

# Renal Genomics Community of Practice – Key Learning Points Summary



This session focused on the use of preimplantation genetic testing (PGT) in renal genomics, bringing together both clinical perspectives and real patient experiences. A key theme throughout was how important it is to support families not just medically, but emotionally, with clear communication and strong teamwork across services.

## PGT in Renal Genomics

PGT gives families affected by inherited kidney conditions the chance to make informed decisions about future pregnancies.

It can significantly reduce the likelihood of passing on a known genetic condition. However, it's important that PGT is discussed alongside other reproductive options, with counselling tailored to each family's individual needs, values, and circumstances.

## Understanding the Patient Experience

Hearing directly from patients reinforced that the PGT journey can be complicated and emotionally challenging. What matters most to families is:



Clear, honest, and compassionate communication



Consistency of information across services



Access to emotional support



Coordinated care between teams



Realistic expectations about timelines and outcomes



## Emotional impact and challenges

PGT and fertility treatment don't always lead to success, and that uncertainty can be really tough for patients and their families.

The discussion highlighted:

- The emotional strain of ongoing treatment
- The impact of repeated cycles and long waiting periods
- The need for continued support, even when things don't go to plan

Many patient experiences reflected a huge amount of resilience and determination.



## Working together across specialties

Everyone agreed good outcomes rely on strong multidisciplinary working. Genetics, nephrology, fertility teams, embryology, counselling and lab services all play a role.

When these teams work closely together, it creates a more seamless experience for patients and helps ensure continuity of care.

## Resources and next steps:

Following the meeting, we would encourage you to explore additional resources by:

- ✓ Register with NHS Futures
- ✓ Join the Renal Genomics Community of Practice

These provide useful guidance, updates and support for improving genomic care in practice.

You can also take a look at the following educational resources:

- GeNotes has produced a helpful clinician summary of PGT with lots of useful links: [Preimplantation genetic testing — Knowledge Hub](#)
- Guys PGT service: [Pre-implantation genetic testing \(PGT-M/SR\) - Overview | Guy's and St Thomas' NHS Foundation Trust](#)