The Scottish Pre-Implantation Genetic Diagnosis and Screening Service
Framework for Decision Making

Date of issue: May 2014
Version 2.0
This document has been produced by the Expert Panel on Pre-Implantation Genetic Diagnosis and can be found on the National Services Division website at www.nsd.scot.nhs.uk

If you have any queries regarding this Framework, please contact:

Dr. Helen Lyall
Consultant Gynaecologist
ACS Unit
Walton Building
Glasgow Royal Infirmary
G4 0SF
helen.lyall@nhs.net

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Executive Summary

An Expert Panel for Pre-Implantation Genetic Diagnosis (PGD) was established in 2010 to develop a framework for ensuring that decisions made relating to access to and prioritisation of patients in the Pre-implantation Genetic Diagnosis Service in Scotland are reasonable, transparent and justifiable.

The Panel included wide representation from those involved in the clinical delivery of the service, to service planners, lay representatives, as well as those working in the field of law and medical ethics. Reasonableness, transparency, justifiability and equitability were central principles embraced by the Panel to ensure procedural fairness and accountability in the decision making processes.

The criteria that should be applied in deciding which individuals should be offered access to the PGD service include:

- Predisposed risk of genetic condition.
- An accurate test is available and a license has been obtained from the Human Fertilisation and Embryology Authority.
- Referrals to be made before woman’s 39th birthday.
- Woman to have a BMI between 18.5 and 30. [Patients should only be placed on a waiting list if their BMI is ≥ 18.5 and ≤ 30].
- Woman to have Anti-Müllerian Hormone levels greater than 6.0 pmol/l.
- Individuals or both partners should be negative for HIV, Hepatitis B and C.
- Couple must have been co-habiting in a stable relationship for a minimum of two years.
- No previous unaffected genetic children as a couple.
- One partner has no genetic child.
- Couples are eligible for up to 2 cycles of PGD. [Previous NHS IVF/ICSI treatment will be subtracted from this].
- Both partners must be Scottish residents and eligible for NHS treatment.
- Both partners must be non-smoking for at least 3 months before treatment and continue to be non-smoking during treatment.
- Both partners must abstain from illegal and abusive substances.
- Both partners must be methadone free for at least one year prior to the treatment.
- Neither partner should drink alcohol during the period of treatment.

The Expert Panel will continue to exist as a group which clinicians can consult for an impartial expert opinion and will be the first point of contact for advice and expertise. A decision by the Expert Panel is considered final, but the couple will have right of appeal through the existing Exceptions Panel arrangements within NHS Greater Glasgow and Clyde.
1. Introduction

Difficult decisions are made at all levels of healthcare organisations on a regular basis; whether they relate to the planning and prioritisation of services for the population, or decisions about individual patients. The challenge is to ensure that such decision-making is reasonable, transparent and justifiable\(^1\). This document provides a framework for ensuring that decisions made relating to access to and prioritisation of patients in the Pre-implantation Genetic Diagnosis Service in Scotland meet these goals.

2. National Services Division

National Services Division (NSD) is a division within NHS National Services Scotland (NSS). Each year, NSD receives top-sliced ring-fenced funding from the Scottish Government Health Directorates (SGHD) to commission and to performance manage nationally designated specialist services, National Managed Clinical Networks (NMCNs) and screening programmes on behalf of NHS Scotland. NSD’s primary purpose is to ensure the provision of high quality, effective, specialist health and screening services to meet the needs of the population of Scotland. This is done through a continued cycle of performance management. NSD works within the principles of safe, equitable, efficient, effective, person centred and timely care as defined in The Healthcare Quality Strategy for NHS Scotland\(^2\).

The Scottish Pre-implantation Genetic Diagnosis Service is one of the nationally designated services commissioned by NSD. A full list of designated services can be found at on NSD’s website at [http://www.nsd.scot.nhs.uk](http://www.nsd.scot.nhs.uk).

3. Scottish Pre-implantation Genetic Diagnosis (PGD) service

The Scottish Pre-implantation Genetic Diagnosis (PGD) service was designated as a national service in 2005. Cytogenetic testing for fetal chromosome abnormalities is offered at the Glasgow Royal Infirmary, NHS Greater Glasgow and Clyde. On 1\(^{st}\) April 2010, the nationally designated PGD service was expanded to provide molecular single gene testing for PGD at The Royal Infirmary of Edinburgh, Edinburgh, NHS Lothian.

4. Pre-Implantation Genetic Diagnosis

4.1 What is Pre-Implantation Genetic Diagnosis?

Pre-implantation genetic diagnosis (PGD or PIGD) refers to procedures that are performed on embryos prior to implantation or oocytes prior to fertilisation. PGD is a procedure which allows the testing of embryos at an early stage of development to identify whether they are affected by genetic disorder / chromosome abnormality. It can also be used to determine the sex of the embryo where there is a risk of an X-linked disorder.

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Couples undergo a standard in-vitro fertilisation (IVF) or intra-cytoplasmic sperm injection (ICSI) procedure with PGD being performed on the resulting embryos. This allows only unaffected embryos to be transferred back to the woman’s uterus knowing that any resulting pregnancy should be unaffected by the condition for which diagnosis is performed. PGD thus is an adjunct to assisted reproductive technology, and requires in vitro fertilization (IVF) to obtain oocytes or embryos for evaluation.

4.2 What can PGD be used to identify?
There are over 5,000 diseases that result from a genetic change in one or both copies of a particular pair of genes. Pre-implantation genetic diagnosis can only be offered to couples where the genetic change responsible for the disease that their baby is at risk of has been able to be identified.

4.2.1 Chromosomal Abnormalities
In the case of chromosomal abnormalities, PGD is mainly carried out for reciprocal and Robertsonian translocations, and in a few cases for other abnormalities such as chromosomal inversions or chromosomal deletions.

4.2.2 Single Gene Testing
PGD is also available for a large number of single gene disorders. There are essentially 3 categories:
- **autosomal recessive disorders** including Cystic Fibrosis, Beta-Thalassaemia, Sickle Cell Disorders and Spinal Muscular Atrophy type 1
- **autosomal dominant diseases** such as Myotonic Dystrophy, Huntington's Disease and Charcot-Marie-Tooth disease
- **X-linked diseases**, including fragile X syndrome, haemophilia A and Duchenne Muscular Dystrophy

5. The PGD Expert Panel
Due to the high profile and difficult ethical issues involved in deciding who should be able to gain access to the Pre-Implantation Genetic Diagnosis service, an Expert Panel on PGD was established. The Panel, which includes wide representation from those involved in the clinical delivery of the service, to service planners, lay representatives as well as those working in the field of law and medical ethics, was tasked with advising on the criteria that should be applied in deciding which individuals should or should not be offered access to the PGD service. **Reasonableness, transparency, justifiability** and **equitability** were central principles adopted by the Panel to ensure **procedural fairness** and **accountability in the decision making processes**.

5.1 Remit of the PGD Expert Panel
The Pre-Implantation Genetic Diagnosis Expert Panel was established to:
- Develop a framework for decision making, including agreeing access criteria to be used by the PGD service in determining who is able to gain access to the service.
- Act as a reference panel to offer expert independent advice as a result of changes in legislation, technology or in instances where there are particularly complex cases.

A full list of Panel members can be found at Appendix 1.
6. How were the criteria for access to the PGD service developed?

6.1 Ethical Issues

The group considered ethical issues involved with the service and the following headings attempt to capture the wide discussion that was undertaken:

6.1.1 The Primary Ethical Justification for Offering PGD

The primary ethical justification for the offer of PGD is that it can prevent harm to babies who are predisposed to a risk of a genetic condition.

The harm which can be prevented may be to:

- possible future children likely to suffer from disease or disability caused by chromosomal abnormalities or genetic mutations.
- existing children suffering from a genetic condition who otherwise could be treated for this by stem-cells from the cord blood of a tissue matched sibling born after PGD with pre-implantation tissue typing

The perception of the seriousness of the condition by those seeking treatment is an important factor in determining the conditions for which PGD should be licensed.

6.1.2 Some Ethical Issues in the Running of the PGD Service

Consent

The woman always has the final say on whether or not to establish a pregnancy and to continue with the pregnancy. This is on the grounds that the woman has the right to control what happens to her own body.

Equity

PGD, in common with other nationally commissioned services, is offered at only two centres in Scotland but it is important that it should be equally accessible to all people in Scotland. The referral pathways to access the PGD service must be clearly identified to all relevant health professionals as well as members of the public. [See patient pathway section 9]

Realism

The service must be careful not to raise expectations in patients referred into the service above the realistic expectations of what PGD can offer. The technologies used within the service, while proven, continue to evolve and are still being developed and all must be clear and explicit on what can and cannot be achieved by the service. Patients must therefore be warned both of the risks and uncertain outcomes associated with the procedures and that predictions of long-term outcomes may not be accurate. It is important to remember that resources are limited and are not available for experimental treatments.

The Human Fertilisation Embryology Authority (HFEA) states that ‘the perception of the seriousness of the condition by those seeking treatment is an important factor’ in determining the conditions for which PGD should be licensed. Moreover, a recent paper observes that ‘staff find it hard to argue against women’s/couple’s own conclusions about what constitutes seriousness in the context of supporting individual autonomy and choice’.3

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The HFEA is currently the UK licensing authority and the Expert Panel concluded that only those conditions licensed by HFEA can be offered. In determining the conditions for which PGD should be licensed, some room for judgements of proportion must be left to the regulators and professionals involved. However, the HFEA currently invites and considers public responses on conditions awaiting consideration for licensing.

**Flexibility**

The service is designed to allow testing for known or suspected abnormalities in the embryo, but it may for special reasons go beyond this remit; i.e. recognising the evolving science and based on a couple’s own conclusions about what constitutes seriousness in the context of supporting individual autonomy and choice. Ensuring that the professionals are working within a framework, but have the opportunity to consult the Expert Panel, will ensure that the framework is sufficiently flexible to accommodate these ‘special reasons’.

**Humanity**

It is important that those delivering the service are able to communicate in a clear and compassionate way what it is possible to offer to the individual couple. The issues may be technical and complex. However it is important that patients should have a good understanding of what they are consenting to and what the impact of their decisions will be. Readily intelligible information sheets should be available and the service must offer the possibility of follow-up consultation.

### 6.2 Resource Decisions

There are resource implications for all services provided by the NHS, and the PGD service consumes considerable resources. This must of course be off-set by the resources involved in caring for a child/person with a particular genetic condition during their lifetime. While not all of this expenditure will come from the NHS budget, there would likely be a cost on the total welfare budget as well as an impact on the family itself if caring for a child/person with the condition during their lifetime. Some may say that cost is not an ethical issue, but resources spent on one service cannot be spent on another (opportunity cost) so questions of equity are relevant and these do have an ethical dimension.

Ensuring that the professionals are working within a framework that considers resource implications will ensure that the framework is sufficiently ‘realistic’. The Framework that has been designed, acknowledges that resources are finite; however, with a focus on clinically justifiable criteria, it is designed to be used as much in hard economic times as in times when funds are more readily available. The criteria can be tightened or loosened as appropriate by the Expert Panel, depending on the resources at the service’s disposal.

### 6.3 Justiciability and Legal Challenges

The Expert Panel on PGD has considered a range of legal cases which highlight the importance of due process in decision-making. Any challenge to clinical decisions will concentrate on the reasonableness of the decision taken. It is, therefore, important that health professionals are aware of, and routinely use, the criteria developed. This is similarly advised in the Making Difficult Decisions in NHS Boards in Scotland, referred to in section 7.

The Expert Panel on PGD has, therefore, developed a framework for decision making in PGD which is documented below. This identifies the processes and roles and responsibilities of those involved in the decision making process, including the involvement of the Expert Panel and also those of individual clinicians in the service.

As the Panel will have an oversight role in the future the considerations raised in previous cases may prove helpful should the Panel be required to make decisions or advise on particularly complex cases.
The Panel agreed to adopt the generic framework developed by the National Planning Forum as a basis for decision making with regard to access to, and receiving treatment from, the PGD service. This will help to ensure that the decisions reached when discussing individual cases are reasonable, transparent and justifiable. By introducing the approach described here, the NHS Board will be able to build reasonableness, transparency, procedural fairness and accountability into its decision-making process. It is emphasised, however, that good communication is essential at all stages of the process.

### 7. The Framework for making decisions in the PGD service in NHS Scotland

The planning/prioritisation cycle, individual treatment request panels and appeals panel should report direct to the NHS Board, and should each include representation at director level.

#### Requirements

<table>
<thead>
<tr>
<th>Communication and Involvement</th>
<th>Approach</th>
<th>As applied to PGD</th>
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<tbody>
<tr>
<td>Publicise, consult and involve professionals, patients and public in the development of approaches to be used in difficult decisions</td>
<td>Develop approach</td>
<td>The Expert Panel met to agree the approach, and to develop the framework including the criteria and process for decision making.</td>
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<td>Ensure clear communication of decisions</td>
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<tr>
<td>Making difficult decisions</td>
<td>Refine approach</td>
<td>The Expert Panel to publish the framework document.</td>
</tr>
<tr>
<td>Identify and clearly define:</td>
<td>Consult public, professionals (and patients)</td>
<td>The PGD service in partnership with patient representatives to develop the patient information leaflet.</td>
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<td>- the people involved in making the decisions and their roles, responsibilities and qualities</td>
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<tr>
<td>- criteria that trigger the decision-making process</td>
<td>Identify the dilemma</td>
<td>Clinical geneticists and the clinicians involved in the running of the PGD service use the framework to decide who has access to the service.</td>
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<tr>
<td>- values/principles for specific contexts</td>
<td>Identify the values/principles which frame the decision to be taken and where there is agreement and disagreement over these values/principles</td>
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<td></td>
<td>Consider application of values/principles to the evidence presented; consider possible outcomes of preferring one option over another</td>
<td>a) apply framework</td>
</tr>
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<td>Ensure the ability to appeal decisions with clearly defined referral criteria and process</td>
<td></td>
<td>b) Where there are difficulties in applying the framework, the Expert Panel will convene to discuss individual cases.</td>
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<tr>
<td>Enforcement</td>
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<td>Ensure accountability and responsibility at NHS Board level</td>
<td>Decisions should be communicated back to clinicians/managers and patients</td>
<td>If the decision of the Expert Panel is appealed by the patient (or a clinician), then it will be presented to and considered by NHS Greater Glasgow &amp; Clyde’s Exceptions Panel (as the primary host NHS Board of the nationally designated PGD service).</td>
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Identify the dilemma

Identify the values/principles which frame the decision to be taken and where there is agreement and disagreement over these values/principles

Consider application of values/principles to the evidence presented; consider possible outcomes of preferring one option over another

a) If agreement: identify justification and assess reasonableness of decision

b) If disagreement: consider reasonableness of disagreement and relative justifications; revisit core considerations if necessary

If the decision is contested then there should be an appeals process, and this should be well publicised and meet the conditions of good decision-making summarised in the text.
8. Access Criteria for the Scottish Pre-Implantation Genetic Diagnosis Service

Access to the Scottish Pre-implantation Genetic Diagnosis (PGD) service is dependent on individuals meeting the following criteria:

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<thead>
<tr>
<th>Criteria</th>
<th>Type of decision</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>1. Predisposed risk of genetic condition</td>
<td>Clinical</td>
<td>PGD can prevent harm to babies who are predisposed to a risk of a genetic condition.</td>
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<td>The harm which can be prevented may be to:</td>
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<td>• possible future children likely to suffer from disease or disability caused by chromosomal abnormalities or genetic mutations.</td>
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<td>• existing children suffering from a genetic condition who otherwise could be treated for this by stem-cells from the cord blood of a tissue matched sibling born after PGD with pre-implantation tissue typing</td>
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<td>• cross contamination of siblings with compromised immunity e.g. cystic fibrosis</td>
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<td></td>
<td>The perception of the seriousness of the condition by those seeking treatment is an important factor in determining the conditions for which PGD should be licensed. Further details are available from the Human Fertilisation and Embryology Authority (HFEA) website.</td>
</tr>
<tr>
<td>2. An accurate test is available and a licence has been obtained from Human Fertilisation and Embryology Authority</td>
<td>Clinical safety</td>
<td>A full list of tests is available from the Human Fertilisation and Embryology Authority (HFEA) website.</td>
</tr>
<tr>
<td>3. Referral to be made before woman’s 39th birthday</td>
<td>Clinical</td>
<td>Referrals to be made before the woman’s 39th birthday. HFEA data shows a success rate of 11.8% live birth rate with fresh treatment and a 17.4% live birth rate with frozen embryo transfer is achieved up to and including 42 years of age.</td>
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<td></td>
<td>The Expert Panel agreed that a success rate of 10% should inform the upper age limit at which NHS funded infertility treatment should be offered.</td>
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<td>Criteria</td>
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<td>5. Individuals or both partners should be negative for HIV, Hepatitis B and C</td>
<td>Clinical</td>
<td>The service is unable to provide the PGD service to people who test positive for Hepatitis B, C and HIV due to risk of cross contamination and risk to staff. This is inline with <strong>Clinical Pathology Accreditation</strong> requirements.</td>
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6. Anti-Müllerian Hormone (AMH) levels greater than 6.0 pmol/l

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<th>Evidence</th>
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<tr>
<td>Anti-Müllerian Hormone (AMH) levels greater than 6.0 pmol/l</td>
<td>Clinical</td>
<td>In recognition of the available assays and evidence, the Expert Panel agreed that an acceptable Anti-Müllerian Hormone (AMH) levels greater than 6.0pmol/l should be considered as the appropriate level.</td>
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</table>

Plasma AMH is a superior predictor of live birth and anticipated oocyte yield compared with FSH and age, facilitating individualization of therapy prior to first assisted reproduction treatment (ART) cycles. The use of circulating Anti-Müllerian Hormone (AMH) to individualize treatment strategies for controlled ovarian stimulation (COS) may result in reduced clinical risk, optimized treatment burden and maintained pregnancy rates.

- The predicted ‘reduced’ response category (AMH 1.0 to 5.0 pmol/l).
- The predicted ‘normal’ or ‘safe’ response category (AMH 5.0 to 15.0 pmol/l).
- The ‘high’ response category (AMH greater than or equal to 15.0 pmol/l). Women with an AMH of ≥15 pmol/l were younger, produced high oocyte numbers and higher clinical pregnancy rates than other AMH categories after controlled ovarian stimulation.
- Above an AMH concentration of 7.8 pmol/l there was no discrimination in live birth rates.

The evidence from a recent publication demonstrate that similar precision and excellent between-assay agreement should be obtained when laboratories change from the DSL to the AMH Gen II ELISA and they should expect an increase in AMH values of approximately 40%.

- Using the linear regression equation for the full data-set the corresponding cut-offs for the Gen II assay, are 6.4 and 20.4 pmol/L.


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<td>7. Couples must have been co-habiting in a stable relationship for a minimum of two years</td>
<td>Welfare of the child / need for supportive parenting</td>
<td>The Expert Panel agreed that professional clinical judgement should be exercised in this area. The importance of being able to screen extended family members was also noted by the Panel.</td>
</tr>
<tr>
<td>8. No previous unaffected genetic children as a couple</td>
<td>Resource allocation</td>
<td>This issue was debated in detail by the Expert Panel. Members agreed that, in a world where resources for the service are finite, there was an inherent fairness in trying to give more couples one child rather than, for example, one couple having two or more children and one couple remaining childless.</td>
</tr>
<tr>
<td>9. One partner has no genetic child</td>
<td>Under review by National Infertility Group</td>
<td>This would ensure that anyone who could benefit from treatment and fit the criteria should be treated including those whose partner has had a child from a previous relationship. For transparency: The Expert Panel recognises the difference in accessibility between PGD and IVF. This criterion may change dependent on National Infertility Group guidance in 2015.</td>
</tr>
<tr>
<td>10. Couples are eligible for up to 2 cycles of PGD.</td>
<td>Resource allocation</td>
<td>It was noted that within the existing financial envelope two cycles of fertility treatment per couple were available, and this was likely be the case for access to wider fertility services - In Vitro Fertilisation (IVF). The Panel agreed that couples would be entitled to a total of two cycles funded by the NHS. This meant that couples who have received two previous cycles of NHS funded PGD treatment or who have received two cycles of NHS funded IVF/ intra-cytoplasmic sperm injection (ICSI) would not be entitled to any further NHS PGD cycles in the NHS in Scotland. There may be clinical exceptions to this, which would be referred to, and discussed by, the Expert Panel where a decision will be made.</td>
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<tr>
<td>Criteria</td>
<td>Type of decision</td>
<td>Evidence</td>
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| **11. Both partners must be Scottish residents and eligible for NHS treatment** | Establishing the Responsible Commissioner. The Panel recommend that a national decision is made on who is eligible for treatment. | In understanding who pays for a patient’s care the Department of Health has published a framework for establishing responsibility for commissioning an individual's care within the NHS, i.e. determining who pays for a patient’s care. Legislation for Wales, Scotland and Northern Ireland provides that the responsible authority for an individual’s healthcare provision is the one where a person is usually resident and is not based on GP practice registration as provided by English legislation. Department of Health (Sept 2007)  *Who Pays? - Establishing the Responsible Commissioner*  
**Charging for other UK residents**  
Assuming that there is no diminution in the service made available to Scottish residents, UK residents may be treated under this agreement with the associated costs being paid by the responsible commissioner.  
**Other international patients**  
Treatment of European Economic Area (EEA) residents can be offered through reciprocal health arrangements. The associated costs should be paid by the responsible commissioner. Anyone not covered by reciprocal health care agreements is considered a private patient and must provide / be able to provide proof of funding (either personal or from their own health system) before any referrals can be accepted.  
Scottish Government (May 2013)  *National Infertility Group Report* |
| **12. Both partners must be non-smoking for at least 3 months before treatment and continue to be non-smoking during treatment** | Clinical Testing will be applied before placement on the waiting list. | Smoking is associated with reduced fertility. The evidence is consistent, through a range of pathways affecting both male sperm production and many female aspects including hormone levels and egg development  
There is compelling evidence of a negative effect of smoking on IVF outcome which has been shown to apply to females in relation to active and passive smoking, and in addition there is evidence of reduced success with male smoking.  
Scottish Government (May 2013)  *National Infertility Group Report* |
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<tr>
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<tr>
<td>13. Both partners must abstain from illegal and abusive substances.</td>
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<td>Any substance misuse during pregnancy will reach the developing baby and may cause harm.</td>
</tr>
<tr>
<td>14. Both partners must be methadone free for at least one year prior to the treatment.</td>
<td></td>
<td>There is a responsibility on patients to follow these access criteria which are in the interest of the welfare of the child and the effectiveness of treatment. Clinicians may conduct testing to ensure that patients adhere to the criteria, and in the event of a positive result, the patient will not be given treatment. Where there is a known history of former drug addiction, alcohol abuse or domestic violence, patients must receive appropriate counselling prior to being referred as suitable for treatment, and will still be required to meet the welfare of the child criteria. NHS Boards should ensure engagement with the appropriate counselling services.</td>
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</table>
| 15. Neither partner should drink alcohol during the period of treatment. | | Every pregnant woman in Scotland is given a copy of the NHS Health Scotland and Scottish Government publication Ready, Steady, Baby24 which states that there is no ‘safe’ time for drinking alcohol during pregnancy and no ‘safe’ amount. Drinking no alcohol in pregnancy is the best and safest choice. The National Institute for Health and Care Excellence (NICE), which advises healthcare professionals (GPs and nurses), says:  
  - Pregnant women and women planning to become pregnant should be advised to not drinking alcohol in the first three months of pregnancy, because there may be an increased risk of miscarriage.  
  - Women should be advised that if they choose to drink alcohol while they are pregnant, they should drink no more than one or two units of alcohol, once or twice a week. There is uncertainty about how much alcohol is safe to drink in pregnancy, but if a low level is consumed there is no evidence of harm to an unborn baby.  
  - Women should be advised not to drunk or binge drink (drinking more than 7.5 UK units of alcohol on a single occasion) while they are pregnant, because this can harm their unborn baby.  
  - If women want to avoid all possible alcohol-related risks, they should not drink alcohol during pregnancy, as the evidence on this is limited. |
9. Pre-implantation Genetic Diagnosis Patient Pathway

Once it has been agreed that individuals meet the criteria, up to two cycles of treatment may be offered with a full review after each cycle. If it is decided that the treatment is unlikely to benefit the couple, further treatment should not be offered. Frozen embryos from each cycle should be replaced before another fresh cycle is given. Subsequent cycles should be available without patients returning to the end of a waiting list after each cycle. A cycle of treatment is defined as one fresh cycle including ovulation induction, egg retrieval, fertilisation, PGD testing, implantation of fresh embryos followed by freezing of suitable embryos and subsequent replacement of these. It is good practice that all couples are offered counselling before, during and after receiving PGD services.
Appendix 1

Membership
The Panel is Chaired by Professor Emerita Sheila McLean, International Bar Association Professor of Law and Ethics in Medicine, and membership includes representation from experts in genetics, gynaecology, embryology, service planning, as well as those in the field of medical ethics. The interests of the patient group are represented by the Genetic Alliance UK (formerly Genetics Interest Group (GIG)) and a member of NSD’s Public Reference Group.

Professor Emerita Sheila McLean, International Bar Association Professor of Law and Ethics in Medicine, University of Glasgow (Chair)
Mr Jonathan Best, Regional Services Director, Southern General Hospital, NHS Greater Glasgow & Clyde
Professor Kenneth Boyd, Professor Emeritus of Medical Ethics, University of Edinburgh
Dr Emilia Crighton, Consultant in Public Health Medicine, NHS Greater Glasgow & Clyde
Professor Robin Downie, Emeritus Professor of Moral Philosophy, University of Glasgow (no longer member)
Ms Natalie Frankish, Patient Engagement Project Officer, Genetics Alliance UK [Ms Claire Cotterill prior to 29th September 2010]
Mr Brian Gorman, Member of NSD’s Public Reference Group (no longer member)
Dr David Goudie, Consultant in Clinical Genetics, NHS Tayside
Dr Gordon Lowther, Consultant Clinical Scientist, Cytogenetics, NHS Greater Glasgow & Clyde
Dr Helen Lyall, Consultant Gynaecologist, NHS Greater Glasgow & Clyde
Dr Zosia Miedzybrodzka, Head of Medical Genetics Service & Consultant Clinical Geneticist, NHS Grampian
Dr Sue Pickering, Consultant Embryologist, NHS Lothian (no longer member)
Professor Mary Porteous, Consultant Clinical Geneticist, NHS Lothian
Dr Margo Whiteford, Consultant Clinical Geneticist, NHS Greater Glasgow and Clyde
Sr. Helen Walton, PGD Co-ordinator, NHS Greater Glasgow and Clyde
Dr Jon Warner, Consultant Clinical Scientist, Molecular Genetics, NHS Lothian

Secretariat
Mrs Louise Wilson, Programme Manager, NSD
Mrs Shruti Babre, Programme Support Officer, NSD
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