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Genomic Medicine Service

HOW CAN WE IMPROVE THE EXPERIENCES OF PEOPLE WHO ARE ENTITLED TO GENETIC TESTING FOLLOWING RECURRENT MISCARRIAGES?

June 2026



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Executive Summary

Our Vision for Delivering Equitable Access to Genetic Testing for Women Experiencing Recurrent Miscarriage

One in four pregnancies in the UK ends in loss.

This equates to an estimated 250,000 pregnancy losses each year—approximately one miscarriage every two minutes.

Many of the women who courageously contributed to this report have been deeply traumatised by the loss of their babies and continue to seek answers about why their pregnancies ended.

We know that up to 60% of miscarriages are associated with an underlying genetic cause in the baby. Women who experience three or more pregnancy losses are eligible for genetic testing of pregnancy-loss tissue, which can provide valuable information about the cause of miscarriage and inform future care.

To better understand barriers to accessing genetic testing following recurrent miscarriage, the South East Genomic Medicine Service explored both clinical practice and the experiences of women affected by recurrent pregnancy loss. While many of the ten women who shared their stories described receiving compassionate care, only one had been offered genetic testing following her recurrent losses. This left women seeking answers elsewhere and having to advocate for themselves whilst grieving the loss of another pregnancy.

The review identified significant gaps in service provision, including a lack of clear and sensitive information about genetic testing, the absence of appropriate receptacles for collecting pregnancy-loss tissue at home, and limited access to psychological support. Healthcare professionals reported that genetic testing pathways are often poorly understood, resulting in inconsistent access to testing and unacceptably high rates of rejected samples. Staff working in Early Pregnancy Units also highlighted a need for education and training to better support both clinicians and families.

Executive Summary

These findings align with those reported by Miscarriage UK in Miscarriage in the UK: Still a 'Dismissive' and 'Dehumanising' Experience (2026).

Their report found considerable variation in care across the UK, with insufficient guidance available to families, leading to misinformation, reduced informed choice, and a lack of dignity in care. Only 40% of women experiencing recurrent miscarriage reported being offered testing.

Similarly, the Pregnancy Loss Review (2023) heard accounts from women who miscarried at home and were advised to retrieve their baby's remains from the toilet and store them in household containers. Both reports highlighted the urgent need for clearer guidance, improved communication, and enhanced clinical education.

Urgent action is needed to ensure that women experiencing recurrent miscarriage can access equitable, compassionate, and informed care. This must include clear guidance for healthcare professionals on when genetic testing should be offered, why it matters, and how discussions can be conducted sensitively to support informed choice. Women must also be provided with accessible, compassionate information about testing and appropriate resources for managing pregnancy loss at home.

Without these improvements, we risk continuing to fail both the clinicians who strive to provide high-quality care and the families who depend on them during one of the most difficult experiences of their lives.



Background & Context

Fifteen percent of clinically recognised pregnancies end in miscarriage with 80% of miscarriages occurring in the first 12 weeks of pregnancy. The Department of Health and Social Care estimate that every year in the UK, 250,000 pregnancies end in miscarriage - this equates to one miscarriage every 2 minutes. No national data set exists, so the numbers could be much higher.

The available data (Tur-Torres et al, 2017) shows that as many as 60% of miscarriages are caused by chromosome abnormalities in the fetus.

Genetic testing via QF-PCR and/or microarray, can identify these chromosomal abnormalities. For example, QF-PCR testing can identify common numerical chromosomal abnormalities (aneuploidy). Most aneuploidies are sporadic or de novo (occurring via non-disjunction), with the incidence risk increasing with maternal age.

What is recurrent miscarriage?

According to NHS England, recurrent miscarriage is defined as three or more miscarriages (these do not have to be consecutive) and approximately 1% of women will experience them. Of this 1%, only 2% are due to underlying parental chromosomal rearrangements that could result in inherited chromosomal imbalances in the fetus, which increases the risk of miscarriage.

Genetic testing on the products of conception (PoC) is currently offered on the NHS for any woman who has three or more miscarriages. In exceptional circumstances, parental karyotyping can offered to women who have had five miscarriages, but for whom the products of conception were unable to be collected or tested for any of the previous losses. The test can also be offered to women who have had three miscarriages and the products of conception were collected but were unsuitable for testing.



Background & Context

Equal access to testing

The South East Genomic Medicine Service continuously reviews genetic testing data to ensure that genetic tests are being offered equitably across the South East of England.

Our partners in Clinical Genetics raised concerns with us because they felt they were receiving lower than expected referrals following recurrent miscarriage. We wanted to understand if that was indeed the case, and if so, what was causing it.

At the same time, the genetics laboratory raised their own concerns because they were seeing an increased number of referrals for genetic testing for recurrent miscarriage that did not meet the testing criteria set out in the National Genomic Test Directory. There was a concern that women were being offered genetic testing by clinicians which would then have to be rejected because they didn't meet the NHS eligibility criteria.



Genetic testing for recurrent miscarriage in the NHS

What genetic testing is available on the NHS?

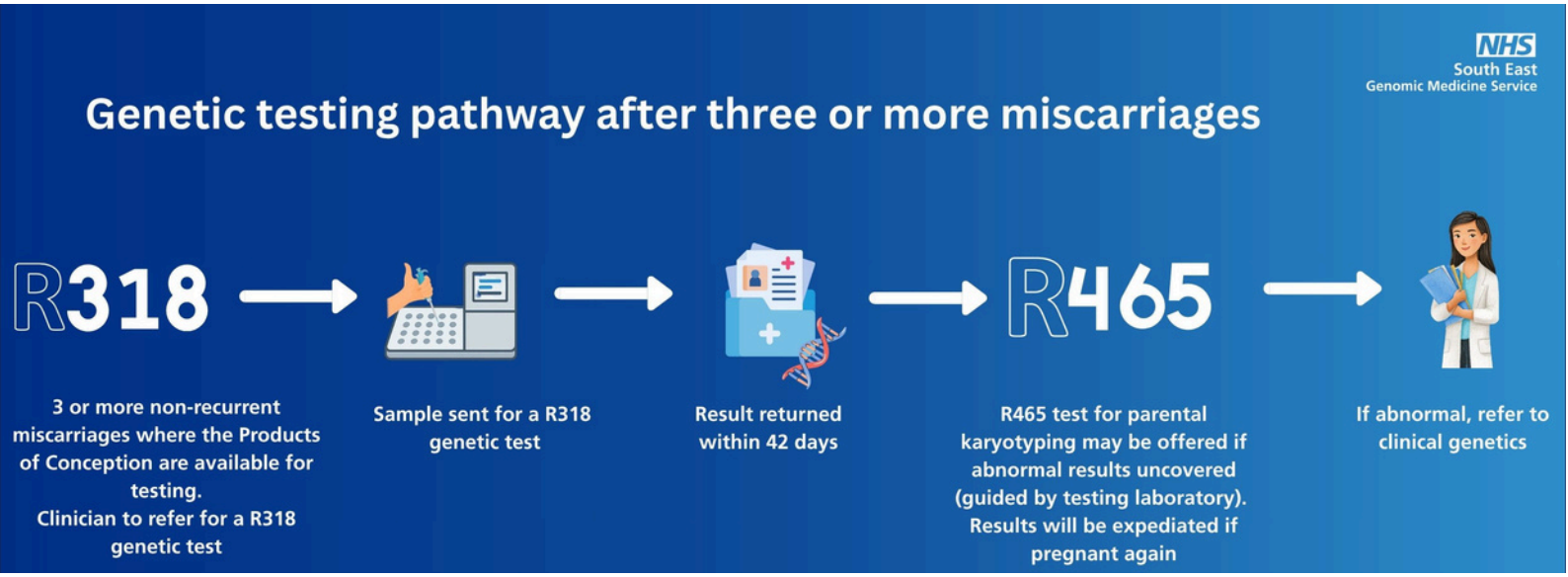
All genetic testing available on the NHS in England is outlined in the National Genomics Test Directory.

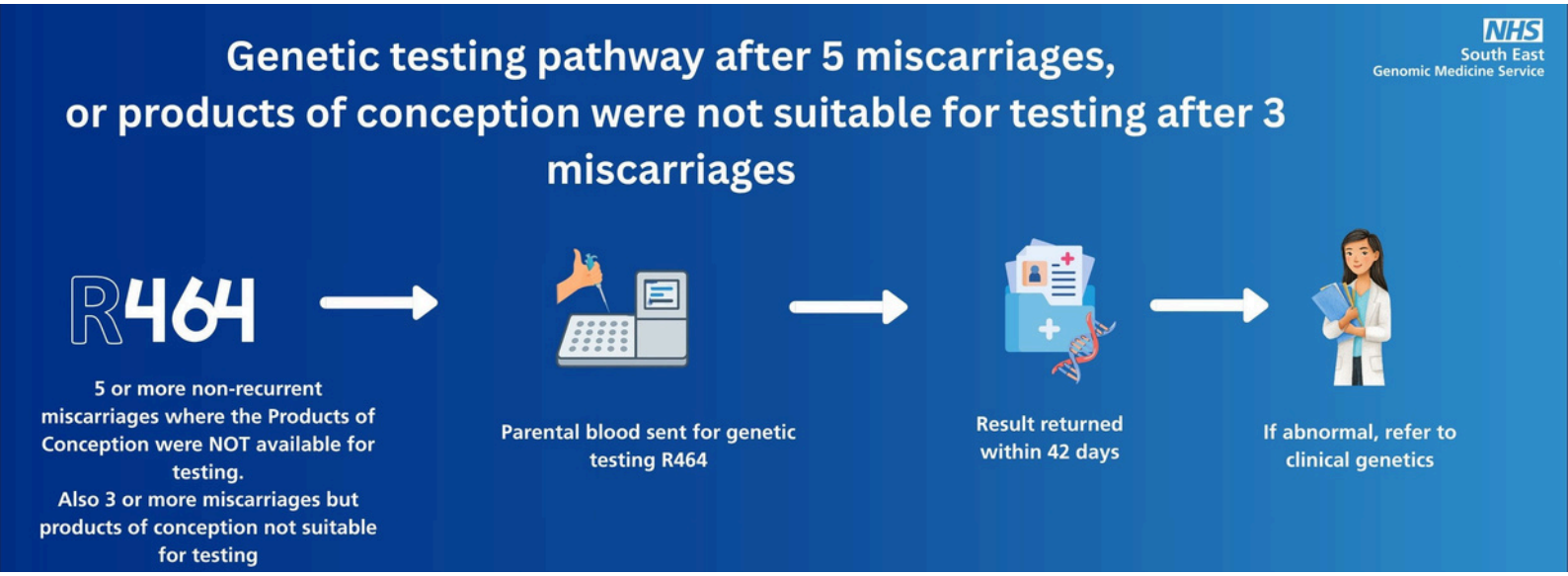
Test name	Purpose of test	Important details
R318	gold standard genetic test for recurrent miscarriage	Requires 'products of conception' to be appropriately collected and transported to the laboratory. Genome wide aneuploidy testing is carried out as a first line test, followed by genome wide microarray if no aneuploidy is identified.
R464	following 5 miscarriages where products of conception are not available for testing, or hadn't been tested.	Parental karyotype testing is performed to identify any structural chromosomal rearrangements that could be inherited by the fetus. R464 is also available following three miscarriages when products of conception are sent but are unsuitable for testing (e.g. no fetal tissue). Note that although parental karyotype analysis is available following a failed test, this is of limited utility and the most informative pathway is to test any subsequent pregnancy loss.
R465	following an abnormal result on products of conception testing.	A parental karyotype or targeted chromosomal analysis is performed to identify possible structural chromosomal rearrangements in the parents.

Clinical pathway following recurrent miscarriage

The clinical care pathway for recurrent miscarriage is complex.
Women with a suspected miscarriage can present to their General Practitioner, Accident & Emergency or directly to their local Early Pregnancy Unit (EPU).

Women who present to their GP or A&E will be referred to EPU. Following 3 or more miscarriages, women will be referred via the EPU to a recurrent miscarriage clinic to discuss potential causes of recurrent miscarriage, including genetics. The wait to be seen is variable, with reports ranging from 2-12 months depending on capacity.





AIMS & OBJECTIVES

We wanted to understand if there were any barriers that were preventing women from being offered genetic testing after their third miscarriage and explore what could be done to ensure equitable access to genetic testing.

In addition, we wanted to understand people's perceptions about what information and support is available to help both patients and professionals to understand the genetic testing referral pathway.

Understand the barriers to genetic testing following multiple miscarriages

Understand what information & support is available to people and professionals

OUR APPROACH

Our approach was centred around the experiences of women and their personal perspective of the pathway.

At the South East Genomic Medicine Service we have fostered a strong culture of involving patients in our work. People and patients are involved in every aspect from attending board meetings, being part of key decisions and having an equal voice within our projects.

We had heard from a few people that their personal experience after recurrent miscarriages was not as we expect, so we wanted to hear more voices and explore the issues that they raised.

We designed this project to ensure women were offered a sensitive, safe and supportive space to share their experiences. Conversations were planned around their individual needs and wishes. Patients were offered an individual conversation with an involvement expert who was supported by the South East Genomic Medicine Service Lead Midwife. Conversations followed an agreed framework that allowed women to share their experiences indepth, allowing for as much time and support as they needed.

Healthcare professionals were also offered a one to one conversation with our lead midwife to share their views on how the current pathway could be improved and to explore what support they needed.

METHODOLOGY

This is a service improvement project where we sought to hear from 10 women about their experiences of the current pathway, coupled with insights from 10 healthcare professionals. Their collective feedback would be reviewed alongside the referral data for genetic testing following recurrent miscarriages.

In 2026 we spoke to:

- 10 women
- 10 healthcare professionals who are directly involved in the care and treatment of women who have experienced multiple miscarriages
- Charities including Tommy's Miscarriage Charity

As part of our evidence gathering, we invited people to take part in an individual conversation about their experiences. Within these conversations both patients and professionals spoke in depth about their experiences and what could be improved.

All conversations followed an agreed framework. All participants gave their consent for their feedback to be used anonymously in this report and to support our desire to improve the experiences for others.

Everyone we spoke to has asked to remain involved as we progress.

Confidentiality

All responses have been anonymised and stored securely in accordance with Guy's and St Thomas' NHS Foundation Trust (which hosts the South East Genomic Medicine Service) information governance policies.

Data Analysis

All the feedback we collected through interviews with both patients and professionals has been thematically analysed to categorise feedback into the key themes.

The Headlines



- Significant lack of education for healthcare professionals
- Access to genetic testing is often not part of routine care
- Information & support for women is critical
- Access to genetic testing isn't currently equitable
- Everyone we spoke to felt that the knowledge genetic testing gave them was invaluable

OUR FINDINGS

From patients, the key themes were:



Women are not routinely offered genetic testing



Women forced to advocate for themselves to get genetic testing



Better education for professionals needed



Lack of suitable information for women



Genetic results aren't explained to patients and families



No psychological support offered to women

"I was given no information, no support. I have had to find the answers for myself."

"After three miscarriages, I expected my care to become more proactive and to get help to find some answers. It didn't."

"I wish someone had told me what to expect and then I might not have felt so alone."

"Information would have given me back some control."

"I had done my research so I knew what I was entitled to. I don't think the staff would have offered genetic testing to me if I hadn't have asked for it. The staff needed to go away and discuss it before they agreed."

"Information upfront would have been really helpful. I understand that some clinicians shy away from it as they don't want to appear negative, but leaving us on our own is not the answer."

WHAT DID WE HEAR?

From healthcare professionals, the themes were:



Better education for professionals needed



Lack of information about how to identify suitable samples



Support needed to understand genetic reports



Patient information needed to explain genetic testing and miscarriage



Professionals want to feel more confident talking about genetic testing



Limited provision of receptacles for women

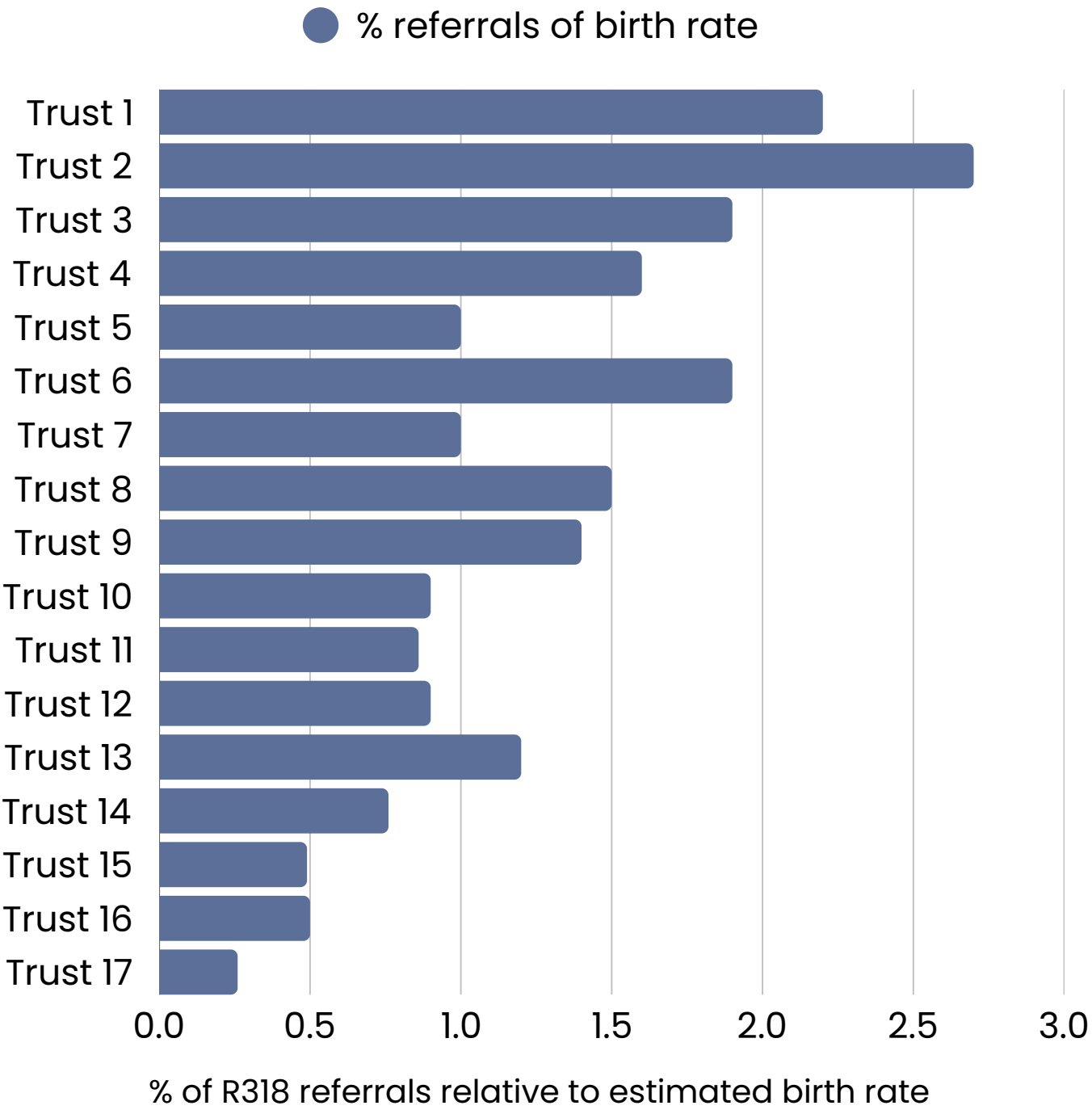
“I know my staff working in early pregnancy units would be receptive to training, but currently nothing exists’- Matron

“I have seen clinicians shy away from having conversations about recurrent miscarriage and genetic testing. It is such a sensitive topic, so without training on how to have these conversations and why we are offering this testing, I can understand why clinicians avoid it”.- EPU nurse

“Parents are desperate for information and are always receptive and grateful for any information we can give”- EPU nurse

“We have so many families who are desperate and angry they are not eligible for genetic testing. As clinicians we need to be able to signpost them to why this is the case, but we have nothing.”

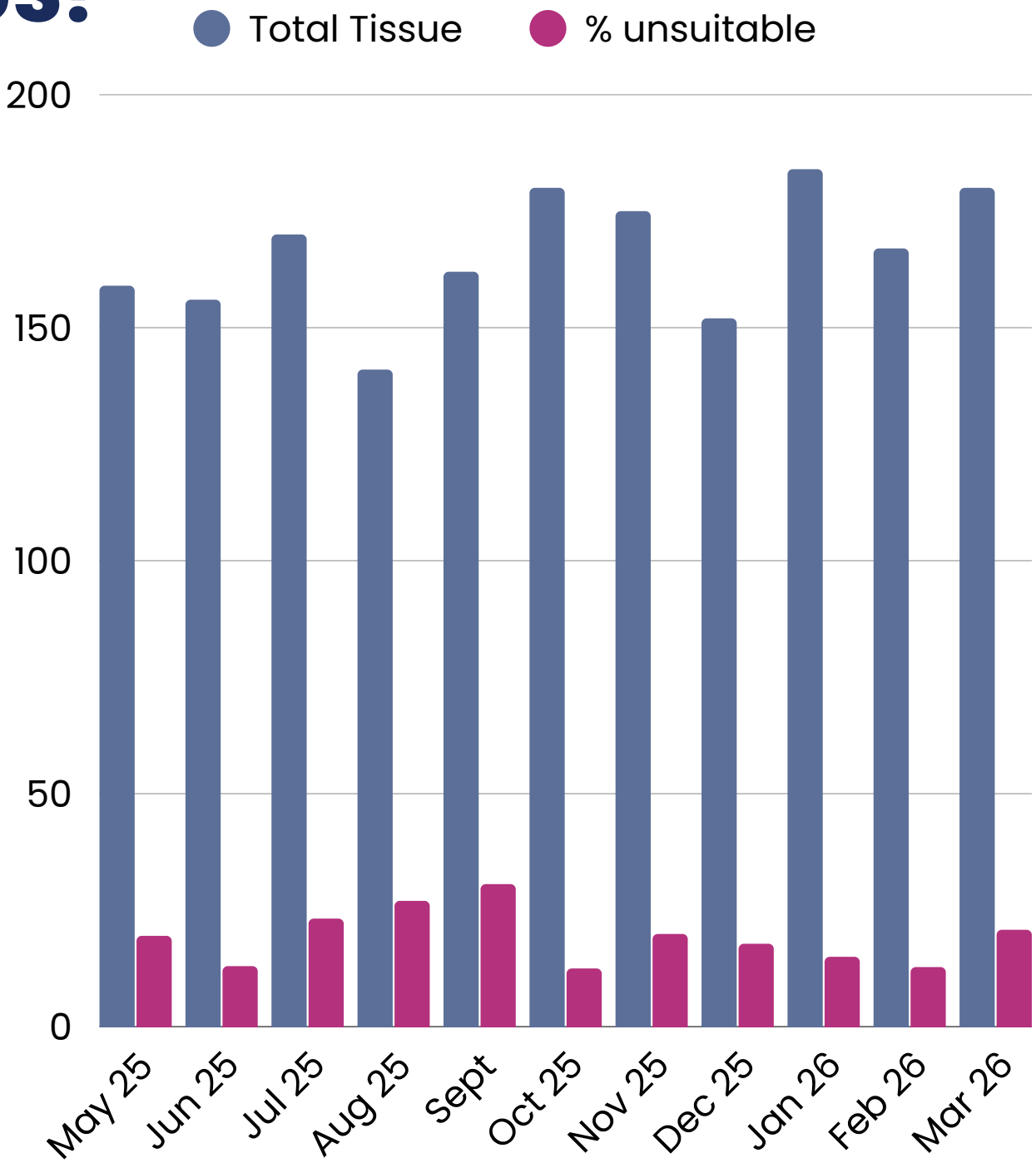
WHAT DOES THE DATA TELL US?



There were 978 referrals for R138 testing between April 2025 - March 2026. We have anonymised the Trusts.

The number of expected referrals is unknown due to the lack of national data. However, when comparing the percentage of referrals relative to the estimated birth rate, per trust, clear inequity in referrals is demonstrated.

WHAT DOES THE DATA TELL US?



Total fetal tissue samples and percentage unsuitable samples

There were a total of 1,968 fetal tissue samples (including R318 & R22*).
The total number of unsuitable samples from May 2025 to March 2026 were 307.
The data shows that 16% of samples were on average unable to be tested.

*R22 : fetal loss accompanied by features of chromosomal abnormality/ or stillbirth >24weeks gestation in the absence of other likely cause

Our Recommendations

Thanks to all the feedback that we have heard and the experiences that people have shared, we have gathered a wealth of insights.

Based on the rich insights, we were able to make two main recommendations to support the needs of patients and healthcare professionals:

- Patient friendly information is needed for women who are facing multiple miscarriages to explain the options available to them

- There is an urgent need to educate and support healthcare professionals who see and care for women after, or during, miscarriage

Next Steps

Based on these recommendations, we will undertake the following:

Develop a bespoke educational package for healthcare professionals to increase confidence and competence in explaining genetic testing options to women and their families.
This should include training on referral criteria and sample collection, to reduce the high number of rejected samples.

Clear information for healthcare professionals about how to refer women for genetic testing after three or more miscarriages.

We will facilitate the delivery of this education via face to face sessions in every NHS Trust in the South East region.

We will co-create alongside women who have had direct experience, an information resource for women and their families to help them to understand what to expect and what genetic testing is available to them.

All the resources will be shared widely across the NHS Genomic Medicine Service to benefit all patients and professionals nationally.

OUR THANKS

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Thanks to all the women who came forward to share their personal experiences with us and to all the healthcare professionals who gave us their insights.

Your valuable contributions have enabled us to develop a number of resources that will improve the experiences of people who have recurrent miscarriages. We are looking forward to working with you in the coming months.



References

Clark-Coates, Z. and Collinge, S. (2023) The independent pregnancy loss review: care and support when baby loss occurs before 24 weeks gestation.

Miscarriage Association (2026) Miscarriage in the UK: still a 'dismissive' and 'dehumanising' experience.

Tur-Torres, M.H., Garrido-Gimenez, C. & Alijotas-Reig, J. (2017) 'Genetics of recurrent miscarriage and fetal loss', Best Practice & Research Clinical Obstetrics & Gynaecology, 42, pp. 11–25.