Reference no: 2122
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# Clinical commissioning policy

# Pre-implantation genetic testing (PGT) of embryos at significant risk of serious genetic conditions [URN 2122]

**Publication date: 18 November 2026 version number: 2.0**

## Commissioning position

### Summary

PGT is recommended to continue to be available through routine commissioning for individuals at significant risk of having children affected by serious genetic conditions within the criteria set out in this document.

### Equality statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

## Executive summary

## Plain language summary

### About Pre-implantation Genetic Testing

People in the general population who have, or are carriers for, a serious genetic condition, may want to avoid passing the condition on to their children.

For people in this position, the technique PGT in conjunction with in vitro fertilisation (IVF) can be an option. IVF involves obtaining eggs and a sperm sample and combining them in a laboratory and allowing the embryo to develop. IVF is usually used to help people with fertility problems have a baby. PGT involves checking these IVF embryos to see if they have inherited the genetic condition in question. Only those that are found not to have inherited the genetic condition are transferred into the female. As the embryos need to be tested in a laboratory, a person undergoing PGT needs to use IVF, even if they do not have any fertility problems (Royal College of Obstetricians & Gynaecologists, 2022).

### About the conditions tested for in PGT

The Human Fertilisation and Embryology Authority (HFEA) regulates fertility treatment and research using human embryos. Only genetic conditions that are approved by the HFEA can be tested for. Currently, the HFEA has approved almost 2000 genetic conditions for which PGT may be performed in the UK. The majority of these conditions are extremely rare.

The HFEA must ensure PGT is carried out only where there is a 'significant risk' that a child born with the condition in question would have, or could develop, a 'serious' medical condition (HFEA, 2022). The seriousness of a condition is assessed on: age of onset; if the condition and/or symptoms are life-limiting or reduce life expectancy; quality of life; and, availability, efficacy and invasiveness of any treatment.

## What we have decided

NHS England has carefully reviewed the evidence to revise the implementation criteria for the use of PGT for the testing of embryos at significant risk of serious genetic conditions. We have concluded that there is enough evidence to make the treatment available for the expanded patient cohort at this time.

## Links and updates to other policies

This document updates Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGD), April 2014, reference: E01/P/a

## Committee discussion

Clinical Panel agreed with the policy and recommended this proceeds as a routine commissioning policy. Panel members recognised and agreed that, all studies contain very low certainty evidence. Panel members agreed that the age cut-off in the policy is now in line with the NICE guideline recommendation. See the committee papers for full details of the evidence.

PGT can be offered when one or both genetic parents have, or are carriers of, a known genetic condition which could leave a child with serious symptoms if they are affected [1]. Testing is performed on the embryos created through IVF to determine whether they will be affected by the condition.

The use of the term PGT in this policy encompasses PGT-M (monogenic disorders) and PGT-SR (structural rearrangements of chromosomes). This does not include the PGT-A screening test which is an aneuploidy screening test for chromosome abnormalities in couples with no prior risk[2].

People known to be at risk of having children affected by a genetic condition have various options to consider when making their reproductive choices (or decisions).

These are:

- To not have (more) children.
- To adopt a child.
- To pursue gamete donation – (this process involves assisted conception techniques in which one or both parents would not be the biological parent of the child).
- To conceive naturally, and accept the risk of their child inheriting the genetic condition (this might include recurrent miscarriages of non-viable pregnancies as a result of the genetic condition).
- To conceive naturally and undergo conventional prenatal diagnosis (PND) following conception. The two most commonly used PND procedures are amniocentesis and chorionic villus sampling (CVS) at 16 and 11 weeks respectively. If the foetus has the

[1] https://www.hfea.gov.uk/treatments/embryo-testing-and-treatments-for-disease/pre-implantation-genetic-testing-for-monogenic-disorders-pgt-m-and-pre-implantation-genetic-testing-for-chromosomal-structural-rearrangements-pgt-sr/

[2] In-line with the latest ESHRE "Good practice recommendations for preimplantation genetic testing (PGT)" it is acceptable to perform 'Comprehensive PGT', taking aneuploidy results into account when the PGTM testing will also accurately detect aneuploidies. In this situation comprehensive counselling should be provided in line with the guideline and HFEA Code of Practice.

genetic condition, the parents can then decide to continue or to end (terminate) the pregnancy.

- To undergo PGT, which enables individuals to have a biologically related unaffected child without the need to consider ending an affected pregnancy. PGT involves obtaining eggs (from the mother or donor) and fertilising them outside the body with partner or donor sperm ['in vitro' fertilisation (IVF) or intracytoplasmic sperm injection (ICSI)]. Once the eggs are fertilised, the embryos develop, and a number of cells are removed from each embryo and tested for the specific genetic condition. A range of methods are used for embryo testing depending on the genetic condition.

### About the conditions tested for in PGT in the UK

There are currently almost 2000 genetic conditions for which PGT may be performed, as licenced by the HFEA. The most common indications for PGT are chromosomal structural rearrangements (translocations), cystic fibrosis, haemoglobinopathies (sickle cell anaemia and thalassaemia), Huntington's disease and Duchenne muscular dystrophy (NHS Commissioning Board Clinical Reference Group for Genetics, 2013). The three most common monogenic conditions for PGT testing as per the European Society of Human Reproduction and Embryology (ESHRE) consortium include Huntington's disease, cystic fibrosis and fragile X syndrome (De Rycke et al., 2015).

## Epidemiology and needs assessment

Data from the HFEA shows a steady increase in utilisation of PGT. The number of PGT cycles undertaken increased by 178% from 2009 to 2019; PGT was undertaken by 223 patients in 2009 and by 620 patients in 2019 (1% of all fertility treatments in both 2009 and 2019).

## Evidence summary

An independent evidence review was conducted for the continued use of PGT for testing of embryos at significant risk of serious genetic conditions and NHS England has concluded that there is sufficient evidence to support this. The evidence review which informs this commissioning position can be accessed here: NHS England » Clinical commissioning policy: Pre-implantation genetic testing (PGT) of embryos at significant risk of serious genetic conditions

## Implementation Criteria

### Inclusion criteria

- The individual/s must be at risk of having a child or pregnancy with a serious genetic condition

AND

- The individual/s must have been referred to the PGT provider by an NHS Clinical Genetics Service or other specialist NHS service which includes genomic testing provision AND genetic counselling about reproductive risks prior to PGT referral (e.g. Inherited Cardiac clinics)

AND

- The risk of conceiving a pregnancy affected by a serious genetic condition must be 10% or more[3]

AND

- The genetic diagnosis must be made by an accredited genetics laboratory

AND

- There must be a comprehensive fertility assessment with the PGT fertility team prior to starting treatment, involving ovarian reserve testing and semen analysis. This should also include an assessment of maternal and fetal safety and suitability of a proposed pregnancy, noting having a high pre-pregnancy BMI can impact maternal and fetal safety[4].

AND

- A female undergoing PGT must be under 43 years[5] of age at the egg collection. Where the female is aged less than 40 years old at the time of egg-collection, using her own eggs, and meets the inclusion criteria, they will be entitled to up to three cycles of PGT. Where the female is aged 40-42 years and meets the inclusion criteria, they will be entitled to one cycle of PGT if there has been a discussion of the additional implications and risks of PGT and pregnancy at this age[6]. Where egg collection occurs in line with the above, then transfer of unaffected embryos can occur under this policy up to the 45th birthday.

AND

- The HFEA must have authorised the indication for PGT, or if not, the PGT provider accepting the referral must be willing to apply for authorisation for that indication. Funding for treatment can only be released after the licence has been issued.

AND

- If donor gametes are being used in PGT they must be procured through a HFEA licenced centre. Where donor gametes are required for the treatment, these are not funded under this policy. As such they may be self-funded by the individual/s or locally by the NHS. It is reasonable to consider patients using donor eggs by the age of the donor at the time of donation. This should be in line with UK donor guidelines[7].

AND

- The individual(s) undergoing PGT has agreed to and accepted that all affected embryos within each cycle will be discarded.

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[3] This means there must be a 10% of greater chance that the individual/couple will have (another) affected child. The chance of having an affected child is based on the inheritance pattern, empirical risk estimates or regression analysis. The 10% threshold is based on weighing up the benefits, risks and costs of PGT (see for example De Wert et al. 2014)

[4] Royal College of Obstetricians and Gynaecologists Green Top Guidance. Care of Women with Obesity in Pregnancy (No 72), 2019.

[5] Age limits for PGT are in line with those for in vitro fertilisation (IVF) NICE [CG156] Fertility Problems: assessment and treatment.

[6] These implications and risks include but are not limited to: increased risk of miscarriage, low birth weight, hypertension, subfertility, and gestational diabetes (Attali et al., 2021). Females undergoing PGT aged 40-42 must not have previously had any PGT cycles over the age of 40.

[7] https://www.hfea.gov.uk/donation/donors/

Individual/s meeting the above criteria will be eligible to receive up to three (3) complete cycles of IVF/ICSI in conjunction with up to three (3) cycles of PGT, dependent upon their classification by the female age criteria.

A complete cycle is defined as egg collection, fertilisation, PGT and the transfer of any available embryos. All suitable unaffected embryos created from a cycle should be transferred prior to moving onto the next cycle.

A failed cycle could occur after commencement due to a number of reasons. For example, failure to retrieve an egg, failure to fertilise or a failure of embryos to develop, resulting in no embryo transfer to the uterus taking place. These are known risks of treatment and will be fully explained to the patient along with the likelihood of success.

After any failed cycle, there is a mandatory requirement for medical evaluation prior to offering a second or third cycle, to assess suitability to continue treatment.

PGT can be used for Human Leucocyte Antigen (HLA) typing to produce a donor sibling for a child requiring an allogeneic stem cell transplant as long as the individual/s are concurrently at risk of having a child or pregnancy with a serious genetic condition and fulfil the inclusion criteria above for PGT. If an HFEA HLA licence has been approved for the case, it is appropriate to move through further cycles, as defined by the eligibility criteria, to attempt to achieve the HLA match. In this scenario, unaffected embryos need not be discarded.

NHS England will provide funding for storage for up to two years from last treatment event (fresh or frozen). This presumes timely compliance with treatment (i.e. frozen embryo transfer after fresh cycle; second FET with no more than six months delay; etc). Beyond these two years, any storage needs to be self-funded.

**Self-funding**

Individual/s who have previously self-funded PGT will be entitled to NHS treatment according to the following criteria:

- Where the female is aged less than 40 years old and meets the inclusion criteria, they will be entitled to up to three cycles of PGT.
- Where the female is aged 40-42 years old and meets the inclusion criteria, they will be entitled to one cycle of PGT if there has been a discussion of the additional implications and risks of PGT and pregnancy at this age.
- Any suitable unaffected frozen embryos from self-funded PGT must be used before undergoing a new fresh NHS funded PGT cycle. Transfer of unaffected embryos from self-funded PGT can occur within NHS funding as long as all criteria are met.
- Where self-funded cycles have occurred, the number of NHS funded cycles will be reduced accordingly (for example, where 1 fresh cycle has occurred and been self-funded, NHS funded cycles would be reduced by 1 fresh cycle).

Where individual/s have previously had an IVF or egg-freezing cycle without PGT (NHS or self-funded), any suitable frozen eggs or embryos can be used in an NHS funded PGT cycle.

Where individuals have a child, affected or unaffected by the condition, they are eligible for the number of cycles of treatment as defined above..

The NHS England Commissioning Policy “Defining the boundaries between NHS and private healthcare”, provides further clarification on the Commissioner’s position on co-payment and retrospective funding. Co-payment is strictly excluded in this NHS commissioned treatment. This means, within an NHS funded treatment cycle, any other additional treatment options (“add-ons”) cannot be self-funded.

**Exclusion criteria**

- Females aged 43 years and above.
- Either genetic parent is a current smoker or vaping (including all forms of nicotine).

**The following uses of the PGT technology are excluded from this policy:**

Non-medical gender selection e.g. for the purpose of family balancing. This is illegal in the United Kingdom.

HLA typing to produce a donor sibling for a child requiring an allogeneic stem cell transplant in cases where the individual/s are not concurrently at risk of having a child or pregnancy with a serious genetic condition.

Using PGT to address infertility or to prevent miscarriages of unknown aetiology.

Pre-implantation Genetic Screening (PGS) also known as PGT-A (aneuploidy testing). Here, genetic testing is used to screen embryos for various abnormalities in chromosomes typically the number of chromosomes (chromosomal aneuploidies)[8].

No statements in this document or the policy should be used to encourage a Thaw-Biopsy-Refreeze approach, such as the patient(s) initially utilising routine NHS funding to expedite faster creation of embryos – this is specifically ruled out and discouraged.

**Starting criteria**

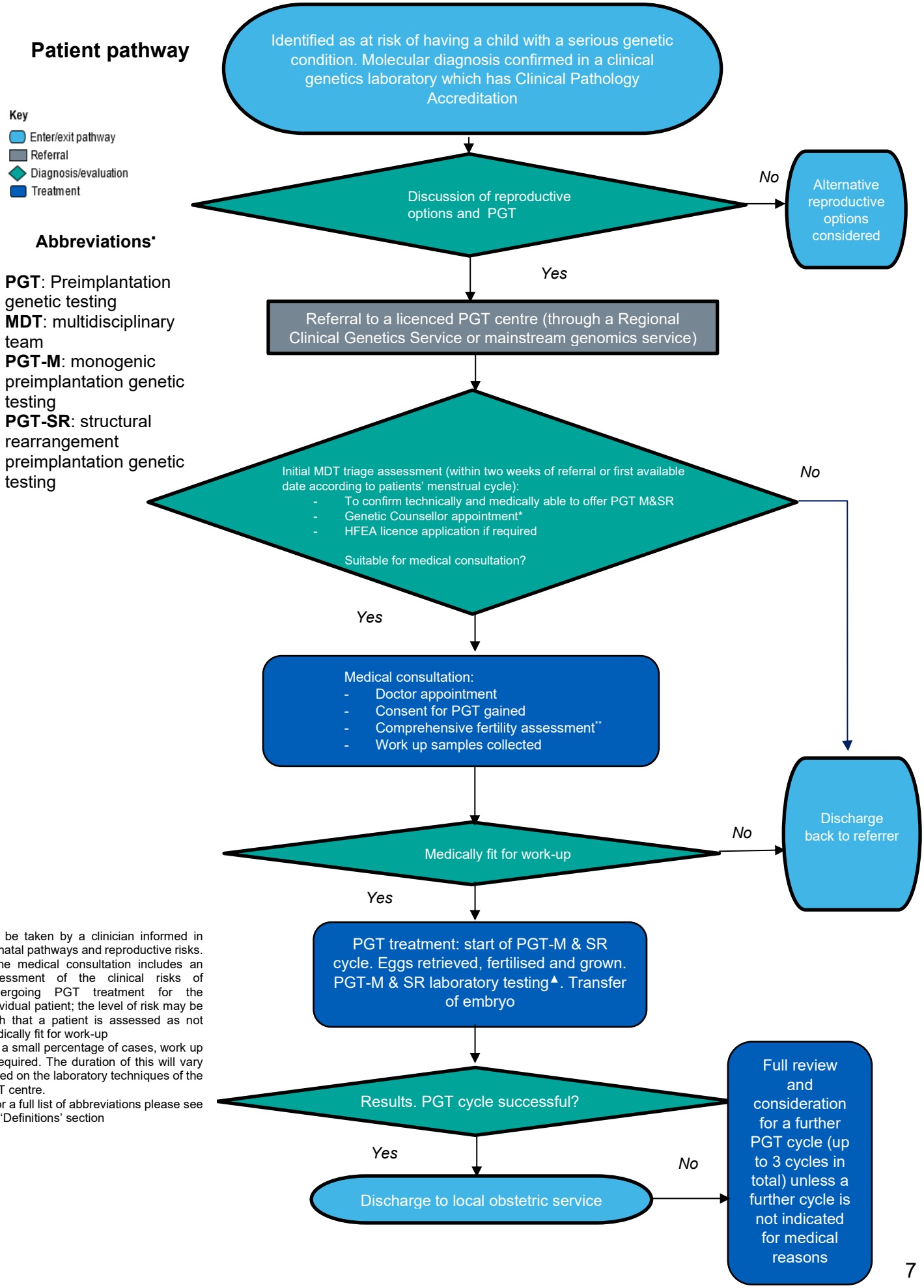
Once the work up of the PGT-M test is complete (or the assessment of a PGT-SR Case), treatment should only proceed in cases where the accuracy of the test, as quoted by the PGT laboratory, is at least 95%.

**Stopping criteria**

Completion of up to 3 PGT cycles for a female undergoing PGT under the age of 40 years and completion of 1 PGT cycle for a female undergoing PGT aged 40-42 years.

[8] In-line with the latest ESHRE “Good practice recommendations for preimplantation genetic testing (PGT)” it is acceptable to perform ‘Comprehensive PGT’, taking aneuploidy results into account when the PGTM testing will also accurately detect aneuploidies. In this situation comprehensive counselling should be provided in line with the guideline and HFEA Code of Practice.

## Patient pathway




### Abbreviations▪

**PGT**: Preimplantation genetic testing
**MDT**: multidisciplinary team
**PGT-M**: monogenic preimplantation genetic testing
**PGT-SR**: structural rearrangement preimplantation genetic testing

*To be taken by a clinician informed in prenatal pathways and reproductive risks.
**The medical consultation includes an assessment of the clinical risks of undergoing PGT treatment for the individual patient; the level of risk may be such that a patient is assessed as not medically fit for work-up
▲In a small percentage of cases, work up is required. The duration of this will vary based on the laboratory techniques of the PGT centre.
▪ For a full list of abbreviations please see the 'Definitions' section

**Governance arrangements**

The governance arrangements are described within the Service Specification E01/S/a NHS Standard Contract for Medical Genetics (all ages). This can be accessed: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/e01-med-gen.pdf.

NHS England expects that robust mechanisms will be put in place to support clinical governance to comply with the HFEA Code of Practice.

1. The centre must have a valid HFEA licence which includes the provision of PGT, and abide by the HFEA regulations for PGT testing. The HFEA provides details of licenced PGT clinics online. NHS England will monitor the inspection reports provided by the HFEA and will discuss the findings with the providers where appropriate.

2. The laboratory where the genetic test is being carried out must have current UKAS accreditation. See UKAS website (https://www.ukas.com/find-an-organisation/) for the licenced PGT providers that have current UKAS accreditation.

3. There must be an existing licence to carry out a genetic test for the relevant genetic condition from the HFEA or the PGT clinic must apply for and receive a licence prior to treatment if that condition is not currently licenced.

In addition to the approval of the HFEA, clinics must make their own judgement about whether PGT is appropriate treatment for a particular individual, using guidance contained in the HFEA's Code of Practice.

Provider organisations must register all patients using prior approval software and ensure monitoring arrangements are in place to demonstrate compliance against the criteria as outlined.

**Mechanism for funding**

NHS England contracts with suitably accredited providers via the relevant area team. Area teams will not pay for PGT services from providers they do not have contracts with.

**Audit requirements**

There is currently no central database to which PGT service providers report on NHS activity. As part of this commissioning policy, PGT Service providers will provide two sets of auditable data to NHS commissioners for all the NHS PGT cycles they have provided:

Data set 1: Monthly minimum data set on the PGT cycles for that month (to include activity by egg collection cycles and frozen embryo transfer cycles).

Data set 2: All providers must submit data to the HFEA Register for all of the treatments undertaken including any PGT cycles. The data fields to be reported on and by which route will be outlined in the information schedule of the NHS Standard Contract.

All PGT Providers with a commissioned service from NHS England will have to maintain a suitable audit trail proving compliance with all the mandatory criteria including the patients full review after completion of each cycle.

## Policy review date

This document will be reviewed when information is received which indicates that the policy requires revision. If a review is needed due to a new evidence base then a new Preliminary Policy Proposal needs to be submitted by contacting england.CET@nhs.net.

Our policies provide access on the basis that the prices of therapies will be at or below the prices and commercial terms submitted for consideration at the time evaluated. NHS England reserves the right to review policies where the supplier of an intervention is no longer willing to supply the treatment to the NHS at or below this price and to review policies where the supplier is unable or unwilling to match price reductions in alternative therapies.

## Definitions

| | |
|---|---|
| Chromosomal disorder | A variation in one or more chromosomes, or in the number of chromosomes. |
| Chromosome | A structure within cells that contains genetic information. |
| Embryo | A fertilised egg. |
| Gene | Segments of DNA that appear on a chromosome. Genes are responsible for controlling physical and inheritable characteristics of individuals. They also specify the structure of particular proteins for normal body functions. |
| Haemoglobinopathies | A group of inherited genetic conditions affecting the haemoglobin (iron storage) component of blood. |
| Human Fertilisation and Embryology Authority (HFEA) | UK's independent regulator overseeing the use of gametes and embryos in fertility treatment and research. |
| In Vitro Fertilisation (IVF) | This is a process whereby eggs are removed from the ovaries and fertilised with sperm in the laboratory. It is utilised in the PGT process in order for the fertilised eggs (embryo's) to be tested for a specific genetic condition, with an unaffected embryo subsequently being placed in the female's womb. |
| Pre-implantation genetic testing for aneuploidy (PGT-A) | Involves checking embryos for abnormalities in the number of chromosomes (known as aneuploid embryos). These embryos have less chance of developing into a baby or may result in a baby being born with a genetic condition. PGT-A identifies aneuploid embryos that are unsuitable for fertility treatment. |
| Pre-implantation Genetic Testing for Monogenic/Single Gene Disorders (PGT-M) | A technique that involves testing genes from embryos created outside the body by IVF for a specific genetic condition. |
| Pre-implantation genetic testing for chromosomal structural rearrangements (PGT-SR) | A technique that involves looking at the chromosome structure of embryos and finding where segments may have been deleted, duplicated or inverted. It can be used for people with a known chromosome structural |

| Reference no: 2122<br>Publication date: 18 November 2026 | rearrangement to improve the chance of a healthy pregnancy. |
|---|---|
| Pre-implantation Genetic Testing (PGT) | A technique that involves testing cell(s) from embryos created outside the body by IVF for a genetic disorder. Tests are carried out for the specific disorder that the embryos are known to be at significant risk of inheriting. Unaffected embryos are selected for transfer to the uterus in the hope that an unaffected birth will ensue. |
| Chromosome translocation | Chromosome translocations occur when pieces of chromosomes break off and reattach to other chromosomes. |
| Unsuccessful cycle of PGT | Includes failure of fertilisation; failure of cleavage of embryos, failure to produce any unaffected embryos or failure to conceive following embryo replacement. An abandoned cycle will count towards the three commissioned cycles. |

## References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