not be enabled either. However, they are enabled if a thorough discussion of values etc. of importance to the counsellee is encouraged. This can also enable the possibly complex decision-making process in situations of shared autonomous choice. In this case, abilities and opportunities to make choices, by the particular women and men concerned, can be enhanced. This means that they can be helped not to reach a ‘wise decision,’ i.e. a decision with a certain substantive content, but to ‘reach a decision wisely’ as put by the psychologist Shoshana Shiloh (1996:87). 35

In the next chapter, ambivalence, trust and ambivalence in trust relations will be explored and the discussion of choice and autonomous choice can have a bearing on this. Arguably, everyday encounters, in the clinic and elsewhere, can be easier and swifter if we trust others. As a psychological strategy, trust in others can diminish our ambivalence regarding what to do. In the medical context, if we are ambivalent regarding whether to trust a particular medical professional to provide us with relevant and accurate information, decision-making can be more complicated than if we trust in this respect. Ambivalence in trust may enhance ambivalence in what to choose and what to do. Trust can also restrain autonomy. In arguing for patients’ autonomous choices, it is often assumed that patients’ choices should reflect what they want and not only their trust. If we trust someone to the extent that we stop reflecting on what really matters to us, trust can become seductive. I will now turn to the discussion of the nature of ambivalence and trust.
In this chapter, I will discuss what characterises ambivalence and trust. I will discuss core elements of all trust relations as well as what distinguishes different kinds of trust relations. When such distinctions are made, empirical examples from the previous empirically oriented chapters will be drawn on.

Characteristics of Ambivalence and Ambivalence in Trust Relations

Though ambivalence has been discussed from a sociological or social studies perspective on human existence or on technologies in late-modern society (Lupton 1994, Smart 1999, Burke 1992, Giddens 1990), it has less often been a topic of philosophical analysis in bioethics. Ambivalence can be articulated in many ways, but it is typically present when we vacillate between different beliefs, expectations, feelings, attitudes or states of mind. It is present when we cannot make up our minds, when we cannot come to a decision and when the reason is not that we do not have the opportunity to do so. Instead, we consider two alternatives as just as good or bad, as valuable or as pointless, or we cannot come to a decision since alternatives in part promote what we consider valuable and in part do not. We can also have ambivalent feelings; we do so when two conflicting feelings coexist, and, arguably, we can be ambivalent in a more ontological sense. Such is the case if we
hold that human beings are necessarily morally ambivalent beings: we are, at heart, morally good and bad, as argued by Bauman (1995:18).

As has been seen in the empirically oriented chapters, we may be ambivalent as to whether we like or dislike something, as to whether something is important to us, as to how to value and assess certain phenomena. As has also been seen, we may be ambivalent as to whether to trust someone or something in a certain respect. Ambivalence, Giddens says, lies at the core of trust relations (1990:89). I suggest that the potential for ambivalence lies at the core of all trust relations. This is so since trust is demanded in circumstances where there is an element of ignorance and since ignorance provides us with grounds for caution. For instance, we do not know if experts’ claimed knowledge is correct, we do not know the thoughts and intentions of the close friend. If we trust these persons, we just expect them to be reliable. Though ignorance may result in ambivalence, it need not. It has only the potential to do so.

Trust can function as a psychological strategy in the face of ignorance and as such it can reduce ambivalence. This is particularly so in the case of advanced technologies. Seldom do we have full knowledge and often we are aware of the lack of it. We have to trust the competence of others, often even if we are experts, if we want to use technologies. The more often this is the case, the more often do we face situations in which we may trust or not – and be ambivalent as to whether to trust. We may also be either more or less ambivalent in our trust; and though ambivalent, we may still trust to some degree. However, descriptions such as these tell us only a little about what trust is.

Trust

In bioethics, the concept of trust has received more attention than has ambivalence, but it first became a regular topic of theorising in the mid 1980s. Though the theoretical literature of trust in the area of bioethics is still limited, there is an extensive theoretical and empirical literature on trust in non-medical settings. The theoretical literature on trust in medicine is also expanding rapidly (see for example Pellegrino 1991, Veatch 1991, Zaner 1991, DuBose 1995, O’Neill 2002, McLeod 2002).
The phenomenon of trust is familiar to virtually all of us and the human capacity for trust is astonishing. Though whom we trust, what we trust, how much we trust and in what areas we are inclined to trust varies, in everyday life we trust close friends and strangers, persons and abstract systems. We trust our partner to care about us, we trust the bus-driver not to lie about the destination of the bus, we trust money to be a good with which we can buy food in the local store. We may trust in science, in the divine or in nature. We often trust ourselves to be able to do what we plan to do.

Trust, some say, is reliance on the expected but not necessarily existent good will of another person. Trust is an ‘accepted vulnerability to another’s possible but not expected ill will (or lack of good will) toward one’ (Baier 1996:99). This understanding takes interpersonal relations to be a salient feature of trust. Others propose definitions of trust that are open also to trust in abstract systems, such as trust being a ‘confidence in the reliability of a person or system, regarding a given set of outcomes or events, where that confidence expresses a faith in the probity or love of another, or in the correctness of abstract principles’ (Giddens 1990:34).

When defining trust, theorists have taken different routes. Many are those who have started with interpersonal trust and used it as a prototype (McLeod 2002) or confined themselves to interpersonal trust either only (Jones 1996) or primarily (Baier 1996, Pellegrino and Thomasma 1988, 1993). Some have discussed the notion of a basic trust, a spontaneous and unmotivated trust that is indicated by individuals’ will and aspiration to continue to live, crucial to the handling of everyday life events (Kurtén 1995:23-24). The notion of a basic trust has also been discussed in a number of writings on psychological development as a phenomenon crucial to human development. Basic trust is learnt in close caring relations during earlier childhood and from these primary trust relations we can later orient ourselves towards others in other trust relations (Erikson 1950). These approaches have their advantages, but for the present purpose, another route is to be preferred. First, I discuss core conditions of all trust relations that I believe to be common to all kinds of trust. Second, I discuss five different trust relations in which trust takes a specific object: personal trust, system trust, personal-system
merger trust, trust in the non-human and self-trust. When this is done, examples will be taken from the medical context and from the previous empirically oriented chapters.

What Is Trust?

Trust is a mental and social phenomenon. It is, I shall suggest, an attitude that rests on faith in the reliability of someone or something to be of certain kind, to have certain characteristics or to act or function in a certain manner.  

The notion of faith can be understood within the context of religions, but here I mainly use it in a secular context. However, in its theological context, faith has been described as reaching beyond the cognitive domain, or at least as being not only a matter of cognition (Aulén 1967, Kierkegaard 2002 [1846], Ekstrand and Martinson 2004). This is instructive. I take cognitive, emotive and volitional elements to be combined in the phenomenon of faith. They are also combined in the phenomenon of trust. However, faith is also different from trust. Faith, I suggest, need not but may include volitional elements. Such volitional aspects are necessarily present in trust. Faith is also a logical condition for trust and it is, in this sense, prior to trust. If we do not have faith in the reliability of A, we do not trust A. As a consequence, logically speaking, we can have faith without trust, but not trust without faith.

Trust as faith in the reliability of someone or something also accentuates the subjective dimension of trust. The trusted may or may not be reliable, but this is not what matters in trust. The heart of the matter is whether the truster, the person who trusts, has faith in the trusted’s reliability in a certain regard.

Trust Implies Expectations, Feelings and Volition

When we trust, I shall suggest, we expect the trusted to have the abilities required in order to be/do/function in the way we expect her/him/it to. Trust also presupposes that we make some kind of conscious or unconscious value judgement about the trusted on which we base further expectations. We expect something good or desirable when we
trust. We do not expect the trusted to treat us badly, to harm us on purpose or to function in a bad manner. This also distinguishes trust from mere reliance on the predictability of others’ behaviour or reliance on the predictability of functions of systems. We may predict that someone will act badly or even in an evil manner and we may rely on that prediction, but this is not a matter of trust.

When we trust, expectations are also often open-ended. We do not present a list of what exactly we expect of the trusted, but expect her/him/it to be/do/function as is appropriate in the particular context. Furthermore, even if we should try to spell out expectations, there is in most cases a practical limit to what can be spelled out.

In trust, expectations are accompanied by feelings. Trust has ‘its special “feel,”’ as stated by the philosopher Annette Baier, often first acknowledged when lost (Baier 1996:132). When we trust, our expectations are accompanied by a feeling of optimism or security. If we trust a friend to listen to us, not only do we expect her to be able to do so but we also feel positive about her being able to do so. This also distinguishes trust in A from acceptance of A being in a certain way due to a number of beliefs that I hold about A. Such acceptance need not involve a feeling of optimism or security.

Finally, trust has a volitional element. When we trust, we are willing to rely on the trusted. This is a crucial condition for trust. We rely, not trust, in scenarios where we are not willing to rely, but where we feel that we cannot but do so. This being the case, we rely on A, but we do not trust A. When we trust, we are also willing, and inclined, to interpret the trusted in a positive way. In this sense, trust confirms the trusted. It structures our interpretation of the trusted.

*Trust Implies Uncertainty, Reliance and the Risk of Being Let Down*

When we trust, I shall also suggest, we do not have full knowledge. What we trust to be the case need not be so, though we expect it and feel optimistic about it. This cognitive uncertainty is a necessary condition of trust and it is a reason why the described potential ambivalence
lies at the heart of trust relations. It indicates that trust is not only a matter of calculation but also, in the end, a step into the dark. When we trust, we are willing to rely on the trusted, and we do so, in spite of the always-present cognitive uncertainty.

Reliance can be of different kinds. We may take someone’s words to be true and rely on these words when we decide what to do. We may put ourselves or some good that we value in someone else’s hands and rely on the trusted to take care of us or that good. We may also rely on other persons’ abilities to assess a technology in the correct way and trust these persons to do so. In all of these scenarios, an element of exposure to the trusted is implicit. The person or object on whom or which we rely may let us down in our trust; and when trusting, we take this risk. If there was no risk of failure of trust, the element of lack of control would be dissolved, as would trust’s greatness when it is maintained (and its closeness to love).

This is not always straightforward. When we trust, the trusted needs not be aware of our trust and hence not of our reliance and exposure. We may also have misunderstood the trusted, we may have misinterpreted her/him/it. Still, even if we trust under those circumstances, we do rely on the trusted. As in any such relation, we become vulnerable.

When we trust, we have faith in the reliability of the trusted, we are willing to and we do rely on the trusted. Though trust can lessen our vulnerability in a psychological sense, we may also, when trusting, incur vulnerability by entering into relations of trust where we may be let down (McLeod 2002:61).

**Trust is Relational**

Trust is relational in the sense that it always, conceptually, takes an object. There is no trust if there is no object of trust. Trust relations can also be qualified with regard to in what respect we trust the trusted (and in what domain). This can be put in a formula as follows:

A trusts B in respect C only if A has faith in the reliability of B, A is willing to rely on B and A does rely on B in respect C, where ‘B’ are
persons with whom A has personal relations or non-personal relations, institutions, collectives, human-made things, science, the divine, ourselves (and so on) and ‘C’ are behaviours, acts, characteristics and functions of B.

The formula indicates that what matters is not the actual character of the trusted, but how the truster perceives and interprets the trusted. 9

Trust also stands in causal relations. More precisely, it is learnt in social relations. From childhood, we learn to trust and/or not to trust, and there are complex psychological processes involved in this learning.10 There is also a causal relation between my interpretations of previous experiences and my present trust. Some hold there to be a difference between trust in certain things and in persons, where trust in things is a priori in the sense that it is based on assessments of pre-given properties and trust in persons is a posteriori in the sense that it is based on previous experiences of encounters with that person (Potter 2002). However, no matter what or who we trust, our own previous experiences or those told by others, are important. In this sense, someone’s trust is dependent on her or his interpretation of previous experiences. This does not mean that we necessarily trust others when or because they have previously proven reliable. We also sometimes trust others who have proven unreliable. In the philosopher Onora O’Neill’s words (2002:14), trust is ‘given, built and conferred, refused and withdrawn, in ways that go beyond or fall short of that evidence [of past reliability].’ Still, trust often extends over time; it is both retrospective and prospective. Though what or who we trust differs, trust starts in interpretations of the previous and the present and projects us into the future.

Finally, trust is dynamic and not static; trust may be built and destroyed, rebuilt and changed. It can be domain-specific and it is graded. It may be conscious or unconscious on the part of the truster and it may be unwanted. I take trust to be sometimes reflected and sometimes unreflected, sometimes well-founded and sometimes ill-founded. Trust relations may also be one-, two- or multiple-way relations.

If these threads of trust are taken together,
A trusts B in respect C if and only if
A has faith in the reliability of B in respect C,
when A expects B to be or do C but where this is not certain,
when A expect something good or desirable of B,
when A's expectations are accompanied by A's feeling of optimism
or safety (at least at a minimal level),
when A is willing to rely on B and does rely on B and
when A accepts the risk of being let down.

Finally, in order to trust, we need to have the ability and the opportunity to do so. These are prerequisites for trust in general. Depending on what the object of trust is, different trust relations have their own characteristics in terms of, for example, what we expect when we trust.

When Trust Fades or Fails

We may trust even if others tell us not to and even if they explain why we should not. We may also trust and confess to ourselves that the trusted is not trustworthy in general, nor has the trusted proven trustworthy in the particular domain in which we now trust her or him or it. We still trust. We expect the trusted to be trustworthy on this one occasion. Still, certain experiences and expectations may be more difficult to reconcile with trust.11

If my trust fades, I have once trusted. If my trust fails, I need not have started to trust – my trust never comes about. If personal trust fades, I do not trust this specific person, but my trust in other persons may still be intact.

Personal Trust

Relations between children and parents, between lovers and between friends are typical examples of relations in which personal trust can flourish. Personal trust presupposes personal relations. As I characterise it, it is a trust in people based on their personal qualities and characters and on the fact that the truster and the trusted stand in a personal
relation. In the medical settings, which are the settings that I will focus on here and from which I will take the examples, such trust relations can be present between a woman and man who visit an IVF clinic together.

Some theorists use the notion of interpersonal trust as the label for any trust relation between human beings, independently of whether the truster and the trusted have a personal relation (McLeod 2002, O’Neill 2002). I take this to be unfortunate, since relations with persons with whom we have a personal relation and relations with persons with whom we have an impersonal relation have different characteristics. Instead, I shall suggest, trust in professionals can be a version of system trust, such as a trust in the system of education of professionals or a trust in professionals’ acting in accordance with their professional roles, or it can be an example of a ‘merger’ between personal trust and system trust (to be discussed). This being the case, trust in professionals does not qualify as personal trust, as I use the notion.

Following the previous characteristics of core conditions of all trust relations, when we trust in personal trust relations, we expect the trusted to have the abilities necessary for what we trust the trusted to be or do. We also make some kind of conscious or unconscious value judgement about the trusted, and we expect something good or desirable when we trust. We expect, I believe, the trusted to have good will or probity vis-à-vis us or love for us (Baier 1996, Giddens 1990). Some theorist suggest that what we expect is not good will but moral integrity. We expect those we trust to act on what they take to be ‘the best moral reasons for everyone to act’ (McLeod 2002:26). However, this is a problematic and, I believe, misleading criterion for trust.

Imagine that I ask a close friend to show some students around at the University while I am away during the holidays. She says she certainly will do so and I trust her. Or imagine that I trust my partner to care for me when I have the flu. In such cases, why should I expect my close friend or partner to act on the basis of what they take to be the best universalisable moral reason instead of expecting them to act on the basis of their good will towards me? The reason, the philosopher Carolyn McLeod says, is that expected good will is not a relevant con-
dition for trust since we can trust people ‘without expecting them to have kindly feelings for us’ and especially so ‘when we trust them without expecting them to show specific concern’ for us (2002:21). This, I suggest, can certainly be the case in impersonal trust relations; it is not the case in personal trust relations. I believe McLeod’s reasoning to build on confusion between conditions for trust in persons with whom we have a personal relation and trust in those with whom we do not have a personal relation. Hence, a distinction needs to be made between these two kinds of trust relations.

We certainly trust some people without expecting good will and without expecting them to show specific concern for us, but we do so when we do not have a personal relation to them. This is often so in the doctor-patient case (which is also the case that McLeod takes as an example to make her point). However, in the case of personal trust relations, we do expect the trusted to have good will towards us and to show a special concern for us particularly since we have a personal relation with the trusted. We expect our partner to treat us differently from just anyone and we expect him or her to care for us in a different sense than if we were just anyone. We also expect this to be the case with friends, children or parents. 12

McLeod also explains that we, when we trust, expect there to be some similarities between what the trusted and we ourselves stand for. If this is not the case, our trust may fade. Again, I disagree. We need not expect similarities. What matters is that, if we expect the trusted to have a (more or less correct) idea of values that we hold, we do expect the trusted to respect these values that may be different and at least not to act contrary to them. This also clarifies that expected good will is a crucial, but still not sufficient criterion for trust. Someone may act out of good will towards us, but her or his idea of what is good may be contrary to what we consider good; given our values, her or his idea of good may be many things – but not good. 13

Hence, in personal trust relations between adults who are (more or less) equals, what we expect is not only good will. We expect the substantive content of the trusted’s good will to be guided, shaped and limited by certain values that, as a minimum, are not contrary to our own
values or, if they are contrary to our own, we expect the trusted not to act on them against our will. We do this consciously or unconsciously and for good or bad reasons.

Finally, when we trust our expectations are accompanied by a feeling of optimism or security, and we are willing to and do rely on the trusted, though we can always be let down.

Personal trust could be discussed in empirical studies that focus on interaction between patients, as is typically the case when it comes to reproductive genetics, or between close friends who have a personal relation and who trust each other on the basis of personal qualifications. In the previous chapters, the topic of personal trust relations was mainly present in indirect questions, rhetorically put by the interviewees concerning how the relation between the woman and man (a possible personal trust relation) who underwent IVF and PGD was influenced by their experiences.

System Trust

System trust is sometimes labelled general, institutional or social trust. It is present when we trust social institutions, abstract systems or collectives or when we trust representatives or products of these institutions, systems or collectives (Giddens 1990, 1991). All these system trust relations are impersonal. Even if the trusted is a professional who represents a system, we do not trust her or him because of any personal qualities, nor do we have a personal relation with the trusted. Still, a system trust relation implies expectations, feelings and volition, as suggested in the description of core elements of all trust relations. Likewise, it implies uncertainties, reliance and the risk of being let down.

It has been held that system trust relations are a response to the complexity of modern societies, in which a number of interdependent transactions between social actors take place and this across time distances and large, geographical space (Giddens 1990). In this situation, some suggest that institutions act as the foundation of trust as a property of the overall social system and as a guarantee of trust in repre-
sentatives of the system (Misztal 1996). In the specific field of medicine, some suggest that there is an increased disillusionment with medicine and at the same time an increased dependence upon it as a provider of answers to medical and social problems (Lupton 1994) that may causes ‘lay’ people to be ambivalent towards medicine – and that such ‘lay’ ambivalence may be aggravated by an erosion of trust in the health-care system. However, in the UK, it has also been shown that the public retains greater trust in doctors than in any other group (MORI 2001, 2002).

The empirical question of whether and to what extent such erosion of trust is underway or already present will not be discussed here. Instead, empirical examples from the previous chapters will be used in a discussion of four kinds of system trust: trust in systems, trust in products of systems, trust in representatives of systems and trust in users of systems.

**Trust in Systems**

If we trust a system, for example the health-care system, I suggest that we expect it to function in accordance with and for the fulfilment of certain agreed goals and purposes – though these may be general and also vague. We expect the particular system of health-care to function for some good of the patient, such as treatment of disease and/or restored health. This indicates one difference and one similarity between personal and system trust relations. In personal trust relations as I have characterised them, we expect good will on the part of the trusted. We also expect the substantive content of the trusted’s good will to be guided, shaped and limited by certain values that are, as a minimum, not contrary to our own values. If they are, we expect the trusted not to act on them. In system trust relations, there need be no agent capable of having good will. Still, I suggest, we expect the health-care system to function (more or less well) in accordance with certain agreed goals and purposes. These goals and purposes are underpinned by certain values, and, if we trust this particular system we expect it to be guided by values that are, at least, not contrary to values that we hold. This view can be underpinned by empirical research that indicates a causal relation between trust in institutions and expected shared values. It has
been argued that if we expect a certain system to promote values we hold or if we expect the constructors of a system to share our values, system trust is more likely to be present than if we do not harbour these expectations. If we trust the health-care system, we also feel positive about our expectations.

Some empirical examples can now be discussed. What if we expect a certain medical unit to have an understanding of what the purpose of reproductive medicine should be, which we don’t share? What if we, as did a few of the interviewees, expect other medical units to offer or use technologies in ways that we consider morally problematic? Are these examples of trust relations that fade or, possibly, fail? The distinction between trust and mere reliance on the predictability of someone’s behaviour is helpful in this regard. If we trust, we expect something good or desirable and expectations are accompanied by a feeling of optimism or security. If we rely on someone’s predictability we need not expect something good or desirable, nor need reliance be accompanied by a feeling of optimism or security. Therefore, if we expect others to offer morally problematic technologies or offer technologies for morally problematic purposes, we do not expect something that we consider to be good, and we do not trust. We only rely on a certain predictability.

System trust can also be exemplified with trust in ‘society’ and trust in society may be concretised through trust in different societal institutions or bodies, such as legal bodies. Again, some of the previous empirical examples are helpful in this discussion. If we expect society’s legal bodies to be able to regulate the use of certain technologies, if we feel positive about this expectation, if we are willing to and do rely on the legal bodies to exercise such regulation, even if this is not certain, we may trust the system. Though one interviewee emphasised that legal bodies did regulate practice and that practice was responsible and morally thought-through, not all interviewees seemed to trust the system. Some seemed either to be ambivalent in their trust or trust was fading (or failing). As seen, one interviewee said she wondered if present-day society was mature in the sense of being capable of drawing and maintaining moral boundaries.
Trust in System Products

Another version of system trust is trust in products of the system. If the system is the health-care system, its products are, among other things, medical technologies. What expectations do we have if we trust such technologies? Probably, I suggest, we expect the technologies to function as intended by their constructors and as is desirable in the particular context. We also expect them to be constructed on the basis of accurate technical knowledge and to be used for the good of the patient in the reaching an agreed goal. In the case of PGD, such an agreed goal could be to try to make as sure as possible that embryos implanted in a particular woman’s uterus do not have a particular genetic disease.

There is also a difference between trust in systems as described above and trust in products of systems. If I am hesitant as to whether the medical system is underpinned or guided by a set of values that I share, my trust may fail or, if present, fade. If I trust the use of a certain technology, I may do so even if I believe that it is constructed by someone with values that are contrary to mine. Or, at least, I may do so if I don’t expect the constructor’s values to have made her or him careless in the construction of the technology.

What about expected technical safety and accuracy? As has been seen, many of the interviewees described the lack of technical safety as the major reason why germ-line gene therapy should not be allowed. Several of them stated that technologies used in IVF/PGD were not as safe as they should be, ideally. Interviewees also said that PGD did not always function as intended, i.e. it did not result in the birth of a child without a particular genetic disease and this for various reasons. However, whereas lack of technical safety and accuracy and lack of desired result can result in the fading or failure of trust, it need not do so. Even though the woman and man concerned know that around 15-20 per cent of the IVF cycles started result in the birth of a living child when IVF and PGD are combined (Lavery et al 2002) they may still trust that the technology will be used in an accurate way. Furthermore, in some situations, as when someone has had an accident and is attached to a respiration-sustaining machine, the truster typically trust a number of advanced technologies and often without reflecting upon it.
In the case of PGD, and in any planned use of a technology, such reflection is possible to another extent than at the emergency unit.

As regards interviewees’ possible trust in the use of medical technologies trust can but need not be the issue. Rather, some interviewees predicted – and, in their reasoning, relied on the prediction – that success rates could be low. Such was the case when some interviewees said they knew technologies would fail, in the sense that the use of them would not result in the birth of a child without a particular genetic disease, in 80 per cent of cases.

Finally, if we trust in the use of a technology, we expect that there is someone who knows how to use it and we feel positive about this expectation. In this sense, as long as we cannot use a certain trusted technology by ourselves, the discussion of trust in the use of technologies should also contain a discussion of trust in the professionals who offer them.

**Trust in Representatives of Systems**

Medical professionals are representatives of health-care systems. When we trust professionals, we can trust ‘in the system of education, credentialing, and the processes of licensure’ (Pellegrino and Thomasma 1993:68). We can also trust professionals to act in accordance with their professional roles in a defined area, and conditions for trust are guided by what we expect of someone in her or his professional role. Here, we trust in spite of having little or no idea of their personal qualities, as is the case if we trust medical professionals the first time we meet them.

If we trust professionals to act in accordance with their professional roles in a particular medical context, we most likely expect the trusted to have correct and relevant knowledge with regard to what their tasks are. As part of the professional roles, we also expect them to act with our best in mind, and we either expect that their idea of what the best is for us is not contrary to ours or if it is contrary to ours, we – again as part of the role of medical professionals – expect the trusted not to act on values that are contrary to our own. Or, at least, such is the case in a context where paternalistic acts are not accepted as part of the medi-

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cal professionals’ role. This indicates the context-sensitivity of expectations in trust relations. Furthermore, as part of the professional role, we expect the trusted to act in accordance with the goals of the healthcare system.¹⁹

Some of these expectations were commented upon in the empirical data, as when some interviewees wondered if certain colleagues working at PGD units did not have a ‘vested interest in encouraging people’ into that practice, or when some of them wondered if technologies were not offered ‘for the money.’ These reflections focused on behaviours that were not consistent with a certain professional role. A distinction must be made between trust in professionals and the possible trust in successful treatment based on technologies. As has been seen in the previous chapter, a woman who had undergone different reproductive treatments explained that she trusted that the professionals had done their best. Still, the treatments failed in the sense that they did not accomplish what was hoped for.

Trust in representatives of systems is at the heart of studies of trust in the medical profession (Pellegrino 1991; Hall et al. 2002). Lack of trust in professionals is also articulated in certain disability movement writing on genetics, as analysed by the sociologist Tom Shakespeare (1999).²⁰ Less often is the focus on health-care system representatives’ trust in their fellow-health-care representatives. As a general rule, the more distant and undefined colleagues were, the more frequently did interviewees articulate doubts about whether others would develop, offer and use technologies in ethically acceptable ways/for ethically acceptable purposes (the exception being the Italian interviewees).

In the discussion of medical professionals as experts, a distinction can be made between medical professionals and lay-people and also between medical professionals with a particular competence in a certain field or with regard to a certain technologies and medical professionals in general. A distinction can also be made between professionals who work in clinical settings and professionals in research; their roles are different, as is, probably, what we expect of them when we trust them. In all of these cases, if the truster trusts the trusted, the truster expects the trusted to have the requisite knowledge to do what

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the trusted is trusted to do. This was also what one interviewee doubted was the case, as when he said he wondered if colleagues knew about recent developments in prenatal and neonatal surgery.

Some interviewees also questioned whether certain colleagues shared their interpretation of what were acceptable means in reaching a particular goal; a few stated that such was not the case. One interviewee, for example, stated that the birth of healthy children was desirable but that she considered sex-selection for medical reasons to be common, technically easy and questionable. She also said she knew that some of her colleagues did not share her view. Another interviewee described all selections in PGD as, in principle, morally problematic since embryos were disposed of on the basis of genetic knowledge. Other interviewees said that they considered embryo disposal as such to be morally questionable – but they knew that some colleagues did not share their view. If these situations qualify as trust relations where trust is fading or as ambiguous trust relations, this presupposes that medical professionals have expected something good, have been willing to rely and have relied on the trusted colleagues in a certain regard. If not, these are not examples of trust, distrust or ambivalence in trust. If so, professionals just rely on the predictability of someone else, a colleague, acting in what they consider to be a morally questionable way.

Trust in Users of the System

It has been suggested that medical professionals’ trust in patients lays the foundation for relations in the clinical encounter. It has also been suggested that ‘the burdens of misplaced trust’ fall heavier upon patients than upon doctors (Rogers 2002:80). Therefore, it has been stated, though there may be good reason for medical professionals not to trust all patients, medical professionals should direct their attention towards trusting patients (Rogers 2002). Arguably, this may be easier if the professional and patient have met before, but what I discuss here are trust relations where professionals trust patients not on the basis of personal qualities, nor have they a personal relation with them. In this sense, trust in users of the system as I characterise it has certain similarities with trust in representatives of the system.
As a start, if professionals trust patients in the clinical encounter, they most likely expect patients to be seeking medical care. Professionals also expect patients to give more or less accurate descriptions of their experiences of the problem (Rogers 2002:78) as part of their patient role.

This can be further complicated. As we have seen, in the UK PGD context the medical professionals have a duty to consider and act for the welfare of the child. What if a couple have an idea of what is best for them, and for the future child, which professionals do not share – such as sex selection or implantation of affected embryos as described in the previous empirical chapters? Or, what if professionals expect certain patients to have a different understanding of the meaning of reproduction, as put by one interviewee when she described uses of in vitro fertilisation by women aged 60 or more? What if these patients then state that professionals should help them in acting for what is best for them, as they see it? As has been seen, such was the case in situations where interviewees described women and men at risk for a certain genetic disease saying that they had a right to use the technology – and a right to receive treatment from the professionals. What is probable, I suggest, is that if professionals expect certain patients to want to use or not to use technologies in ways the professionals consider to be contrary to the goals and purposes of the health-care system or in ways that promote values that they consider problematic, their trust will fade or fail.

Arguably, since trust is a matter of degree, certain problematic uses may be compatible with trust. There is also probably a limit to it. A distinction can be made between on the one hand situations in which professionals expect patients to want to use or to use technologies in what they consider to be problematic ways, and on the other hand where patients are expected to want to and, if given the possibility, misuse technologies. In the latter situations, trust is likely fading. As before, if professionals rely on the prediction that this is always the case with a certain group of people, this is not a matter of trust.

If professionals trust patients, they also feel positive about the expectations, are willing to rely and do rely on the trusted in these regards.
Personal trust and system trust relations are different, but on some occasions they merge. In my view, such merger scenarios are worthy of note since they explain why all forms of interpersonal trust cannot be brought together under one umbrella term without confusion.

As an example, if a couple at an IVF and PGD clinic meet a certain medical professional for the first time, and if they trust this professional, they do so without knowing her or him. They have no previous experience of the professional as a person. This is trust in representatives of the system. However, if they get to know the particular professional, they may trust her or him as a professional and as a person. They do not only trust her or him as they trust any friend or neighbour that they may have, nor do they only trust her or him as they trust any professional. They trust the professional partly because they know her/him on a personal basis and partly because of her/his professional role. This is the merger scenario. The same also applies for the professional’s trust in patients, whom the professional trust partly because s/he knows them on a personal basis and partly because of their patient role.

The dual character of merger scenarios has implications for what we expect of the trusted. As in trust relations with unknown professionals, we expect the trusted to act professionally, to have relevant abilities or competencies, to have the intention to fulfil the role and to act in accordance with the goals of medicine. We also expect good will towards us; as has been seen, this was not the case in system trust.

If this reasoning is accepted, nuances between different kinds of doctor-patient trust relations can be explored. The lack of a distinction between personal trust relations, system trust relations and the merger scenarios may also be one reason why an expected good will has been so much questioned in the discussion of trust in medicine.22 Let me turn to two of the criticisms of good will as a condition for trust between doctors and patients.

First, when we are ill, what matters is not that a medical professional has good will, but that s/he has the relevant knowledge. If we suspect that the professional does not have this knowledge, our trust is
likely to fade or disappear (O’Neill 2002). Second, we can have more trust in a medical professional who shows no good will towards us but who acts in accordance with ethical principles that we support, and especially so if we expect and feel that the results of this person’s actions come closer to what we want than do the results of the actions of the one who has good will towards us (McLeod 2002). Since this is the case, these theorists conclude, good will is not necessary in the trust relation between medical professionals and patients. It is not necessary in interpersonal trust.

These remarks are accurate in the case of system trust relations involving representatives of the system, I hold, but not in the merger scenarios. If we trust the professional partly as a person with whom we have a personal trust relation, our trust will fade if we do not expect the trusted to have good will towards us. Hence, using doctor-patient relations in a sweeping manner and drawing conclusions concerning all person-to-person relations is unfortunate.

Some argue that system trust in medicine is not enough, since we ‘expect to open the most private of domains of our bodies, minds, and social and familial relationships to her [the professional’s] probing gaze’ and ‘our vices, foibles and weaknesses will be exposed to a stranger’ (Pellegrino and Thomasma 1993:68). If this is correct, it is also a reason why mergers occur. We need to trust in the ‘person of the physician’ – in her or his personality and character – but we always also need to trust her or him as a professional. Doctor-patient relations constitute the typical example of merger scenarios, but mergers are also present when we trust colleagues at work both on a personal basis and on the basis of their professional training. Such could be the case when some interviewees brought up the topic of how thoughtful and responsible the medical team that they participated in were. Some interviewees described situations that emphasised that they and their colleagues knew what they were doing, i.e. they had relevant medical knowledge and they cared for their patients. Given these descriptions, some of the major conditions for trust were met.

Other interviewees described scenarios that called for a more cautious understanding of fellow-experts and of whether conditions for
trust were met. Some interviewees questioned whether colleagues understood what topics women and men wanted to discuss, whether certain close colleagues understood that to bring up certain issues for discussion may be intrusive and an ‘invasion of the last bastion of personal life.’

**Trust in the Non-Human**

The topic of nature was present where interviewees questioned technologies as well as where selection in PGD was described as morally acceptable. It was also present when interviewees stated that ‘Mother Nature’ knew best and that we, as human beings, should be cautious and not ‘mess around’ with genetic material. These views can be interpreted symbolically and need not centre on the actual ability of nature, nor on trust in nature’s ability in a certain regard. Similarly, the language of playing God was symbolic; one interviewee explicitly explained that she didn’t ‘mean it literally, I don’t refer to any theology.’ Instead, these referrals to nature and God indicated either ambivalence about whether to trust that humans were able to, and indeed should, intervene in the human genome or the view that such ability was lacking and that intervention in the human genome should not take place.

A trust in nature or in the divine has been empirically explored in the work of Scandinavian lifeview researchers, and their studies indicate that people value nature and that they regard it as a whole: no part of it should be lost, every organism has its function (Uddenberg 2000:23-25, 1998); or that nature provides them with moments of rest and devotion (Kurtén 1995:38-41). However, whereas we may value nature without trusting it, trust may be an issue for those who hold that it is not the task of human beings to alter the balance in nature; nature is able to take care of itself. For these people, this may be a matter of trust in nature’s ability.

In the previous empirical chapters, one interviewee described a conviction that resembled a belief in fate. The interviewee laughed and said he was superstitious, but he had the conviction and the feeling that the embryo that he, in the end, implanted was the one that ‘was always
going to be,’ as was the particular child born after IVF and PGD. Though he and his colleagues worked with the purpose of selecting a particular embryo without a specific genetic disease and though they did not know beforehand which one to implant, the children that were not born were ‘never going to be, somehow.’ This reasoning implied the idea of some kind of predestination or fate. Such fate is also different from fatalism in the sense that fatalism implies the idea that control should be rejected but fate need not do so. We may, as explained by the interviewee, decide what embryo to implant, but what eventually happens, i.e. which embryo we implant, was going to happen anyway. Such ideas have, interestingly, not disappeared in modern societies (Giddens 1990).

Can we trust fate? As part of the general characterisation of trust I stated that trust always takes an object, which means that if fate is an object we can trust it. Such was the case among the Romans and the Ancient Greeks. Fate was personified. More common in our time is the understanding of fate as a set of rules or principles or the randomness that guides human lives. Here, fate is an object. This being so, we can trust it. If we do, we have certain expectations, feelings and a volition as in any trust relation. However, though the risk of being let down can be present also if we trust fate, it may be difficult to know if we are let down when trusting fate: if we trust that what happens should happen it becomes difficult to realise that we have been let down if we should so be. We may also interpret fate as a metaphorical way of describing human conditions, and if so, we do not trust fate (fate is not an object of trust).

Clearly, objects of trust in the non-human vary. So also do expectations that we have when trusting the non-human. They vary depending on what the object is and, among other things, on how personal/impersonal we take the trusted to be.

If we trust nature, we expect there to be principles that guide biology in its different forms, and we expect nature to be guided by these principles in an accurate and desirable way. If we trust impersonal fate, we trust fate to make sure that what should happen also happens, be it good or bad.

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Just as any form of trust influences our willingness to rely on the trusted, trust in the non-human can dispose us to certain behaviours and interpretations, though in no straightforward manner. The interviewee who said that nature knew best and not humans was hesitant when it came to interventions such as PGD but less hesitant with regard to germ-line gene therapy, and the interviewee who talked of fate was positive about PGD and less so about germ-line gene therapy.

Self-Trust

Self-trust is the last example of trust relations to be addressed in this chapter, and it relates back to the earlier discussion of choice and autonomous choice. Minimal self-trust, I have argued, is important to decision-making. Self-trust implies that I expect that I am able to do what I trust myself to do and that I feel optimistic about it. Self-trust also implies, necessarily, that I have an expected special concern for myself. I care about what I do or how I am in a different sense than if I was just anyone, and the special concern also results in an expected good will towards myself. Self-trust is different from any other form of trust since, in self-trust, the subject is also the object. The truster is the trusted. As a consequence, expected shared values (compare personal or system trust) becomes redundant.

A distinction can be made between situations where we have a certain ability but a particular task is still difficult, situations where we lose our ability to perform the task and situations where we lose trust in our ability in a particular regard. When interviewees described difficulties in discerning what relevant genetic information was, even though they had been trained in this respect, such difficulties were of the first kind. It did not imply, and certainly not necessarily, a fading trust in the ability. However, such can also be the case. The topic of the self’s ability to engage in a certain reflection was also present in the previous chapters, in particular where interviewees were self-critical. One interviewee questioned whether he did reflect on his own values and how these changed in the course of the work. This was ‘insidious,’
as he put it: his perceptions changed without him noticing it. In this case, the interviewee doubted his ability to see clearly and to get the necessary distance to what happened in the field, when working in this area. Again, this need not imply a fading self-trust as regards this particular reflection; it implies only that this ability can be difficult to exercise or that, possibly, the ability is lost, to some degree, in the particular PGD context. However, other empirical research has indicated that some women who undergo IVF experience a loss of self-trust. These women interpret their bodies in a certain way, but their experiences are questioned by medical professionals to the extent that women feel upset and frustrated, eventually doubting that they did experience what they thought they experienced. They lose trust in their ability to interpret their bodies correctly (McLeod 2002).

I take self-trust to be important in medicine, no matter if we are patients or professionals. Loss of it is also a particularly serious form of loss since self-trust is important for human interaction in a more basic sense than many other forms of trust. Minimal self-trust is important for personal identity: it is present when we reflect on who we are, it is present when we interpret and describe experiences that we have had, it is present when we remember years that have gone and when we make plans for the future. When so doing, we trust that we are able to do these things – we trust that we remember, interpret, reflect etc. more or less correctly. Self-trust, Trudy Govier says, is most obviously relevant when one’s capacities, judgements, motivations and actions either are questioned or are at issue (1993:106). This can be the case in medicine as in many other areas.

Does the Phenomenon of Trust in Medical Settings Matter?

On the one hand, interviewees’ concerns that others would develop, offer and use technologies in morally questionable ways or for morally questionable purposes and the possible ambivalence in trust of this ‘other’ in these particular respects should not be surprising. In a field as
complicated as biotechnology and in which many interests can conflict, it would be more surprising and conspicuous if no such concern was expressed. Who could trust that technologies will not be misused, somewhere and by someone? On the other hand, keeping in mind that what is sometimes described as ‘the problem’ in the ethics of gene technologies is lack of trust on the part of the public, professionals’ ambivalence concerning whether to trust others with regard to the correct use of such technologies is not a banal topic. Furthermore, experts’ ambivalence towards gene technologies is seldom discussed. As a counterpart to studies of lay-people’s perception, experts’ ambivalence concerning whether to trust is interesting since it indicates that trust is not obtained in any simple way by means of more or better technical knowledge. Lack of (medical/technical) knowledge can hardly be said to be the reason for the ambivalence in trust revealed in this study since the interviewees were medical experts.

The importance of trust between doctors and patients has been explained in terms of effective treatment (Axelrod and Goold 2000) and patients’ willingness to seek care and to follow advice (Hall et al 2002). In these kinds of reasoning, trust is understood as important for what it contributes to: patient compliance. Trust, however, is not a simple matter of choice and decision. I may choose to act as if I trusted someone, I may choose to put myself in circumstances where I believe that my trust will be enhanced, I may also reflect on the lack of it, I may state that I have little reason not to trust (or to trust), but if trust comes about it is not the result of a simple decision to trust.28

Some argue that trust is not needed in medical practice and that we can make do with explicit contracts instead. I take this to build partly on a misunderstanding. Contracts also presuppose a certain level of trust: a trust that the contract will be adhered to.29 As argued by Anette Baier, in a discussion of relations between adults and children, the more we ignore dependency relations between the grossly unequal in power and ignore what cannot be spelled out in an explicit acknowledgement, the more readily will we assume that everything that needs to be understood about trust and trustworthiness can be grasped by looking at the morality of contract. (Baier 1996:106)
It takes more or less equal adults to make a contract. Within the contract, not only is an equality of power presupposed but also, Baier argues, a ‘natural separateness from others.’ Implying no other similarities between adult-child relations and medical staff-patient relations, both situations present power inequalities and what may be called a necessary dependence on others.

Trust can be very important in social interaction, in medicine or elsewhere. In medicine, it is sometimes described as unavoidable or ineradicable (Zaner 1991:49, Pellegrino 1991:69). However, this may be a reason for concern if we consider there, at occasion, to be good reason not to trust.30
How can the results of this study be summarised? And, are there any possible difficulties with the combination of analytic approaches that need to be discussed? These questions are addressed in the first section of this concluding chapter. In the second section I return to the concept Grenzsituationen, a concept elaborated upon by Thielicke (1964) and briefly discussed at the beginning of this book. There, I suggested that PGD and GLGT did imply such border-line situations in which what we previously had held to be impossible was no longer so, calling for a (re-)examination of what we may have considered well-established and/or taken-for-granted moral boundaries. In what sense this is the case will now be explored. PGD and GLGT, I will show, result in new ways to perform old practice and new practice. PGD and GLGT also evoke old and new moral questions. In the exploration of these matters, I will point to certain questions in need of further analysis.

Summary

The Theoretical and Methodological Framework

As described in chapter two, the framework’s key concepts were moral perception, concrete others, ethics, morality, empirical ethics and bioethics. Moral perception, I said, causes us to perceive some issues as moral issues, some situations as moral situations and other situations as morally important situations. The question of how to understand what issues others perceive as moral issues, I also said in chapter two, can be further explored by being related to the discussion concerning the generalised other versus the concrete other (Benhabib 1992:178-
If the generalised other is the other human being to whom I can generalise starting in my own experiences, the concrete other is necessarily distinct and different from me without, however, being completely other. The concrete others’ distinctiveness matters for her or his moral perception, for what she or he perceives – and for what I perceive in terms of morality. This is an important element of the framework. Concrete others, with experience from within a certain practice, can perceive moral complexities and nuances from within that practice in a different sense than I can, as a researcher with no such experience. This makes it important to analyse concrete others’ reflections if the morality of a particular practice is to be understood. This in turn, I have argued in chapter two, is important if the gap between theory and practice is to be bridged.

As is commonly done in ethics, I distinguished between ethics and morality; ethics was understood as the systematic analysis of morality. Empirical ethics, I also said in the second chapter, is conducted when empirical research concerning moral issues is combined with a philosophical or theological analysis of these issues. I characterised bioethics as the analysis of moral issues evoked by new biological knowledge and applications, in medicine and elsewhere, in a wide sense. Hence empirical ethics clarifies what kinds of analyses are performed whereas bioethics clarifies what kind of moral issues are addressed.

As parts of the framework I also characterised the project’s objects for study, also called moral constituents. Morally relevant life interpretations were interpretations of how human life is and should be, interpretations of the meaning(s) of life, of what are important ways of handling difficulties in life that are not necessarily moral but that clarify why something is seen as morally relevant and/or as evoking moral questions. Morally relevant life interpretations also included interpretations of notions that were not typical moral notions but that had moral implications and that contributed to the understanding of how human life is or ought to be. Other objects of study were norms, i.e. prescribed guides for conduct or patterns of normatively governed behaviour and values, i.e. things that are considered or described as
worth having, getting, acting for, since they are considered valuable for their own sake or as a means to something else. Whereas norms and values are very common objects of study in ethics, moral experiences are not yet so. *Moral experience*, I stated in chapter two, was the experience of consciously choosing, of consciously approving or disapproving of actions or states of affairs. It was also the experience of a changed life situation whereby I engage in reflection on, exploration and evaluation of the moral aspects of that situation.

Finally, these objects of study could be articulated in many ways; in arguments for or against a certain phenomenon, in narratives etc. The emphasis on concrete others’ moral perception also mattered for the choice of methods. Qualitative interviews and qualitative analysis of the data allowed the exploration of complex moral practices and moral aspects of uses of PGD and GLGT, as described by the interviewees. A philosophical, conceptual analysis of concepts that were discerned as central in the qualitative analysis allowed a systematic discussion of some of the empirical results.

**Main Empirical Findings**

The main findings in the empirically oriented chapters, i.e. chapter three to chapter six, can be summarised as follows. Interviewees described how a medical progression took place through the development of, in different senses, better technologies. In doing so, some of them told *narratives of progress*. Some interviewees also told *narratives of life with genetic disease* that indicated that such a life could be tragic and painful. In some of these narratives, there was hope articulated in the language of choice: some couples could choose to use PGD in order to avoid implantation of embryos with a particular genetic disease. Interviewees also told four kinds of *narratives of concern*. The first kind of these narratives highlighted interviewees’ concern about the difficulty in defining and evaluating genetic disease as well as quality of life. The second and third kind of narrative of concern focused on whether women and men had choices in the sense that interviewees said ought to be the case. Interviewees told narratives that indicated
their concern that medical, epistemological and technology-derived risks were not clarified to the extent that they thought should be the case. They also told narratives of complicating circumstances in concrete situations of choice. They were concerned about perceived pressures on women and men as regard their choices as well as about perceived pressures on medical professionals’ choices in this area. Finally, and as a fourth kind of narrative of concern, interviewees told narratives that highlighted their concerns with uses that went beyond a certain perceived boundary – exaggerated uses and misuses. Such concern was also articulated in discussions in which no narratives were told.

As said in the interlude, what the interviewees were concerned about and the reasons for their concern varied. Still, many of them articulated hesitancy, concern or worry with regard to certain present or potential uses of the technologies. They expressed ambivalence concerning whether to trust that others would develop, offer or use technologies in morally acceptable/desirable ways or for morally acceptable/desirable purposes. The ‘others’ included fellow-experts, society, some patients and some philosophers.

It is noteworthy that even though interviewees described uses that should not take place but that they thought might take place or uses that had taken place even though they should not have taken place, many of them were hesitant in their evaluations of whether – and, if so, to what extent – exaggerated uses or misuses were morally problematic. They articulated ambivalence in discussions of PGD, concerning how to interpret, describe and evaluate the uses of it; this was much less so in discussions of germ-line gene therapy.

Another way to summarise the main findings of the empirical data is to point to the main moral constituents: values, norms, morally relevant life interpretations and moral experiences. Interviewees articulated the value of parenthood, in particular the value of biological parenthood. They also emphasised the value of minimising distress for couples who were at risk for a particular genetic disease, and the value of having something more than prenatal diagnosis to offer to these couples. Though genetic disease was sometimes described as something that it was good not to have, other things being equal, interviewees were
careful to describe the possibility of avoiding certain genetic diseases as important, not avoidance of genetic disease as such. Following this logic, the value of choice for women and men at risk for a particular genetic disease was much emphasised.

As regards norms, interviewees’ reflections included the norm of wanting to have children. Choice provision was another norm – couples should be given choice, within certain limits – as was the norm of a present and prospective professional responsibility for uses of PGD. In discussions of some uses of technologies that possibly went beyond a particular boundary, interviewees also articulated the norm of the natural. The natural, in the sense of what took place in nature, was used as a model and a prescribed guide of conduct, in arguments for PGD as well as in arguments against PGD.

Interviewees’ reflections also included morally relevant life interpretations, most clearly articulated in the discussion of embryos, in the discussion of life with genetic disease and in the discussion of uses that went beyond the boundary of the desirable or acceptable. One of the interviewee, for example, stated that human beings did not have and should not search for ‘too much’ control of their lives. Another interviewee explained that he thought that even if deliberate selection took place in PGD, the child born after its use was the child that was ‘always’ going to be born.

Finally, interviewees related a number of moral experiences, such as the experience of frustration in the pre-PGD situation when there were no secure diagnostic methods, the experience of having something to offer to couples when secure methods were available and the experience of approving or disapproving of different uses of PGD.

There were also certain national differences in the data. Some of the Italian interviewees discussed moral difficulties regarding the disposal of healthy embryos but this was not present in any other interviews. The Italian interviewees also discussed exaggerated uses and misuses as present in their own country. This was seldom the case in the other interviews. Furthermore, four of the six Italian interviewees referred to the official views of the Roman-Catholic Church in their discussion. Such referal to official views of the Roman-Catholic Church or any other church was never present in other interviews.
Main Findings in the Philosophical Analysis

In chapter seven, I distinguished between the general concept of choice and the subcategory of autonomous choice. This, I argued, had the theoretical benefit of allowing a more precise discussion of degrees in constraints on conditions of choices. It also allowed a more precise discussion of different kinds of constraints on conditions of choice, than if no distinction was made.

If someone has a choice, I said, she or he needs to be in a situation of choice in which there are at least two alternatives that she or he perceives as alternatives. In order to have a choice, person A must also be able to, have the opportunity to and the intention to come to a decision and execute the decision, i.e. act on it and/or have others act on it. As regards autonomous choice, it was present only when the conditions for choice in general were met and when person A was able and had the opportunity to reflect on what really mattered to her or him with regard to the particular area, and on whether what really mattered was promoted in an acceptable way through the alternatives present. Person A needed also be able and have the opportunity to decide on the basis of that reflection and to act on the decision the reflection yielded.

In choice and autonomous choice, the abilities necessary were both causally and constitutively relational. I also suggested that a minimal self-trust was important if someone could be said to have choice/autonomous choice. These characteristics of choice/autonomous choice had the benefit of allowing a discussion not only of what takes place at the actual moment of decision-making, but also of how the abilities necessary can be developed. Relational aspects of choices were made explicit.

These conditions of choice and autonomous choice were discussed in relation to five constraints present in the empirical data: i) complex, ambiguous, overwhelming or insufficient information, ii) psychological distress, iii) individual and structural directiveness, iv) marginalisation and cultural imperialism and v) compulsion. Whereas information has been much discussed in bioethical literature on autonomy and choice (Beauchamp and Childress 2001; Faden and Beachamp 1986), discussion of structural directiveness, marginalisation and cultural imperialism and compulsion has been less common. Finally, the characterisations of
choice and autonomous choice were also used in the discussion of shared choice and shared decision-making in the PGD and GLGT context.

The concepts of ambivalence and trust were discussed in chapter eight. Ambivalence, I said in this chapter, is present when we vacillate between different beliefs, expectations, feelings, attitudes or states of mind and when the reason is not that we do not have the opportunity to make a choice. From this general concept of ambivalence, I went on to discuss ambivalence in trust relations. I suggested that the potential for ambivalence lies at the core of all trust relations. As regards the core elements of all trust relations, I suggested that A trusts B in respect C if and only if A has faith in the reliability of B in respect C, when A expects B to be or do C but where this is not certain, when A expects something good or desirable of B, when A's expectations are accompanied by A's feeling of optimism or securit (at least at a minimal level), when A is willing to rely on B and does rely on B and when A accepts the risk of being let down. Furthermore, depending on what the object of trust is, different trust relations have their own further characteristics. I distinguished between five different trust relations in which trust took a specific object: personal trust, system trust, personal-system merger trust, trust in the non-human and self-trust.

The philosophical discussion was also combined with discussion of some of the empirical examples. In previous research, trust in the medical context has mainly been discussed from the perspective of patients or the public (Mechanic 1996, McLeod 2002). This study enabled a discussion of trust from the perspective of medical professionals. It also enabled a discussion not only of medical professionals’ trust in the health-care system, as one example, but also their possible trust in colleagues and in users of the system.

On the Combination of Analytic Methods
At the beginning of the work that resulted in this thesis, some expressed their concern that interviews with medical professionals on moral aspects of technologies would not be very helpful. It was questioned whether these professionals had so much to say and whether what they
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might say would have relevance for a systematic ethical analysis. Though interviewees had reflected less on germ-line gene therapy than on PGD, and given the results presented, I take it to be clear that the interviewees had reflected on some moral aspects of the technologies and that they did tell me about at least some of these reflections. Their reflections were sometimes fragmentary and contained paradoxes and contradictions, but as I believe has been shown, this is not a reason for disclaiming the value of these reflections as a contribution to a systematic ethical discussion. However, it seemed as if interviewees had more difficulty discussing abstract questions directed towards philosophical notions than questions that focused on moral aspects of uses of the technologies that they had some experience of. As seen in chapter two and in appendix B, interviewees were asked about health and about rights and the reflections and discussions that followed these questions were brief and sometimes fragmentary to an extent that was not the case when interviewees were asked how they had been in contact with PGD.

Another, twofold, concern was that I would get biased and partial descriptions of what happened in a certain clinic or that I would only be told the ‘official’ versions of what happened there. In the latter case, if interviewees chose not to tell me about possible difficulties, I would receive homogeneous and mainly positive descriptions of uses of the technologies. Again, it was argued that this would be problematic. Regarding the risk of partial descriptions of what happened in the clinic, I concur with the assumption that such risk can be present. However, partiality in the sense that professionals describe uses of the technologies from their own perspective is also a reason why they are invited as interviewees. Their experiences and reflections, biased as they may be, are interesting.

In another sense, I take the issue of partiality to be an important matter to address: a certain distance to the interviews and to the interviewees is necessary in the analysis in the sense that the empirical data need to be examined and discussed. Regarding the risk of getting only official versions of what happens in the clinic, I agree that there may be such risk. Creating as relaxed and non-judgemental an interview situation as possible is one way to make interviewees feel comfortable.
enough to discuss sensitive examples and to reflect on issues that may be politically incorrect and therefore also delicate. Judging from the examples that the interviewees discussed, most interviewees seemed to reflect and discuss quite freely. I was told about positive aspects of uses of technologies as well as more troubling ones.

A third possible objection is that though there may be benefits to be gained from empirical ethical analysis, empirical research and philosophical discussion easily become two isolated projects and the possible connection between theory and practice is not sufficiently established. This risk could be present in empirical ethics. In order to avoid it, I decided at the time of setting up the project that the concepts chosen for philosophical analysis should be concepts that were discerned as central in the qualitative analysis. I also stated, in chapter two as well as in the interlude, that these concepts should contribute to the theoretical analysis, in the sense that they should either not be commonly discussed in theoretical bioethics or should highlight aspects of commonly discussed concepts that had not been much attended to. Whether I have succeeded in establishing one kind of connection between theory and practice must be judged on the basis of the previous chapters.

Grenzsituationen

At the beginning of this book, the theologian Helmut Thielicke was quoted as saying that the field of reproductive technologies was characterised by the presence of Grenzsituationen (Thielicke 1964:725). The term Grenzsituationen, i.e. border-line situations, was first discussed by the theologian Paul Tillich (1930:11) who explained that the border line is the propitious place for acquiring knowledge. For Tillich and Thielicke, border-line situations involved transitions and complications. Furthermore, for Thielicke (1964) these were ‘abnormal’ rather than ‘normal’ situations, which called for a thorough ethical analysis. Border-line situations seldom, if ever, allowed simple right or wrong moral answers. In my use of the concept of border-line situations, and as seen in chapter one, such situations are situations in which what we pre-

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viously have held to be impossible is no longer so, which calls for a (re-)
examination of what we may have considered well-established and/or
taken-for-granted moral boundaries.

At the beginning of the book, I also suggested that PGD and GLGT
did result in border-line situations, since they implied both new ways to
perform old medical practices and new medical practices. The use of
PGD and the potential use of GLGT also resulted in the sharpening of
certain old moral questions – and in certain new moral questions. Be-
fore exploring these issues, a final distinction is necessary between the
concepts of numerical identity, qualitative identity, personal identity
and two kinds of genetic identity. This is important for the discussion
of in what senses PGD and GLGT imply something new. As regards
the notions of old and new moral questions, I follow the usage of
Draper and Chadwick (1999). Old moral questions in medicine are
questions that arise not only in relation to PGD or, I add, GLGT but
also in relation to assisted reproductive technologies, in relation to pre-
natal diagnosis and selective abortion or in medicine in general. New
moral questions are questions that are evoked only by PGD and/or
GLGT.

*Identities*

A distinction needs to be made between *qualitative* and *numerical
identity*. Such is done by the philosopher Derek Parfit (1984:201) when
he suggests that qualitative identity means that two persons or objects
are ‘exactly alike.’ In order to make his point, Parfit describes a sce-
nario in which it is possible to make a replica or a copy of a person A
that is qualitatively identical with person A. This copy can be called
person A’. Person A and person A’, in Parfit’s scenario, are exactly like
each other. Such would also be the case with two exactly similar balls,
or some other objects. However, though the two persons or the two
balls are qualitatively alike, they are not numerically identical. They
are two, not one. If this distinction is applied to the present medical
context, two embryos can possibly result as qualitatively alike but nu-
merically different in the case of twinning that results in two identical
twin embryos.
Qualitative identity can be an issue in many health-care scenarios; there is also, I suggest, a distinction to be made between *qualitative identity* and *personal identity*. Two scenarios can clarify this point. As a first example, I may experience a life-changing event of some sort which makes me reconsider past experiences and thoughts. This can result in changed views in a number of areas in my life and possibly a more or less changed life-style. If so, I am numerically the same, but qualitatively different. However, imagine also, as a second example, that something happens to a particular person that makes her or him unable to remember past experiences, reflections and feelings. Such may be the case if someone loses her or his memory after a severe accident. If so, this individual is again numerically the same and qualitatively different; however, her or his personal identity is *also* different.

If person A at time t is personally identical with person A at another time, time t', I shall suggest, this requires that she or he remembers at least some previous experiences and is able to reflect on them. If this person cannot do so, she or he has lost her or his previous personal identity (at least temporarily, until she or he regains memory). If this reasoning is accepted, a change in qualitative identity need not, but may, imply a change in personal identity.

Finally, someone’s *genetic identity* is characterised, I suggest, by her or his genome. Most persons have a unique genetic set-up. There are also obvious exceptions, such as is the case with identical twins. Furthermore, two genes are ‘identical-by-descent’ at a particular locus when these two genes are inherited from a single common ancestor, without new mutations (Gagnon *et al* 2005:1). Such can be the case with siblings. Whereas parents and children share exactly half of the genes on autosomal loci, two siblings share this proportion only on average. At a particular locus, they may share both alleles, if each parent transmitted the same allele to both children. They may also share no alleles, if both parents transmitted different alleles. They may, as a third alternative, share one allele, if one parent transmitted one and the same allele to both siblings. This being the case, we can have more or fewer genes in common with our siblings. If the concept of genetic identity is used, we may therefore also be more or less genetically alike. We
may be genetically identical as regards certain loci and not others; we may also be genetically identical with our siblings as regards genes that influence some phenotypic traits and not others. Furthermore, during a lifetime, mutations can occur in some cells and in certain genes in those cells. This matters to the identity at stake. In the case of mutations, a numerically identical person can be genetically different at a particular locus, if her genome at one time is compared with her genome 60 years later, for example.3

This evokes the question if what matters to genetic identity is not that all the genome is qualitatively alike, but that most of it is qualitatively alike or that most of the genes that is phenotypically expressed is qualitatively alike. In the following, this view of genetic identity will be labelled dynamic genetic identity. The view that genetic identity is the sum of all genes and that all genes must be the same if someone shall be genetically the same will be labelled static genetic identity. However, to be plausible at all, I will suggest that even the static genetic identity view allows the kind of genetic changes that can occur under a life-time as a result of new mutations that are not a direct result of human actions.

Both of these concepts of genetic identity differ from personal identity, but, likely, someone’s genetic set-up can influence her or his personal identity. As regards qualitative and genetic identity, genetic sameness is a specification of in what sense someone can be qualitatively the same.

New Ways to Perform Old Practice – and New Practice

There are many ways to exercise an influence on who will live and on the genetic set-up of one’s future children. Choice of partner has been described as one such way, though this choice is most often not made on such grounds (Chadwick 1998, Munthe 1999b). Prenatal diagnosis and selective abortion are another way, as are PGD and selective transfer of embryos. In this sense, PGD is just a new way to perform old practice.

However, what is at stake in the PGD and hypothetical GLGT situation is not only the possibility of exercising an influence on who will live in general. More specifically, PGD implies a quality control of embryos, as put by Chadwick (1994) and as stated by some of the inter-
viewees in chapter six, on the basis of genetic information. If GLGT is used in order to replace mutant genes, this also implies a certain quality control. But then, again, this is only a new way to perform an old practice. A quality control is also possible if prenatal diagnosis is combined with selective abortion on the basis of genetic knowledge.

In another sense the use of PGD does imply new practice. It implies a deliberate choice of which embryo – if any – with what kind of genetic set-up will be implanted out of a number of alternatives soon to exist, since the choice of what kind of embryos to sort out and what kind of embryos to implant often takes place before there is an embryo. This is different from the choice of whether to interrupt an on-going pregnancy in at least one respect: there is not yet an embryo, nor a pregnancy. This is also a new situation of choice if compared to the choice of whether to undergo a selective abortion in terms of the number of alternatives available. In the latter situation, there is the choice of whether to do R or non-R. In the former situations, there is the choice of whether to do A, non-A, B, non-B, C, non-C and so forth, depending on how many embryos there are.

The choice in PGD is also different from the choice of partner, even in the rare cases where it is recommended that certain genetic information is searched for in order to obtain a marriage licence, such as is the case among the Azkenasi Jews. Among this group of people, Tay-Sachs disease has been relatively common and genetic information as regards this disease has been used in discussions of whether a marriage licence should be given (Reichman 2004, Munthe 1999b). While there are certain similarities with the PGD situation (in both cases some genetic information is obtained for the sake of trying to avoid a particular genetic disease), there are also important differences. In the case of the Azkenasi Jews, genetic information is given about the possible carrier-status of grown-up individuals, for the sake of knowing whether the possible future, biological children of a woman and man who plan to marry would be at ‘high risk’ for this disease. In the PGD situation, the genetic information given concerns the actual embryo. Furthermore, the choice in PGD can be a choice to try to avoid a particular disease as
well as, in some cases, a choice to implant an affected embryo, as seen in chapter four. Arguably, this is not the case in the choice of partners.

In what sense GLGT implies new practice is a bit more complex. As described in chapter one, one of the technologies discussed for GLGT at present is transfer of cytoplasm in order to avoid certain mitochondrial genetic diseases. Let me for a moment assume that such could be done, medically speaking. Would such a transfer have identity-changing consequences as regards genetic identity? The answer to this question depends on which view one has of genetic identity.

According to the static genetic identity view, identity-changing consequences are present if GLGT implies a change in the embryo’s genome (the exception being new mutations in the genome that can occur during a life-time and that are not directly caused by human action). Since GLGT implies such a change, after it has been performed the embryo is no longer the same embryo. It is, as regards its genetic identity, another embryo. Hence, if one has a static genetic identity view, GLGT need not qualify as treatment. It can be seen as a selection between embryos, which is of course new practice in the same sense as is PGD.

According to the dynamic genetic identity view, whether the genetic identity has been changed depends on which genes are changed or on how much of the genome has been changed. If one holds a dynamic genetic identity view and if one considers that the changes that take place in the genome due to exchange of the cytoplasm are not enough to change the embryo’s genetic identity, the embryo would be numerically and genetically the same. Thus GLGT could qualify as treatment of embryos. If so, this is new practice in another sense than if one has the static genetic identity view. Deliberate, desired interventions in the human genome that qualify as treatments and that affect future generations constitute new practice.

The fact that something is a new way to perform old practice says nothing in itself about its morality. An old practice may be morally objectionable; it may also be a morally good model. Likewise, the newness of new practice says nothing about its morality, nor does it in itself clarify whether it results in any old or new moral questions. These issues will now be discussed.
What Old Moral Questions?

PGD evokes the question of whether it is morally acceptable to choose who will live. This is also a question evoked by GLGT if one has a static genetic identity view – and in prenatal diagnosis if combined with selective termination of pregnancy. If it is morally acceptable to make such choices, under what circumstances is it so, and why? It needs also to be asked whether it is morally acceptable to exercise an influence on who will live not only on the basis of knowledge of inheritance of severe genetic diseases, but also on the basis of knowledge of inheritance of genetic diseases in general. Here the old issue of the meaning of genetic disease is re-evoked. It needs also to be asked whether it is morally acceptable to exercise an influence on who will live on the basis of sex.

There are also old moral questions that focus on choice and autonomous choice. As has been seen in chapters five and seven, conditions of choice and autonomous choice were sometimes likely to be constrained. The presence of possible constraints on autonomous choice has also been discussed in relation to prenatal diagnosis (Hildt 2002), and the gap between ideal conditions of choice and actual conditions of choice can be present in many situations in medicine (Corrigan 2003). Still, it is important that such a gap and such constraints should be addressed if choice and/or autonomous choice is considered morally important in a particular practice. Old moral questions that need to be addressed in the context of PGD and GLGT are ‘Is autonomous choice morally valuable?’ and ‘If autonomous choice has a moral value, what other values, if any, need to be taken into account in the PGD or GLGT context when it comes to the elaboration of a morally acceptable use of the technologies?’ It can also be asked whether a certain level of risk is becoming ‘normal,’ and, if so, whether this has an effect on possible choices in this context.

Another moral question is evoked by interviewees’ descriptions of exaggerated uses or misuses, presented and discussed in chapters six and eight. Exaggerated uses and misuses are possible in most if not all situations where humans use technologies. Empirically, it can be asked whether the presence of such uses – or the concern that such uses may be performed – result in a fading or failing trust. It can also be asked
whether it is morally problematic if trust in medicine is fading or failing, and whether trust is – and can be – justified.

There are also other old moral questions such as the question of what level of risk is morally acceptable when a technology is offered and used; of how to handle embryos in a morally acceptable manner; of whether a certain technology promotes a morally desirable way of living and what characterises such a way of living; of whether the use of technologies can have negative consequences for people with disabilities; of whether the use of technologies such as these implies a slippery-slope and, if so, whether this is morally problematic.

**What New Moral Questions?**

There are four clusters of new moral questions concerning PGD and/or GLGT that need to be further analysed. The first cluster focuses on the new kind of choice that takes place in respect of PGD and GLGT if one has the static genetic identity view: the choice of which embryo, if any, with what genetic set-up, shall be implanted. This is a *genesis choice*, a new and different choice from the choices in the prenatal diagnosis situation. Genesis choice is different from choice in the prenatal diagnosis situation since there is not yet an embryo, nor a pregnancy. The moral basis of this choice needs to be explored.

The second new cluster of moral questions concerning PGD focuses on the implantation of affected embryos, as presented and discussed in chapter four. Is it morally acceptable – and if so, for what genetic conditions is it morally acceptable – to implant embryos affected with a known genetic disease? Whereas the question of whether to implant an embryo without a particular genetic disease is, in some sense, similar to the question of whether to interrupt a pregnancy after prenatal diagnosis, when diagnosis has shown that the foetus is affected by a certain disease, there is no similar situation as regards the implantation of affected embryos (such as congenitally deaf embryos, discussed in Ch. 4). The closest example would be a situation where two persons know that all their children will be affected by a disease, such as would be the case if a woman and a man were affected by the same dominant genetic
disease, and they try for pregnancy. Even in such rare cases the analogy is not complete. In the scenario where two persons want to implant an affected embryo having taken the welfare of the child into account, they ask for medical assistance to make sure that the affected embryo is implanted. This is a different kind of choice. Whereas the couple affected with the same dominant genetic disease have the choice of whether to try for pregnancy or not, the couple who want affected embryos implanted choose to use PGD for this purpose.

The third new cluster of moral questions focus on autonomous choices and decision-making, particularly in the discussion of implantation of affected embryos. It may then be asked, as has been done by Draper and Chadwick (1999), whether there is a power shift at stake in the PGD clinic from women to professionals. As has been seen, according to the HFE Act, a woman should not be provided with treatment ‘unless account has been taken of the welfare of any child born as a result of the treatment’ (HFE Act 1990: sect.13). If the PGD team decide that implanting a particular embryo is not for the best of the future child, treatment should not be given. However, HFEA has also said that this section can imply that a concern for the welfare of the child to be born as a result of the use of technologies ‘should be one, but not the paramount, consideration to be taken into account’ (HFEA 2005:4). If such is the case, this highlights the moral tension between on the one hand the articulated wishes of the woman and man seeking treatment and on the other hand the welfare of the future child, as understood by the professionals offering treatment. Such scenarios also result in other new moral questions such as what will happen to the affected embryos if they are not implanted and if the woman and man do not want them disposed of.

A fourth cluster of new moral questions focus on the morality of the possibly identity-changing consequences of GLGT and the possible moral value of an unmodified genome for future generations. I now return to the distinctions between two kinds of genetic identity.

The possible use of GLGT raises the question of whether it results in identity-changing consequences. Here, I focus on genetic identity. It
can then be asked when my genetic identity is changed to the extent that ‘I’ no longer exist in the sense that ‘I’ have become an entirely different person. As has been seen, if one has a static genetic identity view, it can be argued that GLGT performed through the exchange of cytoplasm in order to avoid a mitochondrial genetic disease results in a genetically different embryo than the embryo present before treatment. Had the procedure not been undertaken, and if the embryo was implanted and carried to term, the child born would have had a certain genetic disease; when undertaken a different child is born and this child is healthy (for an example of this reasoning, see Munthe 1999b, Chadwick 2001). However, this depends on whether we consider GLGT to have such identity-changing consequences.

At the heart of the matter lies, I suggest, the question of how much of the ‘same’ genetic material is needed in order for the child born to qualify as one and the same potential person. In the context of GLGT, and if we have the dynamic genetic identity view, this is a question of how much genetic material can be changed without such change having identity-changing consequences. Does the exchange of cytoplasm result in such consequences? If not, we may hold that the embryo undergoing this kind of GLGT is numerically and genetically the same.9

What genetic identity view we have also matters with regard to our understanding of what GLGT means in comparison with PGD. According to the static genetic identity view, GLGT implies that the embryo is, after treatment, genetically another embryo. If so, if the embryo undergoing GLGT is changed to the extent that it is a different embryo, GLGT implies a choice of embryos – as does PGD. It implies no treatment of embryos. According to the dynamic genetic identity view, the embryo treated with GLGT through the exchange of cytoplasm can be sufficiently identical to the embryo that existed before GLGT was performed on it. The numerically identical embryo is, still, genetically the same. In this sense, the embryo is not another embryo. If so, GLGT does qualify as treatment of embryos.

This matters to the moral questions. If GLGT does imply a change in genetic identity, the child born cannot have been morally wronged,
since without the use of GLGT the child would not have existed.\textsuperscript{10} However, if the embryo is not another embryo, then GLGT is treatment in terms of a changed genome that will affect possible future generations. If so, the future child born \textit{can} be morally wronged when GLGT is performed; she or he can also benefit from the treatment.

Whether we have a static genetic identity view or a dynamic one also matters with regard to the question of the possible moral value of having an unmodified genome. If an unmodified genome is to have a moral value for me, it matters whether there can be an ‘I’ whose genome has undergone modification. Furthermore, we need to ask whether there is such a value.

There are also some new moral questions that are independent on what view we take on the issue of genetic identity after GLGT. In any case, the existing child, when GLGT had been used, would not have the same kind of \textit{relation} to its parents as had previous generations (as noted by Habermas 2003); its genome has been changed in accordance with her or his parents’ wishes. Whether it is morally acceptable to alter the kind of relation between generations is, again, a new moral question.
Notes to Chapter 1

1 For a discussion of similarities and differences between the use of these technologies, the choice to use a certain technology, and genetic identity, see Ch. 9.

2 *In vitro* fertilisation with donor, Thielicke held, would call for a new understanding of parenthood. This was the core question of this kind of *in vitro* fertilisation. The term *Grenzsituationen* was first coined by another theologian, Paul Tillich (1930).

3 Some prefer the notion of gene transfer to gene therapy. I use the notion of gene therapy, since I follow the usage in the Swedish white papers (such as SOU 2004:20).

4 It is not a gender study in that I do not intend to explore gender differences among interviewees or gendered differences attributed to patients that interviewees describe.

5 At present, several kinds of assisted reproductive technologies are available. Some are performed in a woman’s body (corporeal assisted reproductive technologies, such as gamete intra-fallopian transfer) and some outside of her body (ex-corporeal assisted reproductive technologies).

6 According to the UK *Human Fertilisation and Embryology Act* (1990:1), an embryo ‘means a live human embryo where fertilisation is complete’ and ‘references to an embryo include an egg in the process of fertilisation.’ Whereas a distinction can be made between the fertilised egg cell (the zygote) and the embryo that results after the first cell division, I will follow the usage of the term embryo in the HFE Act.

7 In the next step, an embryo or embryos can be transferred into the woman’s uterus, frozen for later use or, in some countries donated for other purposes, such as embryonic stem cell research.

8 At this stage, all cells are totipotent, i.e. they have not been differentiated into specific functions. Each of the cells can develop into new embryos with identical genetic dispositions.

9 Meiosis is a form of cell division that gives rise to sperm and egg cells. It involves two successive cell divisions. In women, at the onset of meiosis I, the oocyte (an immature egg cell) ‘doubles’ its genome. At the
conclusion of meiosis I, the oocyte ‘extrudes’ half of the chromosomes in a first polar body (Strom et al 2000:2). Thus, in women, the products of meiosis I are a large oocyte and a polar body; in the next step (meiosis II) the oocyte gives rise to a mature egg cell and a second polar body. At the conclusion of meiosis II, the egg cell and the second polar body contains one set of chromosomes each (Strachan and Read 1998:41-42). In polar body biopsy, polar bodies are retrieved and analysed genetically.

10 Sometimes, the term PGD is used for pre-implantation genetic diagnosis for a particular genetic disease as well as for pre-implantation genetic screening. In this case, the former is sometimes labelled high risk-PGD and the latter low-risk PGD (Thornhill et al 2005:35). Pre-implantation genetic screening has also been labelled PGD-AS (aneuploidy screening) (ESHRE PGD Consortium Steering Committee 2002). For the sake of clarity, I will reserve the term PGD for genetic diagnosis for a particular genetic disease and use the term pre-implantation genetic screening for the genetic screening of embryos. This usage of the terms harmonises with that in the Swedish governmental white papers (SOU 2004:20) and HFEA (2004).

11 The success-rate for IVF has been low world-wide, though it varies between clinics. The take-home baby rate from PGD in the UK, Lavery et al state (2002:2466), is at best 15-20 per cent per cycle started.

12 It is also noteworthy that during the period 1999-2001, in almost half of the cases of genetic testing on embryos reported to the European Society of Human Reproduction and Embryology, screening was used (SMER 2004:19).

13 In the case of biological methods for transfer, viruses are used as carriers of genetic material. In the case of non-biological methods, the genetic make-up is changed chemically so that genes or gene segments can be transferred into the cells.

14 Mitochondrion is an organelle in the cell’s cytoplasm that produces 95 per cent of the cell’s energy supply. For explanations of medical terms used in the book, see also Appendix A.


16 I believe a European approach to be interesting in the light of the visions of common European values and common guidelines for reproductive technologies. The Committee of Ministers emphasises ‘the Council of Europe’s vocation for safeguarding the moral values which are the common heritage of the member states, based essentially on respect for life and human dignity.’ The aim of the Council of Europe is ‘to achieve a greater unity between its members, in particular by the adoption of common rules on matters of common interest’ (Rogers and
Durand de Bousingen 1995: no. R (90)13). The realism of a ‘European ethics’ has also been questioned (Temporary Committee on Human Genetics and Other New Technologies in Modern Medicine 2001:63).

17 It is also interesting that on Nov 1, 2004, HFEA confirmed that it had given permission for screening of familial adenomatous polyposis coli, which can lead to colon cancer in early adulthood (HFEA 2004). The decision was criticised for not being discussed enough among experts or publicly, and particularly so since the disease, the critics say, is one that usually appears in adult life and that is treatable (Bosch 2004, The Lancet’s editorial 2004).

18 However, examples of conditions that HFEA has licensed are available on its home page (http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/Pre-implantationgeneticdiagnosis/List%20of%20licensed%20PGD%20conditions%20a.pdf). HFEA has also stated that it sees no moral difficulties with sex selection for medical purposes, but that sex selection for social reasons needs to be further discussed (HFEA 1993:7, see also HFEA 2003a).

19 HLA (human leucocyte antigen) typing has been allowed in the UK in conjunction with PGD. It enables the selection of an embryo for implantation that can become a sibling capable of donating life-saving tissue to an existing child.

20 According to Anderson, gene therapy in utero would not affect the germ cells, but his critics argued differently (King et al 1999, Council for Responsible Genetics 1998, Billings 1999).

21 A subgroup within GTAC (established in order to report on areas of new technology which may have implications for gene therapy) also concluded that in utero gene therapy raised no ethical questions that were not recognised in other interventions in utero or in the use of gene therapy in other situations (GTAC 1998).

22 The application of new genetic knowledge, gene therapy included, has also been described as an area in which the UK should lead the world. In the White Paper Our Inheritance, Our Future – realising the potential of genetics in the NHS, in 2003, the Government pledged to spend £50 million over the next three years, of which £10 million has been targeted for gene therapy research (GTAC 2004).


24 The inseparability principle and its ‘act-focus’ has also been discussed and criticised by Roman-Catholic American moral theologians (such as Cahill 1996:233), as has the official understanding of the embryo (Farley 2001, McCormick 1994, Cahill 1993). Roman-Catholic theologians have also been urged not to dissent from the views of the Magisterium (Congregation for the Doctrine of the Faith 1990).
In many respects, Italy could be described as a secularised Western country, but such a picture is too simple with regard to national discussions on sexual and medical ethics. Italy, remarks the Italian philosopher Maurizio Mori, was Roman-Catholic in the sense that there was a ‘shared morality’ in the above-mentioned areas until the late 1960s. According to Mori, the shared morality was mainly a morality corresponding to official Roman-Catholic moral principles, which were legally enforced and built into social institutions (Mori 2002). For a discussion of religious and cultural aspects of the bioethical discussion from an Italian perspective, see also Ventura (2000).

The status of the embryo has been discussed in several of CNB’s documents (CNB 1994, 1995, 1996). Pope John Paul II (1995) also published a document on bioethics that condemned use of IVF when embryos would be disposed of.

The bioethical tension in Italy has also resulted in a discussion of ethics in general. As an example, in June 1996, four philosophers published Il Manifesto di Bioetica Laica, the Manifesto of Secular Bioethics, in a daily newspaper. The authors described the manifesto as a reaction against the official teaching of the Roman-Catholic Church in bioethics that, in their view, put forward principles and reasoning that presupposed a certain kind of belief in God. The manifesto contained a number of principles that the authors considered necessary if bioethics should be discussed in an open and constructive manner. The moral discussion, they concluded, must be separated from the religious faith (Flamigni et al. 1996).

This could be the case with in utero gene therapy that affects the germline. Pope John Paul II’s address to members of the World Medical Association in October 1983 contains the statement that ‘[a] strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from deficiencies of chromosomes will, in principle, be considered desirable’ (John Paul II 1984). Gene therapy (GLGT included) for strictly therapeutic reasons, some state, conforms with the logic of the ‘Christian tradition’ (Grima 1994:325-326).

A white paper in 1989 (SOU 1989:51) emphasised the uncertainty as to whether PGD would have a negative effect on the child’s development. As long as this uncertainty remained PGD should not be allowed.

In the same document, the government stated that it was sufficient that the National Board of Health and Welfare elaborated guidelines for the use of PGD in accordance with national policy and monitored this. There is no Swedish law that regulates the use of PGD.

However, there is not yet any published studies that show that this is indeed the case.
The distinction between arguments related to the use of ex-corporeal assisted reproductive technologies, arguments related to risks with PGD as such and slippery slope arguments are also present in Munthe (1999a). My presentation of these clusters of arguments is inspired by his presentation even though my description of the content of the arguments related to the use of ex-corporeal assisted reproductive technologies differs from his.

As an example, it has been argued that the use of assisted reproductive technologies combined with ova donation goes against the natural life processes (SOU 1985:5:47).

Interestingly, disposal of embryos need not take place when ex-corporeal assisted reproductive techniques such as IVF or ICSI are used. It is possible to fertilise only one egg, which will be implanted. However, in PGD, disposal of embryos is unavoidable.

It has been held that the use of HLA typing, allowed in the UK, in conjunction with PGD is a dangerous step towards allowing parents to choose characteristics of children such as eye colour and sex (discussed by Sheldon and Wilkinson 2003) and that the use of the phrase ‘why not choose the best embryo’ may begin to imply an unacceptable degree of commodification of children (Polkinghorne 2004). For a discussion of slippery slope reasoning and PGD, see Petersen (2005) and Munthe (1999a).

For a description of beta thalassemia and aneuploidy, see Appendix A.

92 per cent of 50 respondents considered PGD to be an excellent alternative, as better or slightly better than PND. 72 per cent said they would be willing to go through PGD. However, the researchers note, some of the respondents in this group also explained that they wanted no more children.

74 per cent of the 50 respondents underlined the importance of being able to be assured that the embryo implanted did not have beta thalassemia.

96 per cent of these 74 respondents said they were willing to undergo pre-implantation genetic screening.

31 per cent of the respondents had an affected child, 56 per cent of them had had prenatal diagnosis and 36 per cent had undergone termination of pregnancy since the foetus had the particular genetic condition.

91 per cent said they strongly agreed that the advantage with PGD was that only unaffected embryos would be transferred to the woman’s uterus, 86 per cent said they strongly agreed that the advantage with PGD was that termination of pregnancy could be avoided.

56 per cent of the women strongly agreed that the low success rate was a disadvantage and 41 per cent of them said the treatment cycle was extremely stressful.

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56 per cent of the respondents said they would like to try PGD another time.

77 per cent of these respondents said they would choose PGD, to be compared with 15 per cent who said they would choose prenatal diagnosis.

25 per cent of all the respondents said they would like to use PGD as the first choice if they should try for another pregnancy, to be compared with 48 per cent who said they would like to use prenatal diagnosis as the first option in a future pregnancy.

50 per cent of the members of the cystic fibrosis association responded that their first choice was PGD.

18 per cent of the carriers of haemophilia A or B and 9 per cent of the women and men affected with haemophilia A or B said PGD was their first option.

24 per cent of the members of the cystic fibrosis association responded that prenatal diagnosis was their first choice, whilst 40 per cent of those affected and 39 per cent of the carriers of haemophilia A or B did so. It is also to be noted that whereas 6 per cent of the members of the cystic fibrosis association preferred to try for pregnancy and not use any diagnostic methods, 38 per cent of those affected and 22 per cent of the carriers of haemophilia A or B described this option as their first port of call.

Interestingly, those affected by haemophilia A or B described their disease as mild whereas carriers of the same disease characterised family member’s disease as severe (Højgaard et al 2002:112).

There is also a quantitative cross-national study that analyses the views of 2903 genetic professionals concerning the selection of desirable characteristics in children in relation to prenatal testing in abortion (Wertz and Fletcher 1998a). This study does not discuss PGD. However, it is interesting since it describes and analyses a trend towards honouring requests for social sex selection combined with a conflict between maintaining one’s own integrity (on the part of the interviewees who did not approve of sex selection) and serving what professionals believed to be the patients’ needs. The patients were described as having a right to make their own decision.

The larger study discusses medical and technical aspects of PGD, moral aspects of the use of PGD, the structure and organisation of PGD units and economic aspects of its use. It also contains the survey of the views of ‘potential users’ of PGD.

It has also been held, as part of an argument for in utero gene therapy, that a widespread and stable gene engraftment may be more feasible in a foetus than in an adult (Caplan and Wilson 2000).
In other scenarios such as if germ-line gene transfer should be a side-effect of somatic gene therapy on foetuses, children or adults, these criticisms are not relevant.

For a discussion of health risks for the foetus and mother in in utero gene therapy, see Coutelle et al (2003:119-120).

For an interesting discussion of the distinction between therapeutic and non-therapeutic/enhancement interventions, see Juengst (1999).

It has also been argued that GLGT for mitochondrial diseases would be morally problematic since it presupposes a 'combination' ovum, i.e. a donated, denucleated ovum from one woman and a nucleus from another woman. This violates the inseparability principle, not only since assisted reproductive technologies are used but also because of the combination of parts of ova (Watt 1999:264-265).

There are also research that engage in ethical analysis and which build on the empirical research of others, such as the study by Carolyn McLeod (2002) on prenatal diagnosis. McLeod explores the moral experiences of women in others' studies, with the aim of elaborating a conceptual clarification of what self-trust and autonomy should mean. This study is very interesting to the present one in terms of its content, but it does not discuss how methods used in empirical research and ethics can be combined.

There is also a study on the meaning of being in 'ethically difficult care situations,' as narrated by nurses and physicians in internal medicine, oncology and paediatrics in Norway. The researcher concluded that most interviewees 'narrated from a relational ethics perspective' and the empirical data were further analysed from the ethical perspective of Knud E. Logstrup (Sørlie 2001:42). For another study that discusses, among other things, narratives of social educators and the ethical perspective of Knud E. Logstrup, see Skaerbaek (2002). In a study on the relationship between ethical codes and the moral praxis of health care staff in the context of priority setting, the ethicist Anna Höglund combines empirical research and a critical discussion of the present Swedish guidelines as regards priority setting (Höglund 2005). For Höglund, empirical research in ethics is a 'logical step' in the development of context-sensitive ethical research (Höglund 2005:24).

The researchers concluded that in most countries, genetic screening projects focus on pregnant women and newborn children (the exceptions being population screening programmes in Cyprus, Greece and Italy.) They also found that social responses to genetic screening programmes varied, from acceptance to hostility, and there was a tension between individual and community in the discussion of implementations of screening programmes (Chadwick et al 1998).
Notes to Chapter 2

1 This description is necessarily general. There are also national differences that contribute to the dynamics of the discussion of ethics within medicine but on which I will not expand here. For a comparison between different descriptions of medical ethics during the twentieth century, see Parizeau (1989), Durand (1999), Hottois (1999), Malherbe (1996) and Doucet (1998) for French-speaking perspectives, Jonsen (1998) for a description of medical ethics in the USA, Viafora and Dell’Oro (1996) for an anthology that discusses different national perspectives and ten Have (2001b) for discussions of European perspectives. There are also certain events and tendencies that mattered to the development of medical ethics in general. Particularly when it comes to the development of bioethics, my description draws on the discussion in the USA and the various (also non-USA) responses to that discussion. This focus is motivated by the fact that field of bioethics was at first developed in the USA of the 1970s.

2 The primary exception being the writings of a few Roman Catholic moral theologians such as Charles McFadden who published articles on medical ethics in theological journals in the 1940’s and 1950’s.

3 A description and analysis of various medical codes of conduct established and revised in the early and mid-twentieth century is available in Veatch (1996).

4 The medical professional Henry K. Beecher’s article is particularly noteworthy since it was among the first to describe and discuss a number of cases of experimentations, which would not have been possible had the patients been truly aware of what they meant.

5 An interesting discussion and analysis of the work of Western moral philosophers during the period 1900-1960 is available in Warnock (1960). For a discussion of the foci on metaphysics and meta-ethics among philosophers at this time, see also Fox and DeMarco (1986). It has also been argued that during the period 1870-1930 the medico-philosophical literature in Europe focused on epistemology, then on medical anthropology (1930-1960) and thereafter on medical ethics (1960-)(ten Have 2001b:64-65).

6 Joseph Fletcher was an Episcopal theologian who, as described, argued that medical ethics should be concerned with the perspectives of doctors and patients alike. So did also the Methodist theologian Paul Ramsey through use of the concept of covenant in his discussion of partnership between patients and doctors (1970). The Lutheran theologian Helmut Thielicke discussed the notion of dignity as well as reproductive technologies (1964), and Roman Catholic theologians such as Karl Rahner emphasised the importance of human transforma-
tion and self-manipulation (1972), Bernard Häring discussed the notion of health (1972) and, somewhat later, Richard McCormick (1987, 1989) analysed a number of issues in the field of medical ethics.

7 The term bioethics was created in 1970, when Van Rensselaer Potter described it as a 'new discipline' that combines knowledge of human value systems with biological knowledge. Almost simultaneously, André Hellegers used the term of bioethics in a more restricted sense, as a concern with moral questions evoked in the development of natural science and its application in medicine. For descriptions and discussions of the events, see Doucet (1998:33-41), Jonsen (1998:27) and Gracia (2001:17-18).

8 Examples are the Hastings Centre 1969 and the Kennedy Institute of Bioethics 1971 in the USA, the Institute of Medical Ethics, replacing the London Medical Group who started as early as 1963, in the UK and Instituto Borja de Bioetica 1975 in Spain (Viafora 1996:11-15).

9 Interestingly, and as described by the theologian James Gustafson, there seemed to be a coinciding trend, where certain theological ethicists stopped writing 'theologically' and started to discuss bioethics mainly in secular terms (Gustafson 1975:386-392). For a discussion of this tendency, see Hauerwas (1996).

10 The principles are the principle of respect for autonomy, of nonmaleficence, of beneficience, and of justice. For a discussion of the dominance of Beauchamp and Childress' principles, see Fox (1999).

11 Beachamp and Childress’ principle-based approach is based on the assumption that there is a common morality, a set of norms that ‘all morally serious persons share’, which also includes principles that are basic to biomedical ethics (Beachamp and Childress 2001:3, 12).

12 Of course, reconstruction (of argument) is a common activity also in ethics, and empirical research is an integral part of ethics in the sense that most (if not all) ethical theories incorporate some psychological and/or sociological data and theories. For a discussion of the latter, see Birnbacher (1999). Furthermore, theoretical concerns can and do arise from within a certain practice.

13 For a discussion of examples of this, including a study of the results of IVF that highlighted the complexities in having multiple pregnancies and that explored not only practical difficulties, but also ethical questions that resulted from such complexities, see Haimes (2002:99-104). Empirical research is also valuable since it allows the exploration of the consequences of different political/ethical policies in medicine or new uses of medical technologies.

14 Haimes (2002) offers an interesting discussion of what theoretical and empirical work the social sciences can contribute to ethics. She also discusses how this theoretical and empirical work can enhance the understanding of ethics as socially constituted and situated.
15 For the sake of clarification, it should be noted that even though I emphasise the value of bridging the gap between theory and practice, I also consider theoretical discussions without empirical research as important.

16 Sherwin states that both philosophical, conceptual and empirical concerns must be brought into ethics, but that this is too seldom done in a systematic way even though there is a ‘surface agreement’ as to its value. It is recognised that we need some knowledge of conceptual matters in the discussion of practical concerns and, though with more ambivalence, that an adequate discussion of theoretical questions must also consider the implications in practice (Sherwin 1996:196).


18 Perception, Nussbaum says, ‘is seeing a complex, concrete reality in a highly lucid and richly responsive way; it is taking in what is there, with imagination and feeling’ (Nussbaum 1990:152).

19 Moral perception or moral seeing, as some label it (Benhabib 1992:74-75), has a classical parallel in physical seeing, though the moral perception is more complex and a myriad of images and representations influence our seeing. The phenomenon is also pedagogically clarified in the rabbit-duck pictures or the vase-faces pictures (Gilligan 1994:261-262). When looking at the picture, some of us will see a rabbit and others a duck – some will see a vase and some will see faces.

20 The focus on relations and interconnectedness has also been carefully explored and analysed by the feminist theologian Mary Grey, who argues for an ‘ethics of connection’ (1991). For an analysis of Grey’s writings, see Sporre (1999).

21 To be more precise, Young argues that ‘no social institution or practices should be excluded a priori as being the proper subject for public discussion and expression’ and ‘no persons, actions or aspects of a person’s life should be forced into privacy.’ Privacy is hence not what is excluded from the public, but what an individual has a ‘right to exclude’ (Young 1990:74.)

22 The latter studies can be most interesting and provide ethical analysis with a deepened understanding of how different individuals view a moral issue, but in order to qualify as empirical ethical analysis I will require that empirical research and a philosophical or theological analysis of moral issues are combined. Following this characteristic, sociological studies of moral issues, if not combined with a philosophical or theological analysis of these issues, will just be called sociological
studies of moral issues. In the same way, historical studies of moral issues, if not combined with a philosophical or theological analysis of these issues, will be called historical studies of these issues.

21 If we hold that PGD should only be used for diagnosis and selective transfer of embryos at risk for a genetic disease, our definition of what is a genetic disease will matter when it comes to what kind of conditions are considered as morally acceptable to search for.

24 Jeffner (1988:7) defines a lifeview as the theoretical and evaluative assumptions (1) that constitute or have a decisive importance for a comprehensive picture of human and the world, (2) that form a central value-system and (3) that express a basic attitude towards human existence (my translation). Critics of this strand within lifeview studies hold that it is (too) theoretical and rationalistic. When discussing lifeviews, as well as views on human nature, Jeffner uses a vocabulary of ‘choice,’ ‘reason,’ and ‘tests’ (Jeffner 1996:44-47, 1989:44-50), which motivates labelling this a theoretical-cognitive strand of lifeviews.

25 The focus on orientation can be further specified, depending on whether orientation is understood as identity forming, whether it motivates actions or emotions, whether the function of the lifeview is primarily practical, psychological, theoretical (in the sense of making a way of living rational and thought-through) and so forth (Westerlund 2002:49, Bräkenhielm 1998:272-280, Uddenberg 1995:13). Finally, the aim of a lifeview has also been described as ‘to lead us to insights about what it means to be a human being in the universe,’ and not knowledge (Herrmann 1995:98).

26 For an interesting discussion of identity, authenticity and lifeviews, see Mikael Lindfelt (2001:305-309). It may also be held that a lifeview contains certain moral guidelines, that a lifeview provides an epistemological basis or reason for certain moral principles, or that certain principles presuppose, in some sense, a certain lifeview (Bergström 1996:13).

27 However, in the analysis of the empirical data, norms in the second sense are only present in terms of described behaviour.

29 No ethicist would argue that a certain view or standpoint deriving from a particular experience is morally justified because of its being empirically present among a certain group of people. Obviously, if it was, a number of oppressive views would be justified because of their being held by someone, such as racism or gender oppression.

30 For an interesting discussion of the benefits of qualitative interviews in projects on ethical reasoning by health-care professionals, see Holm (1997, particularly Chs. 3 and 4).
being influenced by the interview situation. For a discussion of monological versus dialogical/interactional understandings, see Linell (1998, particularly Chs. 2 and 3).

31 This does not imply that I assume that there is consensus regarding how a particular phenomenon shall be interpreted in a certain practice. For a discussion of the coexistence of contradictory ideas of a particular phenomenon, see Eckert (2001, Ch. 2) and Billig et al (1988).

32 I could also have interviewed other medical professionals, such as nurses. Though this would have been interesting, I chose to focus on those who would be in a position where they were able either to develop the technologies, make the final decision as to whether someone should be able to use them (though this, of course, is part of a discussion within the whole clinical team) or decide to refer someone to such a PGD unit.

33 Two junior geneticists and one junior gynaecologist; the other geneticists and gynaecologists were senior professionals.

34 However, two of these four Swedish interviewees explained that they had ‘some kind of belief in God.’

35 Interviewees’ varying personal experience of either genetic diseases or reproductive choices can also influence their moral perception; this was not a basis for the choice of interviewees, but turned out to be present when the interviews were analysed.

36 It was explained that geneticists and gynaecologists were invited since they work with genetic research and applications in different ways, that a strategic sampling according to the interviewees’ sex, age and religious background was done. It was also explained that the idea was not to find any characteristics for certain professional groups or countries, but to focus on the interviewees’ experience of, views and ideas on, non-medical aspects and particularly on moral aspects of uses of the technologies that they identify in their professional life.

37 My intention was not to analyse gender differences among the interviewees. This being so, the change of sex may be considered as less unfortunate than would otherwise have been the case.

38 My intention with the project was not to compare thoughts and deeds, nor to provide a psychological explanation of why a certain question becomes important for a specific person in a specific life situation.

39 Since the purpose of the study was to explore what is said and only to a lesser extent how it is said, a transcription focusing on linguistic structures was not considered necessary.

40 Narratives can be used as strategies and as a means to position oneself, through description of others’ reactions and views. Narratives may be supportive, i.e. used in order to underpin a certain view that the interviewee holds. They may also be used as a contrast to the interviewee’s own view in order to explain that something is not the case.
(that a person or group quoted within the narrative holds a view that
the interviewee does not share). Narratives may also be used in order
to express certain views that interviewees consider it embarrassing to
hold themselves.

41 As noted by Mishler (1986:236), when the analyst determines the point of
the story this is a matter of interpreting the narrator's story. This is
particularly the case since narrators, according to Mishler, tells stories
as part of their self-presentation. Stories are told, which tell something
about the narrator and her or his social/cultural world.

42 I concur with Dworkin in arguing that this condition is not designed to
beg the question of those who deny the possibility of autonomous
choice. I will try to construct a concept of autonomous choice that is
empirically possible, but I may, of course, fail.

43 I take this to be the case also with descriptive, lexical characterisations of
concepts. If chosen, someone has considered it to be the best charac-
terisations of that concept.

Notes to Chapter 3

1 See interview guide, Appendix B.

2 In both cases, a genetic diagnosis is performed on foetal cells. Amniocen-
tesis is often carried out later on in the pregnancy than is chorionic
villus sampling and the result of the latter is available more quickly.
However, the likelihood for a repeated test is greater with chorionic
villus sampling than with amniocentesis and the risk of continuous
abortion as a result of the test has been described as three times higher
(1 in 50 for chorionic villus sampling versus 1 in 150 for amniocentesis)
(Green and Statham 1999:142)

3 At this time, Joyce explained, amniocentesis was used to search for
Down's syndrome or for foetal sexing for diseases like Duchenne's
muscular dystrophy (9.12).

4 The numbers in the parentheses indicate in which interview and in which
section of the particular interview the excerpt can be found. All names
of interviewees are, as said before, fictitious.

5 The information as to whether women and men were carriers was also
'distressing' when these women and men looked back at terminations
of pregnancies that had not been necessary (7.14).

6 The original, Swedish version being: 'Det här har varit ett sista halmstrå
och det känns ju alltid bra att kunna erbjuda något mer.'

7 The word 'easier' when used to describe the present situation contrasted
with former situations was used in a psychological sense. Seeing the
pain and suffering, but not being able to do anything, was difficult.
8 This reflection was articulated in a discussion of human rights. Hilda said that children may well be a human right, since we have this strong instinct for having children. Another example of a discussion of biological children was when Steven compared the pre-PGD era with the PGD-era. He said that for some people, donor sperm or donor egg may be an alternative, but a lot of people ‘want it to be their own baby and [they find] the idea of donor sperm or occasionally eggs too difficult’ (7.14).

9 The purpose of PGD, Joyce explained, was to ‘do a test as early as possible to ensure a couple have the sort of baby that they actually want, given that they’re at risk of something that’s usually a serious genetic condition’ (9.36). In other sections of the interview, she stated that PGD should only be used when there was ‘a demonstrable risk either of a genetic condition that’s in the family or if a woman is a bit older, [in which case] testing [is done] for chromosome aneuploidies’ (9:20).

10 For scenarios when embryos with a particular genetic condition or carriers of that condition were implanted also after use of PGD, see Ch. 5, sect. The Case of Affected Embryos.

11 This view was put forward as an answer at the end of the interview, when I introduced the notion of control and asked whether Andrew saw it as ethically relevant as part of the discussion of selection of embryos.

12 In this study, 91 per cent of the 36 responding couples ‘strongly agreed’ that transfer of only unaffected embryos was an advantage of PGD and 86 per cent ‘strongly agreed’ that avoidance of termination of pregnancy was an advantage.

13 94 per cent of the 134 women and 91 per cent of the 111 men agreed that the birth of a child who would not inherit the genetic condition was an important or very important advantage of PGD.

14 94 per cent of both women and men agreed that the possibility of knowing, from the start, that the child won’t have the genetic condition was an important or very important advantage of PGD. 96 per cent of the 134 women and 88 per cent of the 111 men agreed that ‘no need to terminate pregnancy’ was an important or very important advantage of PGD.

15 For a description of beta thalassemia and aneuploidy, see Appendix A. In Sicily, one couple in 270 may be considered to be at risk for beta thalassemia (Chamayou et al 1998:1936).

16 56 per cent of the 50 respondents who had experience of prenatal diagnosis and who had chosen selective termination of affected foetuses or who, unaware of their carrier status, had given birth to an affected child, described the possibility of avoiding ‘the death of foetus by abortion’ as the greatest advantage of PGD. 77 per cent of the 74 couples with fertility difficulties rated the possibility of avoiding ‘the death of the foetus by abortion’ as the greatest advantage of PGD.
17 24 per cent of the 50 respondents rated avoidance of psychophysical trauma during abortion as the second greatest advantage and 18 per cent rated the possibility of avoiding stress and anxiety while waiting for the results of prenatal diagnosis as the second greatest advantage. 58 per cent rated the possibility of avoiding stress and anxiety while waiting for the results of prenatal diagnosis as the third greatest advantage.

18 51 per cent rated the possibility of avoiding psychophysical trauma during abortion as the second greatest advantage and 70 per cent rated the possibility of avoiding stress and anxiety while waiting for the results of PND as the third greatest advantage.

19 86 per cent of the 134 women, 83 per cent of the 111 men agreed that the birth of a child who would be genetically related to both partners was an important or very important advantage of PGD. For a discussion of biological parenthood and an assisted reproductive technology as in vitro fertilisation, see also Modell (1989 pp.132-134).

20 56 per cent of the 134 women and 44 per cent of the 111 men agreed that the possibility of finding out whether or not the child would be a carrier of the disease was an important or very important advantage of PGD.

21 Koch and Nordahl-Svendsen (2005:824) also argue that the knowledge created in genetic counselling situations and ‘solutions’ encompassed become the framework in which ‘the problems’ of being at risk for a genetic condition are created. Autonomous actors – patients – are created who consent ‘to act responsibly with [disease] prevention as the almost inevitable result.’

22 For a discussion of possible moral differences between PGD and prenatal testing and abortion, in which it is argued that the use of PGD is a more acceptable alternative from a moral point of view, see Cameron and Williamson (2003).

23 46 per cent of the 134 women and 50 per cent of the 111 men described prenatal diagnosis as their first option, to be compared with 28 per cent of the women and 23 per cent of the men who described PGD as their first option.

24 68 per cent of 50 respondents described PGD as more acceptable than prenatal diagnosis, 22 per cent described them as equally acceptable and 72 per cent said they would be willing to go through PGD. However, the researchers note, some of the respondents in this group also explained that they wanted no more children. The conclusion that previous experience of termination of pregnancy was an important factor for these couples’ choices was also drawn in another project on the acceptability of PGD among Italian women at risk for beta thalassemia (Palomba et al 1994).

25 96 per cent of the 74 respondents said they were willing to undergo PGD.
Notes to Chapter 4

1 Three more kinds of narratives of concern will be presented in the next two chapters.

2 At the same time, interviewees emphasised that these procedures could be physically as well as psychologically painful.

3 Compare also interviewees’ emphasis on the difference between reproductive genetics in the 21st century and eugenic movements in the past (Ch. 5, sect. Who Decides and Who Sets the Agenda: Ideals and Constraints.)

4 This was a reply to my question regarding whether the interviewee considered the discussion of rights as relevant in the context of PGD. Simonetta explained that she considered rights to be problematic, but that parental wishes for healthy, beautiful and intelligent children were very understandable (4.26).

5 However, as will be seen, this is a contested statement which leads to questions of how to describe and evaluate genetic disease, whether and if so to what extent and why a genetic disease is disabling (Harris 2000a, 2001, 2002, Reindal 2000, Draper and Chadwick 1999).

6 For a description of fragile-X, see Appendix A.

7 I use the term embodied experience for this professional who had experience of a particular disease in his own body, i.e. not only experience of relatives, siblings or children with the disease. The latter experience is personal but not embodied in the sense I have in mind.

8 For a discussion of exceptions to this tendency, see Ch. 6, sect. Perfectionism and Marginalisation.

9 Hypospadia is a condition characterised by the poor growth and closure of the urethra.

10 Furthermore, it has been stated that ‘PGD guidance should support difficult parental choices rather than appearing to discriminate against individuals with certain conditions’ (HFEA/HGC 2001:5).

11 Though other criteria are also described as important, severity of the disease at least seems to be crucial in the guidelines.

12 For a description of these diseases, see Appendix A.

13 Elisabetta argued that even if the use of reproduction technologies was not a moral question, reproduction ‘should be something that you feel, that it must be associated with the sense of mystery, of something that you wait’ for (5.20).

14 The original, longer Swedish version is: ‘Nu har vi tittat på IVF som infertila, som en handikappad grupp som vi hjälper och så hoppas vi att barnen inte ska bli mer missbildade och mer skadade och mer genetiskt defekta, men embryologen är ju i allmänhet mer restriktiv, mindre tillåtande än mother nature och om vi skulle jobba med en
mycket friskare kohort av människor med samma tekniker och samma ambition skulle vi komma fram till att de skulle få mindre genetiska avvikelser och genetiska sjukdomar än hos normalbefolkningen.’

15 The original, Swedish version is: ‘Allting hamnar i ett annat ljus, tror jag, när man själv är drabbad’ (15.20).

16 This was a response to the question how she would describe health.

17 When asked how she had been in contact with PGD, Giovanna explained that she found PGD interesting but that there were certain misuses. The reflection on healthy embryos was part of the reflection that followed my question.

18 Nils explained that outside the woman’s body, embryos were ‘cells, in some way. […] It is not the beginning of a human being, of a human life under development […] They are embryonic cells that will not be allowed to develop’ (14.53).

19 Vittorio described some obstacles that must be overcome if he should reconsider the interventions. There should be no disposal of embryos, medical risks should be lower than at present and there should be no separation of procreation and the conjugal act (2.10-14).

20 Alva used the Swedish word ‘besedda.’

21 In PGD HLA typing, an embryo is chosen for implantation on the basis that it is a suitable tissue match to a seriously ill brother or sister.

22 The British Human Fertilisation and Embryology Authority, HFEA, granted a licence for PGD HLA typing in the UK in 2002, but the High Court stated that HFEA had acted unlawfully in this regard. In 2003, the Court of Appeal overturned the High Court ruling, stating that HFEA was able to grant this licence (HFEA 2005a).

23 Boys would be affected if they inherited the disease. Girls would only be carriers.

24 For a description of incontinentia pigmentosa, see Appendix A.

25 Andrew also added that they changed the policy afterwards. They make it clear to the couple that no new decisions will be taken once treatment has started.

26 At the time of the interviews, selection of embryos was not forbidden. At present, however, all embryos must be implanted according to Italian law.

27 If the sorting out of some embryos was problematic, a better solution could be to develop a technology where few or no embryos would be disposed of. This was also the purpose of Elisabetta’s efforts to elaborate technologies for polar body biopsy, without disposal of embryos and without production of supernumerary embryos. Polar body biopsy is put forward as a good option in three of the Italian interviews, and in no British or Swedish interview. When asked if the selective aspect would not remain with polar body analysis, Elisabetta argued that it

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was a selection of cells and not of embryos and that it therefore was completely different: 'they are just cells like a skin cell or any other cell so it's just completely devoid of any ethical implications' (5.64).

29 However, she added, it was likely that the time would come when this was not a hypothetical scenario.

29 This has also been described as one of the elements in a possible 'process of geneticization,' in which human life and behaviour are described and articulated in the language of genetics. For a critical discussion of this, see Hoedemaeckers and ten Have (1998), Hedgecoe (1998, 2001) and ten Have (2001a).

30 A few of the interviewees suggested that as more knowledge was acquired we might find genetic bases for other characteristics, such as sexuality (as when Alva commented on the implantation of affected embryos) or intelligence (though they also emphasised the complex interplay between genetics and social environment in the case of intelligence).

31 In his review of medical discourse on disability in international medical journals, Tom Shakespeare identifies 'narratives of tragedy' and 'narratives of optimism' similar to the kinds of narratives of life with genetic disease that I have identified (Shakespeare 1999:673-677).

32 It has also been suggested that this model should be called the "harmed condition" model of disability (Harris 2000a:99). As regards attitudes to genetic diseases, a 36-nation survey of 2901 geneticists and genetic counsellors showed that, as a global tendency, many of the interviewees said they would emphasise negative aspects of genetic diseases, such as Down's syndrome or cystic fibrosis, so that couples 'will favour termination of pregnancy without suggesting it directly' (Wertz and Fletcher 1998b:499). Fifty-eight per cent of the 12 geneticist respondents in Sweden said they would 'emphasize negative aspects so they will favour termination of pregnancy without suggesting it directly' in the case of Down’s syndrome and cystic fibrosis. Such would be the case for 50 per cent of the 22 Italian geneticist respondents with regard to Down's syndrome and for 38 per cent of them with regard to cystic fibrosis. Such was also the case for 15 per cent of the 102 British geneticist respondents with regard to Down’s syndrome and for 10 per cent of them with regard to cystic fibrosis (Wertz and Fletcher 1998b:499). See also Marteau et al (1994a, 1994b).

33 In scientific language, these authors claim, disease is either associated with the structure and function of the body or parts of the body or it is discussed in terms of multi-factorial contributive causes. Such a language was also present in the interviews, but not in relation to discussions of normality. For a discussion of 'normal' women and men and 'normal patients' in prenatal diagnosis, see Ettorre 1999:544.
Empirical research also highlights this subjective dimension. The Danish survey of ‘potential users of PGD’ (Højgaard et al 2002) has shown that the respondents affected by hemophilia A or B described themselves as mildly affected whereas carriers described the disease in their families as severe. Research in the USA, Canada and Europe has also demonstrated the variety of opinion among experienced genetics professionals as to what is a ‘serious’ as opposed to a ‘nonserious’ genetic disease (Wertz and Knoppers 2002:34).

It has been suggested that XYY can result in tall physical stature and severe acne. Oculocutaneous albinism has been described as a disease that results in absent or decreased melanin in the skin, hair and eyes (Caplan 2002).

It could also be asked if there is a morally relevant difference between on the one hand a (hypothetical) situation where a woman and man with fertility difficulties and at risk for a particular recessive genetic disease want to use IVF, but not PGD, since they consider the seen selection as morally problematic; and on the other hand, the scenario where a woman and man have only affected embryos. If, in the hypothetical scenario, implantation of embryos is performed at random, the result could be the same as in the scenario described by the interviewee. The difference would be a difference in terms of knowledge and certainty. In the hypothetical scenario, the couples are at risk but have no certain knowledge of whether the embryo implanted is affected. In the scenario of the woman who could not stand that the male embryos should be disposed of, knowledge is obtained and implantation of affected embryos is, in this sense, deliberate and (more or less) certain.

These questions are old in the sense that similar questions have been addressed in the context of prenatal testing, if not before.

Instead, and as we have seen, this was an issue in one of the interviewees’ discussion of implantation of affected embryos in the context of PGD.

In this sense, even though Italy can be described as a secular country in many respects, the Italian bioethical discussion is influenced by the presence of the Vatican. This was particularly clear in the Italian referendum on the law regulating assisted conception technologies (Governo Italiano, Presidenza del Consiglio dei Ministri 2005). Pope Benedict XVI called for a boycott of the referendum, so that its result would be invalid (and the law be kept) and this was also what happened. Fifty per cent of voters were needed (Nature’s editorial 2005).

For a description of twinning, see Appendix A.

However, Farley also explains, these earlier views were also based on inadequate knowledge of reproductive biology. Farley provides a basis for a graded view of the embryo, as does the Lutheran theologian Ted Peters, though in a different way. In Peters’ view, dignity is ‘a relational
concept that begins first with the external conferral of dignity before it is claimed by a person as something intrinsic’ and it is also future-oriented (Peters 2001:128). Rather ‘than something imparted with our genetic code [...] dignity is the future end product of God’s saving activity’ (Peters 2001:134). Furthermore, becoming a human being, requires ‘an international, nurturing, relational community’ and not only a genome (Peters 2001:128). While Peters discusses embryonic stem cell research and argues that since excess embryos will never reach implantation (and since the described community is missing in the laboratory), they do not have the potential to become human beings and no human dignity. His reasoning can also be applied to the context of PGD. Unimplanted embryos that remain unimplanted will never become human beings and they therefore have no human dignity (which is thought to make the morally significant difference). Whereas some interviewees articulated views similar to that of Farley, no interviewee articulated a view similar to that of Peters. For a discussion of difficulties with the focus on implantation as what gives embryos moral significance as well as on the researcher’s intention (both of these were present in the data), see Harris (2005:221-225).

Notes to Chapter 5

1 I did not ask what a responsible practice should be like but some interviewees brought it up themselves.
2 It is to be noted, as already said in Ch. 1, that the Italian interviews were performed before the law regarding assisted reproductive technologies in 2004 (Legge 19 Febbraio 2004, n. 40, Norme in Materia di Procreazione Medicalmente Assistita).
3 Most interviewees discussed the topic of information at length even though I did not ask any specific questions regarding what should characterise the clinical encounter or what information should be given in such an encounter.
4 As a consequence, he explained, he had tried to re-label genetic counselling as ‘genetic information.’ This notion, he said, was more neutral and it mirrored what he thought should take place in the clinical encounter. Information should be provided and nothing else (14.20).
5 Nils’ concern was that advice was problematic.
6 Alva explained that she had met several women who had told her that they wished there had not been a choice. One of these, whom she had met in abortion situations, had told her ‘if there had not been a choice,
then no one could have forced me into a decision that I, actually, do not want’ (13.24).

Vittorio’s reflection was part of his response to me saying ‘I guess you have heard a lot about this pre-implantation genetic diagnosis and read [about it].’

The original, Italian version is: ‘Ha il senso di interrompere una vita dall’altra, è la tua vita su cui tu stai giocando’ (3.12).

In Angelo’s reasoning, this was also a reason not to allow donor sperm or donor egg. The ‘burden’ was already ‘high,’ particularly for women but also for men. The issue of donation made things even more complicated – and, it was implicitly assumed, more burdensome.

For a description of mosaicisms, see Appendix A.

This disease could not be searched for with PGD at the time of the interviews, but this is now possible where one partner has been shown to have the affected gene.

A somewhat similar view was put forward by Ian when he explained that experiments may be performed and germ-line gene therapy may be used for certain conditions. However, if they are performed, they need to be carefully monitored (12.61). As he saw it, difficulties were mainly due to the time-span before assessment of consequences of interventions in the germ-line could be done. ‘Twenty or thirty years from now, only then will we actually know whether or not we’re causing harm or there’s a potential for harm there,’ Ian stated.

According to Simonetta, we know that we might risk throwing away healthy embryos, and that some embryos will be destroyed through freezing procedures, but it seems as if these difficulties in the end become ‘too simplified, too minimised, sacrificed for the objective of having a healthy child’ (4.2).

A distinction can also be made between risk of failure to achieve the goal of PGD in the sense that embryos with the disease searched for were accidentally implanted and risk of failure of implantation. In the former case, such failure may be due to technologies being inaccurate or imprecise or to their being inaccurately or imprecisely used. In the latter case, failure of implantation (even though the diagnosis was accurate and embryos without a particular genetic disease were found) can either be due to technologies being inaccurate, imprecise or inaccurately or imprecisely used or due to the presence of other mutations within the embryo.

The original, Italian version is: ‘È una diagnosi che ha molte difficoltà e che può avere dei grossi rischi di spagliare’ (3.6).

For descriptions of lived experiences and embodied experiences, see Ch. 4, sect. First Narrative of Concern.

PGD units in Britain and Sweden are centralised and only a few such
units exist. This, interviewees explained, had consequences for what took place in the clinical encounters. Normally, when a couple wanted to use PGD and when the medical professionals at their local hospital considered this appropriate, the professionals got in contact with the PGD unit and made sure that PGD was available for that specific condition. In practice, these structures (though important with regard to having national control over what was offered, under what circumstances, and by what means) resulted in couples needing to be very vocal and to sound as if they were convinced that they wanted PGD, in order to be sent to PGD centres in the first place.

18 Obviously, communicative failures may also be due to misunderstanding or lack of understanding; one party fails to understand what the other party says and vice versa. This, however, was nothing interviewees commented upon. For a discussion of such scenarios in the context of clinical drug trials, see Corrigan (2003).

19 Reproductive rights are also criticised for encouraging a consumer attitude to the area of procreation, forgetting that it all takes place in women’s bodies and not in a neutral market-place (Raymond 1995).

20 However, Steven explained, there cannot be a general positive right of couples to use PGD, nor can there be a related demand on the state to make sure that PGD is available (7.41).

21 The desire to treat anything is understandable, remarks Simonetta, but there cannot be such a thing as a right to a healthy child (4.26).

22 It has been held that if there is a combined imperative of prevention of possible diseases and of choice in reproductive genetics, this may make women and men consent ‘voluntarily to act responsibly with prevention [of diseases] as the almost inevitable result.’ This being the case, the meaning of non-directiveness needs to be re-examined.

23 An American focus-group study on genetic services, which resulted in two distinct ‘wish lists,’ one drawn up by users with or at risk for genetic conditions and one by doctoral-level geneticists and masters-level genetic counsellors, is also interesting in this discussion (Wertz and Gregg 2000). Though performed in a different cultural context than the present study, it is noteworthy that the users’ two major concerns were respect for persons and accuracy of information, which they described as clarifying the limits of the knowledge available. Issues of non-directive counselling and informed consent were missing from their list and, instead, it was stated that advice should be given if asked for. The geneticists and genetic counsellors were primarily concerned about economic, social and time constraints on the services and with access, availability, setting, on-going evaluation and professional education (Wertz and Gregg 2000:262).
Notes to Chapter 6

1 Jörgen draw this conclusion after having discussed use of PGD for Turner’s syndrome and triple X. Women with triple X may have some difficulty in speech, in learning and in emotional responses. For a description of Turner’s syndrome, see Appendix A.

2 The original, Swedish excerpt being: ‘luddigt.’

3 The previous kinds of narratives of concern dealt with difficulties in defining and evaluating life with genetic disease, with risks and with actual, complicating aspects of uses of the technologies. These aspects made a certain use more complicated than desired, as seen be the interviewees, but the use did not qualify as an example of an exaggerated use or a misuse.

4 Such was also the case when Nils referred to an illustration in another journal in which a woman and a doctor discussed the result of prenatal diagnosis. ‘This will be a bright child,’ Nils remembered the doctor as saying, ‘tall and blue-eyed.’ ‘How strange,’ the woman remarked, ‘my husband has brown eyes and he is not that tall. Can I borrow the phone and call him?’ Having made the call, the woman turned to her doctor, saying ‘Well, we won’t have the child.’ Nils commented on the story and he explained that it made him think about the quality control of foetuses as well as embryos (14.32). Quality control in the sense not only of a search for a particular genetic disease for which the couple were at risk, was an example of a misuse (14.32, 12).

5 The original, Swedish excerpt being: ‘Man ser mellan fingrarna.’

6 There were also a few exceptions to this general tendency, such as in the interview with Björn who described all uses of PGD as morally problematic and undesirable as long as it implied embryo disposal.

7 Hypospadias is a condition characterised by the poor growth and closure of the urethra.

8 As a tangent, and as have been seen in Ch. 1, according to the Swedish policy PGD should only be used for certain severe genetic disease. However, the view that PGD should only be used for severe genetic diseases was not more common among Swedish interviewees than among other interviewees, nor did the Swedish interviewees express frustration with the notion of ‘severe’ genetic disease in more detail than did interviewees in other countries.

9 Alva also explained that she considered her previous work with abortions as ‘incredibly important’ work ‘even if it meant that I was killing foetuses,’ particularly when women saw no other opportunity than abortion and when abortions were not based on knowledge of the genetic disposition of the foetus. She considered abortions made on the basis of genetic knowledge to be morally problematic.
One interviewee, Vittorio, also explained that there was confusion in present-day society and among certain groups in society, which derived from the ‘horizontalisation of hierarchic values.’ These groups of people did not share Vittorio’s understanding of the primary value of human life from conception and onwards (2.34).

The original, Swedish excerpt being: ‘Jag menar om jag vore filosof […] och filosoferade på mitt rum då skulle jag va kanske va väldigt säker på min sak och säga att det här kan jag inte acceptera, men så skall man också tänka att man kanske möter patienten eller paret’ (13.22).

The original, Swedish version is: ‘Dom drivs ju av en lust att driva tekniken vidare och (hm) dom är förvridna av möjligheterna, vad som går och göra det måste göras och då finns det ju en risk att utvecklingen drivs framåt utan att vara på nåt sätt grundad i samhällets etiska värderingar’ (13.112).

Giovanna and Elisabetta described PGD as misused by colleagues at private PGD centres, who wanted to use it for a ‘bit of everything’ (not only genetic diseases) and who did it mainly for the money (3.6, 26, 5.2, 56).

Such was the case when Nils explained that one should not use technologies as means to the creation of as ‘perfect’ as human beings as possible. Instead, technologies should be used as a means for humans to live as well as possible, given their limitations (14.71).

The original, Italian version is: ‘Non succederà mai che io andrò verso la perfetazione, andrò verso un buono stato di salute.’

Obviously, Andrew’s former fellow-student did not need to think it was right for children to die any more than did Andrew himself.

This statement was part of her reflection on what she would do if she knew that her (future) child may inherit a certain genetic disease.

The idea that there was a way of nature and that this was positive, that we should not make ‘ourselves masters of nature,’ was also present in a section where Nils wondered (in a discussion of germ-line gene therapy) whether it was not the case that ‘nature shall have its way.’ Nils said that germ-line gene therapy was problematic since its use never was decided by the future child (14.55).

The Swedish ‘herre’ can be translated as master or lord.


The original, Italian version being: ‘È davvero un delirio di onnipotenza davvero secondo me è volersi sostituire a un Dio ipotetico.’
21 It can be noted that in the past some theologians, such as Joseph Fletcher (1987:351 [1974]) and Paul Ramsey (1987:366 [1970]) have even argued that it is a ‘moral responsibility’ and a ‘duty’ not to pass on genes for a particular disease to one’s children when it can be avoided through embryo selection.

22 Here, a distinction can be made between uses of technologies beyond a morally motivated boundary and uses beyond moral reflection. Whereas interviewees described uses of technologies beyond a morally motivated boundary, no interviewee described uses of technologies beyond moral reflection.

24 A comparison can also be made between this line of reasoning and the reasoning of some Greek women who described IVF as a natural technology. These women described themselves as morally responsible for treating their bodies in such a way that they would ‘overcome childlessness’ – and having children was a step in the realisation of their ‘nature’ as women. In this reasoning, as above, IVF did not work against nature. Furthermore, and as was not the case in the interviews in the present study, the Greek women described IVF as a technology that could help to correct damage that had been done to them by nature (Paxson 2003:1857). See also Sarah Franklin’s (1997:103) description of the naturalness of IVF, and Susanne Lundin (1997).

Notes to Chapter 7

1 Autonomous persons, these writers claim, act in accordance with ‘self-chosen’ plans (Beauchamp and Childress 2001:58). The idea of a plan may be interpreted as implying a certain kind of reflection in order to have a plan. This being the case, and if autonomous acts require that reflection on whether acts harmonise with plans has taken place, Beauchamp and Childress’ conception is procedural rather than formal. Still, Beauchamp and Childress contrast their own view with certain procedural accounts and state that theirs is different.

2 Odysseus wished to make sure that he would not steer the ship towards the rocks when he heard the beautiful voices of the sirens and beforehand he asked to be bound to the mast so that he could not do so.

3 The idea that the content of my decision needs to be independent of the will of others (see Dworkin 1996:22-23).

4 Some distinguish between personal autonomy and moral autonomy. In the light of this some hold that we are morally autonomous when we are morally responsible for our decisions, whereas others claim that to the extent that all decisions promote or detract from a certain good life all decisions are moral (though of different magnitude; see Govier 1997:16).
Mere acknowledgement of the vaguely formulated social nature of individuals is not enough, critics have argued. Social relations can be important in a number of different ways, and these ways need to be conceptually elaborated and their relevance for the conception of autonomy needs to be discussed (McLeod 2002:106).

Autonomy, according to Voyer (1996:6) 'au plein sens du terme, c’est le plein développement de ce potentiel qui se déploie en trois facettes: le souci de soi, le souci d’autrui et le souci de chacun.'

Nordenfelt’s (2000:131-132) use of the concept of mental force is helpful in this regard. As an example of physical force, one person forces another person to move to a certain place by dragging her or him to that place. Here, the person being dragged does not have the practical possibility of not moving to the particular place.

See also Nordenfelt (2000:129-131). In his discussion, abilities such as these are abilities constituting autonomy and not abilities regarding choice in general.

What we find acceptable probably varies, but as one criterion, the basic deliberation of those involved in shared decision-making must not be brushed aside, or be disregarded, if the final choice is to qualify as a shared choice.

If we continue living in a certain way, under these conditions, we do so not out of choice.

As stated by Marilyn Friedman in a discussion of reflective capacities for procedural autonomy; I take this to be accurate for all abilities relevant to deliberation.

For a criticism of a narrow focus on informed consent, in the context of surrogacy, see Pariente-Butterlin (2002).

My understanding of intention is different from the understanding of intention as something that can only occur (or primarily occurs) as a result of a decision. Intentions need not be preceded by decisions. In this sense, I also avoid the risk of infinite regress: if intentions are always the result of decisions and if decisions are intentional (as other acts are), such infinite regress seems unavoidable. However, while the decision to X is preceded by the intention to decide X, the decision to X also results in the intention to act on the decision to X. Also, while intention is not graded, wants and wishes that I may have can so be. For a discussion of intentions, acts and decisions see Ryle (1968) and Nordenfelt (2000).

However, I consider strong substantive accounts to go too far. If such accounts are to be used, we need to set up criteria for what qualify as ‘accurate’ contents of choices and I believe that this is problematic. One obvious problem with this approach concerns who should elaborate the criteria.
We may of course have a hidden agenda: we may say that we decide P, while we in fact decide non-P. If so, we have the intention to act in accordance with non-P and not P.

This makes the very notion of patient slightly misleading. Patients in everyday vocabulary often have a disease or an impairment that makes them contact a medical professional, though this is not always the case, as is clear in the whole field of delivery care. Furthermore, if preimplantation genetic screening is used, neither of the partners need have a disease nor be a carrier of a disease, if infertility is not a consequence of a particular disease or is understood as a disease.

There is an important difference between the woman and man in the reproductive clinic, in terms of who will undergo most invasive treatment and be subject to most risks. Still, in homologous IVF, both partners are physically involved in treatment, though the woman has the lion’s share. In heterologous IVF, both partners are also involved since both are needed to establish the need of a donor or donors.

As a consequence, I need not have the intention to reflect on what really matters to me in order to have an autonomous choice (compare discussion of unqualified choice.)

In contrast to other procedural conceptions, what matters is not whether we evaluate which first-order desires, beliefs, values etc. we want to identify with (as argued by Frankfurt 1971), nor that we actually use capacities or skills for deciding what really matters to us with regard to the area of choice (Meyers 1989). The ability to engage in the reflection I have in mind can be compared with a second-order capacity to reflect on our first-order values (Dworkin 1996:20).

Of course, what I regard as important need not be a matter of choice and conscious decision (see Cuypers 2001:98-105).

For an interesting discussion of self-trust and autonomy in the health-care context, see McLeod and Sherwin (2000). To be motivated to exercise choice, they say, the person choosing must trust ‘her capacity to choose effectively.’ The person choosing must also trust ‘the judgements she makes that underlies her own choices’ and her ability to act on her decision (McLeod and Sherwin 2000:263-264).

As said in the discussion of choice, what we find acceptable varies. As a formal criterion, the reflection on what really matters to any of those involved in shared decision-making must not be brushed aside, or be disregarded, if the final choice is to qualify as a shared autonomous choice.

However, I will not discuss whether a particular couple or professional really had a choice or autonomous choice in a particular empirical example. Only in rare cases does the empirical data allow a discussion of whether a particular couple or professional ‘really’ had a choice or autonomous choice.
24 As an example of too little information, a British study of perceptions of women undergoing IVF has shown that whereas the majority of these women felt involved in the decision-making (8 of 10 women of 71 women in total), few women felt they had been given enough information about the advantages and disadvantages of stopping treatments or of other options such as adoption or fostering (Peddie et al 2004).

25 It may be interesting to note that empirical research has indicated that 12 of 20 women who had undergone IVF treatment were dissatisfied with the opportunities to ask questions and discuss treatments (Price 1990).

26 The internalised technological imperative could be understood as an internal constraint in a psychological sense. It is internal – internalised – as a moral imperative, and couples felt that they needed to, or should, follow it.

27 Such a hampering influence may be interpreted as a matter of cultural imperialism, if understood as a systematic and internalised exclusion of certain options, or as weakness of the will.

28 Nordenfelt suggests that in cases of ‘compelled actions’, we still have a practical possibility of acting (Nordenfelt, forthcoming). However, this is not how I use the concept of compulsion. When compelled, we typically do not have the practical possibility of acting.

29 This can also be compared with Nordenfelt’s discussion of ‘physical force’ (2000:131-132) as what takes place when someone has no choice and is, physically, dragged from one place to another. In the above scenario, such ‘drag’ takes place at the mental level: the couples concerned are dragged to choice – they must choose.

30 It may be argued that they could explain their wish not to choose as soon as possible, and then not get so much information, but in that case their situation would have changed. A situation of choice would have arisen for them. For a discussion of the ‘right not to know,’ see Chadwick et al (eds) (1997).

31 Obviously, such gender specificity, if present as a tendency in larger groups of people, will vary with individual background as well as cultural context.

32 Research on prenatal diagnosis has also shown that some genetic counselors experience the expectation that they should support all decisions unconditionally, decisions that they consider morally problematic such as sex selection included, as highly stressful (Burke 1992).

33 Some also state that when PGD is discussed in the gender-neutral language of genetic risk and risk avoidance, it obscures the possible power imbalances between medical professionals and female partners as well as between women and men involved in these choices (Steinberg 1997).

34 As an example of such a criticism, after having reviewed empirical data of interviews with kidney dialysis patients, first-person illness memoirs,
studies of sociological ethnographies of bioethics as a practice within medicine as well as empirical studies of autonomy, Carl E. Schneider (1998) argued that many patients reject the burden of decision-making that is imposed on them. Instead, patients want more ‘personal concern’ and fewer decisions (to be distinguished from information) about treatment.

31 The distinction drawn by Shiloh is further elaborated by Nordgren (2002) in a discussion of how a decision can be reached wisely if casuistry is used as a decision-making method.

Notes to Chapter 8

1 Some hold that in ethics, ambivalence in moral judgements has been understood as a problem and as an unsound phenomenon in need of correction (Bauman 1995:31).

2 In the case of advanced technology we can seldom (construct and) use it on ourselves without the aid of others.

3 Before that, trust has been an occasional topic of discussion in philosophy. According to the philosopher Annette Baier, there has been a suspicious ‘tradition of silence’ as regards the concept of trust (1996:96). However, if this is the case, there are also a number of exceptions, such as discussions of contracts (contracts might be seen as making explicit what is implicit in trust) that imply a trust in the usefulness of such contracts. In theology, analyses have been done of trust in God, but such analyses have not always extended to other forms of trust, though, again, with some important exceptions, such as K. E. Løgstrup (1992 [1956]). In sociology, several analyses of trust have been done (Simmel 1997 [1900], Barber 1983, Luhmann 1988). Some sociologists also hold that the interest in trust is a consequence of modernisation, new kinds of risks and increased complexity and globalisation (Giddens 1991, Beck 1992), and if such is the case, this may partly explain the previous, relatively speaking, silence.

4 In this sense, my definition relates to Giddens’ understanding of trust as ‘what derives from faith in the reliability’ of the trusted (Giddens 1990:33).

5 In traditional dogmatics, a distinction is also made between fides qua creditur, the faith through which one believes, and fides quae creditur, the faith in which one believes. The account of faith that I have in mind is of the former kind.

6 However, the emotional dimension may be more intense in personal trust relations and less so in system trust relations, i.e. when someone trusts in an abstract system.
7 Which, of course, we may have more or less reason for.
8 However, risks are not always consciously thought-through at the time of trust (I may well be in a risky situation without being aware of the risk involved) since trust need not be conscious. I use the term ‘let down’ in a metaphorical sense. In a strict sense, objects cannot let anyone down.
9 This also highlights the aspect of unwanted/unwelcome interpersonal trust. The trusted may not want our trust, nor want to fulfil the expectations that the trust implies.
10 As argued by Daryl Koehn (1998), children-parents trust relations often go through different and distinct phases.
11 We may also ask if we need reasons for trust (arguably, not always) and what it means to have a justified trust. Though we can reflect on and discuss reasons for conscious trust without necessarily being ambivalent about whether we should trust, to ask for guarantees, to be concerned or worried or afraid that what we trust may not be the case, indicates ambivalence. Some hold that it would be an indication of lack of trust to ask for guarantees (Govier 1997). Others hold that trust cannot be a topic for reflection without its changing. As soon as we start to reflect on our trust, we no longer trust in the same way (Lagerspetz 1994).
12 McLeod suggests that this is a component of the expected moral integrity. She also suggests that moral integrity implies that we ‘want’ people to ‘have an enduring commitment to acting in a morally respectful way toward us and we want their actions to accord with that commitment’ (2002:23). This I hold, may be the case, but it is no reason to prefer moral integrity to good will.
13 When Baier analyses trust (1996), she takes trust in child-parent relations as an important example; in such relations expected good will is a typical condition. However, as our ability to reflect on our parents’ characters and behaviour develops, it also becomes clear that what we expect is not simply good will but good will directed by an acceptable idea of what is good for us. Though, of course, a teenager may argue that if we had good will towards her we would allow and encourage a number of things that we don’t since her and our understanding of what is good for her are different.
14 Some make a distinction between trust in a known, specific institution and in institutions in general (Hall et al 2002).
15 It has also been shown that such ‘lay’ ambivalence (or negative attitude) is not as common with regard to gene technologies used in the treatment of severe genetic diseases as with regard to other high-technological medicine (Calnan et al 2005). The study of Calnan et al did not discuss PGD or GLGT for genetic diseases, but examples such as prenatal genetic screening, stem cell implantations and GLGT in order to slow the human ageing processes.
16 Studies show that people described their lack of trust in governments as due to the perception that their own values and beliefs are not reflected in policies of the governments (among other factors) (Zussman 1997:245). If people expected institutions to be guided by values that were contrary to values dominant in society, their trust in institutions was reduced (Listhaugs 1984), as was their trust in medical reforms (Kehoe and Ponting 2003).

17 As we have seen, interviewees also interpreted the lack of technical safety in different ways. Some questioned the use of PGD on the basis of the low success rate, whereas others explained that the technical uncertainty was a reason to continue working on and improving the technologies but that PGD should still be offered.

18 Pellegrino and Thomasma (1993:68) adds that the ‘intimacy, specificity, and personal nature of the relationships with physicians compel us’ to be concerned with ‘personal qualities.’ Ultimately, they say, we trust not primarily the system but ‘the person of the physician.’ However, I suggest, if this is the case this is an example of mergers between system trust relations and personal trust relations.

19 In this sense, we do not simply expect the trusted to act in a predictable way.

20 As previously seen in such writing, Shakespear says, it is possible to detect the theme of a ‘plot against disabled people’ through the construction of a ‘conspiracy story’ that rests on use of the Nazi metaphor and a ‘denial of the relevance of impairment’ (Shakespeare 1999:679).

21 Some writers suggest that patients may not trust medical staff to the extent they would if they had full knowledge of mistakes made on the operating table and in the ward (Giddens 1990:86). In the case of experts, they typically have some ‘inside knowledge.’

22 If we trust the professional as a professional, as in system trust relations, we need not expect good will. This is also the case in the examples used to criticise good will as a condition for doctor-patient relations. If we trust the professional as in merger scenarios, we do expect good will.

23 System trust may provide the starting-point for a later interpersonal trust, but this is not the point here. Even if I do get to know this medical professional – imagine that she becomes my local GP and that I meet her now and then over a period of several years – I still will not only trust her as I trust a friend when I meet her at the local clinic. I also trust her to act in accordance with her professional role.

24 Interviewees also described how every member of the medical team was given the opportunity to share their concern and how this in some cases also resulted in their not offering a certain treatment. They reflected on ethical difficulties and they did so together with all the
other members of the medical team and, as one interviewee put it, with 'anyone who would be relevant'.

25 Among the Romans, this was the task of the God Fatum, in Greek mythology moira had a similar role.

26 As an example, we may expect something 'good' of fate if we reason that 'what takes place as a result of fate is good.'

27 This special concern is not to be confused with egoism or the idea that we are closest to ourselves and therefore put ourselves in the first place; it implies that we are not just anyone to ourselves.

28 For a discussion of whether trust can be 'cultivated', see Govier (1997:40-46) and Hardin (1996).

29 In a similar way, trust is a component when informed consent is given. For a discussion of informed consent, trust and biobank research, see Hansson (2005) and Høyer (2002).

30 See also the philosopher Robert M. Veatch’s (1991) discussion of in what ways professionals should not be trusted.

Notes to Chapter 9

1 No interviewee discussed the issue of genetic identity and its moral implications but, as I will show, it is relevant to some of their reasoning.

2 The distinction ‘old’ and ‘new’ may appear as unnecessarily dichotomising. However, as I said, I follow the usage of Draper and Chadwick (1999) and I consider this to be pedagogically clarifying.

3 This person's particular cells at these two times are also likely different since cells not only divide but also die.

4 See Appendix A.

5 However, if one has the dynamic genetic identity view, GLGT does not imply a changed identity (the issue of who) but still exercise an influence on someone’s genetic set-up.

6 The concept of 'genesis problems' is coined by the philosopher David Heyd (1992:11). He distinguishes between problems as regards the existence, number and identity of future persons and issues concerning the way one generation takes care of the interests of a future generation whose existence, number and identity are 'given.' However, I use 'genesis' in genesis choices in order to highlight that the discussion concerns the genetic set-up of those that will soon be brought into existence, but that do not yet exist.

7 As has been seen, this is also an issue discussed by Draper and Chadwick (1999).
During the period January-April 2005, there was also a public consultation that sought to analyse the issue of what welfare of the child means and how it can be taken into account (HFEA 2005b). However, at the time of this book being printed, the results of the consultation have not yet been published.

If, instead, we have a static genetic identity view, the embryo undergoing GLGT is numerically the same, but genetically different.

Such reasoning also applies to PGD since this is a selection of embryos; if a particular child is born after PGD this child would not have existed without PGD being used. If so, arguably, this child could not have been morally wronged by not being brought into existence.
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Explanations of Medical Notions

Achondroplasia
Achondroplasia is an autosomal dominant restricted growth condition. It causes a distinct form of dwarfism, characterised by short arms and legs.

Allele
One of several alternative forms of a gene or DNA sequence at a specific chromosomal locus, i.e. location.

Aneuploidy
Aneuploidy refers to the occurrence of one or more extra or missing chromosomes.

Autosomal dominant inheritance
A condition is dominant if it is manifest in a heterozygote; an individual is heterozygous at a particular location on a chromosome if she or he exhibits two different forms of a DNA sequence at that location. If a condition is autosomal and dominant, the affected person usually has at least one affected parent. The child of the affected person has a 50 per cent chance of being affected. The condition affects either sex and it is transmitted by either sex.
**Autosomal inheritance**
Inheritance by way of one or more non-sex chromosomes.

**Autosomal recessive inheritance**
A condition is recessive if it is not manifest in a heterozygote but in a homozygote. An individual is homozygous at a location on a chromosome if she or he exhibits two identical forms of a DNA sequence at that location. If a condition is autosomal and recessive, affected persons are usually born to unaffected parents and parents are usually asymptomatic carriers. The condition affects either sex.

**Autosome**
Non-sex chromosome (any chromosome other than the sex chromosomes).

**Beta thalassemia**
Beta thalassemia is an autosomal recessive blood condition. In beta thalassemia minor, the individual has one beta thalassemia gene. This may result in mild anaemia. In beta thalassemia major, the individual has two genes for beta thalassemia. If so, anaemia usually begins to develop within the first months after birth. The infant has difficulty in feeding, bouts of fever, diarrhoea and other intestinal problems.

**Carrier**
An individual is a carrier if she or he has a risk of transmitting a particular gene or chromosome condition to her or his offspring.
<table>
<thead>
<tr>
<th><strong>Cystic fibrosis</strong></th>
<th>Cystic fibrosis is an autosomal recessive genetic condition. In cystic fibrosis, a defective gene causes the body to produce a thick mucus that can clog the lungs and lead to severe lung infections. The mucus also obstructs the pancreas. It can block the bile duct in the liver.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dominant</strong></td>
<td>Describes any trait which is expressed in a heterozygote; an individual is heterozygous at a location on a chromosome if she or he exhibits two different forms of a DNA sequence at that location.</td>
</tr>
<tr>
<td><strong>Duchenne's muscular dystrophy</strong></td>
<td>Duchenne’s muscular dystrophy is an X-linked recessive genetic condition. It results in a fatal progressive degeneration of muscles that usually appears before the age of four. The mean age of death is 17 years.</td>
</tr>
<tr>
<td><strong>Fragile X syndrome</strong></td>
<td>Fragile X syndrome is an X-linked genetic condition. It can result in developmental delay, speech delay, short attention span and mild-to-moderate autistic-like behaviour.</td>
</tr>
<tr>
<td><strong>Gene</strong></td>
<td>A DNA segment which (often) specifies a functional entity in the cell.</td>
</tr>
<tr>
<td><strong>Germ-line</strong></td>
<td>Egg and sperm cells, i.e. gametes, and precursor cells from which gametes are derived.</td>
</tr>
</tbody>
</table>
Haemophilia A or B

Haemophilia is an X-linked recessive genetic condition that results in spontaneous or excessive bleeding. A low level (or absence) of a blood protein essential for clotting is characteristic of both haemophilia A and B. Haemophilia A results from mutations in the gene encoding factor VIII in the blood clotting system, whilst haemophilia B results from mutations in the gene encoding factor IX. In both cases, haemorrhages are common after minor traumas.

Heterologous in vitro fertilisation

In vitro fertilisation – literally, fertilisation in glass – with donor.

Heterozygous

An individual is heterozygous at a locus (location on a chromosome) if she or he exhibits two different alleles at that locus.

Homologous in vitro fertilisation

In vitro fertilisation – literally, fertilisation in glass – without donor.

Homozygous

An individual is homozygous at a locus (location on a chromosome) if she or he exhibits two identical alleles at that locus.

Incontinentia pigmenti syndrome

Incontinentia pigmenti syndrome (IPS) is a dominant X-linked genetic condition. Infants with IPS are born with blistery lesions, which later heal as papules. Papules leave damaged
hyperpigmented (too much pigment) skin behind. People with IPS can also have other problems including dental problems, hair loss and neurological problems. Some children with IPS have mental difficulties, seizures, slow motor development, and muscle weakness in one or both sides of the body.

**Klinefelter syndrome**

Klinefelter syndrome is related to the presence of one or more X chromosomes in excess of the male XY complement. It is a cause of male infertility and a reduced or absent secretion of hormones from the sex glands – in men, in the testis. Klinefelter syndrome can also result in certain mental difficulties.

**Locus**

A particular location on a chromosome.

**Mitochondrial DNA**

DNA in the mitochondria as opposed to DNA carried on the chromosomes in the cell nucleus.

**Mosaicism**

A person is a genetic mosaic if she or he has two or more genetically different cell lines which derive from a single zygote, i.e. an early embryo. This phenomenon is called mosaicism.

**Oculocutaneous albinism**

Oculocutaneous albinism is an autosomal recessive genetic condition. It can result in absent or decreased melanin in the skin,
hair and eyes.

*Oocyte*  
Immature egg cell.

*PGD HLA typing*  
In PGD Human Leukocyte Antigen typing (HLA typing), also called PGD tissue typing, an embryo is selected for implantation on the basis that it can provide a tissue match for transplant to an already existing family member.

*Phenotype*  
The sum of all traits and characteristics observed in an individual or that can be inferred with regard to that individual.

*Recessive*  
Describes any trait which is not expressed in a heterozygote but in a homozygote. An individual is homozygous at a location on a chromosome if she or he exhibits two identical forms of a DNA sequence at that location.

*Spinal Muscular Atrophy, SMA*  
Spinal Muscular Atrophy is an autosomal recessive neuromuscular genetic condition. Muscles weaken and waste away (atrophy) owing to the degeneration of motor neurons (certain nerve cells) in the spinal cord. Normally, these motor neurons pass on signals, which they receive from the brain, to the muscle cells. When these neurons fail to function, the muscles deteriorate. The brain and the sensory nerves are not affected.
Tay-Sachs disease

Tay-Sachs disease is an autosomal recessive genetic condition that causes progressive destruction of the central nervous system. Symptoms appear between six and ten months of age, such as progressive muscular weakness and decreased attentiveness. Most children with the condition die before the age of four.

The XYY male

The only features that are agreed on are tall stature, a tendency towards cystic acne (infections deep within the follicles that are cyst-like) and certain difficulties as regards motor and language development.

Twinning

The process through which an embryo divides and becomes two separate, twin blastomeres (blastomeres form the two- or four-cell embryos). If the two blastomeres produced by the first cleavage become separated, this results in monozygotic twin blastomeres that can implant separately.

X-linked dominant inheritance

If a condition is X-linked and dominant, it affects either sex. The child of an affected woman, regardless of its sex, has a 50% chance of being affected. All the daughters, but none of the sons, of an affected man will be affected.
**X-linked recessive inheritance**  
If a condition is X-linked and recessive, it affects (almost exclusively) males. A woman may be affected if the father is affected and the mother a carrier.

**Y-linked inheritance**  
If a condition is Y-linked, it affects only males. Affected males always have affected fathers and all sons of the affected males will be affected.

APPENDIX B

Interview Guide

Interviewees were asked questions such as those below (though the exact phrasing of the questions varied). Depending on what interviewees chose to tell, I also followed up their reflections with other questions.

PGD: Questions with regard to interviewees’ experiences
How have you had any contact with PGD?
Are there any events or cases related to the use of PGD that have affected you in a special way?
Are there any events or cases related to the use of PGD that have made you reflect on ethical questions specifically?

PGD: Previous and present situations
How would you describe the former situation, before PGD existed as a possibility, for couples at risk of having children with a severe disease?
Has the situation changed in any way with PGD? If so, in what way?
Are there any new questions that couples need to address now that PGD exists as a possibility, as you see it? If so, which are they?
How would you describe your former professional situation, before PGD existed as a possibility, for you as a gynaecologist/geneticist?
Has the technology introduced new questions in the encounter between patient and doctor?

PGD: General questions
How would you describe the non-medical advantages with PGD – as you understand them?
How would you describe the non-medical disadvantages with PGD – as you understand them?
Are there any specific questions that you consider crucial to the ethical discussion of PGD?

**PGD: Specific questions**
To what extent do you think that a woman and a man who want to use PGD shall be allowed to influence what is searched for?
Some argue that certain diseases are very painful and that there is a limit to how painful a life anyone should be ‘forced’ to live. Implanting eggs with very severe diseases could be problematic in this view. What is your view on this argument?
There is a discussion of PGD in which notions such as human freedom, human dignity and human rights recur. Are such notions relevant in your reflections on moral aspects of PGD? If so, in what sense?
Are other notions equally or more relevant?
PGD is sometimes described as allowing the implantation of embryos that are healthy in a certain respect or, less commonly, as promoting health by sorting out embryos with a severe disease. Do you agree with such descriptions? And, what would you say that health means?

**Germ-line gene therapy**
Do you recognise any non-medical difficulties that count against germ-line gene therapy?
What possibilities do you see with germ-line gene therapy?
Germ line gene therapy is carefully regulated in European law. Do you think germ cells should be treated in this special and strict way? Why/why not?

**Lifeinterpretations**
Are there any experiences that you consider particularly relevant to your understanding of uses of PGD and germ line gene therapy?
Are there any aspects of your lifeinterpretation or your religious conviction, if you have one, that you consider particularly relevant to your understanding of the technologies?
Summary
Are there any non-medical aspects of PGD and germ-line gene therapy that you consider it relevant and/or important to discuss but that we have not discussed during the interview? Any moral aspects?
APPENDIX C

Fictitious Names of the Interviewees

Fictitious Names of the Italian interviewees
Interviewee 1: Angelo
Interviewee 2: Vittorio
Interviewee 3: Giovanna
Interviewee 4: Simonetta
Interviewee 5: Elisabetta
Interviewee 6: Chiara

Fictitious Names of the British interviewees
Interviewee 7: Steven
Interviewee 8: Andrew
Interviewee 9: Joyce
Interviewee 10: Ned
Interviewee 11: Evelyn
Interviewee 12: Ian

Fictitious Names of the Swedish interviewees
Interviewee 13: Alva
Interviewee 14: Nils
Interviewee 15: Hilda
Interviewee 16: Åsa
Interviewee 17: Björn
Interviewee 18: Jörgen

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APPENDIX D

List of Abbreviations

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<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>CNB</td>
<td>Centro Nationale per la Bioetica</td>
</tr>
<tr>
<td>GLGT</td>
<td>Germ-line gene therapy</td>
</tr>
<tr>
<td>GTAC</td>
<td>Gene Therapy Advisory Committee</td>
</tr>
<tr>
<td>HFEA</td>
<td>Human Fertilisation and Embryology Authority</td>
</tr>
<tr>
<td>IVF</td>
<td>In vitro fertilisation</td>
</tr>
<tr>
<td>PGD</td>
<td>Pre-implantation genetic diagnosis</td>
</tr>
<tr>
<td>SMER</td>
<td>Swedish National Council on Medical Ethics</td>
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