



ARK Policy Brief

The absence of first-trimester antenatal screening in Northern Ireland: women's experiences and rights

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Introduction

Northern Ireland (NI) remains the only UK jurisdiction that does not routinely offer publicly funded first-trimester screening for Trisomy 13 (Patau's syndrome), 18 (Edward's syndrome) and 21 (Down's syndrome). While pregnant women/persons in England, Scotland and Wales are routinely offered screening between 11 and 13 weeks' gestation, most women in NI receive information about these conditions following the 'anomaly scan' at approximately 18-20 weeks, or in some cases after birth. A diagnosis of Trisomy 13, 18 or 21 can have profound implications for women and families, including timely access to information, healthcare, supporting services, and decisions regarding termination of pregnancy. This policy briefing builds on our 2024 policy briefing, by presenting the perspectives of families affected by Trisomy 13, 18 and 21, alongside the views of healthcare professionals and wider stakeholders (e.g., academics and support organisations). It concludes that the continued absence of first-trimester screening (FTS) raises concerns regarding access to healthcare, informed reproductive decision-making and equality of provision across the UK, likely to trigger human rights violations.

Overview of the 2024 policy briefing

Our 2024 policy briefing examined the absence of FTS in NI and its implications for women's rights, drawing on the views and experiences shared during two roundtables organised in January 2024: one with families who ended their pregnancies following a diagnosis of a fatal or serious fetal abnormality; and one with healthcare professionals and stakeholders (Lougarre, Heaney, Bloomer, 2024).

Our 2024 policy briefing highlighted that the absence of FTS in NI as part of routine maternity care resulted in diagnoses of severe or fatal fetal abnormalities occurring later in pregnancy. Consequently, women who terminated their pregnancies often experienced significant, and arguably avoidable, physical and psychological harm, including time pressures while making life-changing decisions, additional trauma associated with later gestation procedures and the loss of privacy due to visibly established pregnancies. Families were supportive of FTS as an optional antenatal test in NI (Lougarre, Heaney, Bloomer, 2024).

Our 2024 policy briefing also highlighted concerns regarding the UK's legal obligations under human rights law, including freedom from cruel treatment, the right to private and family life, the right to health and the right to be free from gender discrimination. It further identified widespread concern from healthcare professionals regarding the absence of FTS and strong support for its introduction as part of routine maternity care (Lougarre, Heaney, Bloomer, 2024).

Overview of this 2026 policy briefing

This follow-up policy briefing examines the absence of FTS in NI and its implications for women's rights by presenting the views and experiences of families who have had a baby with Trisomy 13, 18 or 21, as well as those of healthcare professionals and stakeholders. Following desk-based research, we held four roundtables in autumn 2025. The first three were attended by families who had a baby with Trisomy 13, 18 and 21, and by representatives from the support organisation SOFT UK. The fourth was attended by healthcare professionals involved in maternity and fetal medicine services in NI, as well as by academics and support organisations; it was followed by several one-to-one meetings with healthcare professionals unable to attend the roundtable.

This follow-up policy briefing highlights that the absence of a FTS service in NI as part of routine maternity care results in diagnoses of severe or fatal fetal abnormalities occurring later in pregnancy or post birth. Whilst some families received excellent support and care, many described significant issues associated with delayed diagnosis, including reduced opportunities to prepare emotionally, practically and medically for the birth and care of their child. Families were supportive of FTS as an optional antenatal test in NI. Stakeholders were also fully supportive of introducing FTS as part of routine maternity care, and many expressed frustration with the NI government for failing to support this.

This follow-up policy briefing also highlights concerns regarding the UK's legal obligations under human rights law, including freedom from cruel treatment, the right to private and family life, the right to health and the right to be free from gender discrimination.

Background

What is first-trimester antenatal screening?

First-trimester antenatal screening allows the detection of three chromosomal conditions: Trisomy 13 (T13), Trisomy 18 (T18), and Trisomy 21 (T21). It is performed either as a 'combined test' involving a blood test alongside an ultrasound scan or as a non-invasive prenatal test (NIPT) involving a single blood test, which measures fetal DNA present in the mother's bloodstream. These screening methods estimate the likelihood of these conditions being present in the fetus; a definitive diagnosis requires confirmatory testing, such as chorionic villus sampling (commonly called CVS) or amniocentesis. FTS is recommended by: the World Health Organisation (2016); the UK National Institute for Health and Clinical Excellence (NICE) (2010); and the Royal College of Obstetricians & Gynaecologists (RCOG) (2010). In the rest of the UK, FTS is offered to all pregnant women/persons and follows a clear care pathway: the combined test is offered as a first step between 11 and 13 weeks of pregnancy; and if this test indicates a high chance result, women are offered either NIPT as a more accurate secondary screening test or a diagnostic test, though they may choose to have no further testing.

Outcomes of Trisomy 13, 18 and 21

Trisomies 13, 18 and 21 all lead to higher incidences of miscarriages, stillbirth, neonatal and infant mortality, with particularly high incidences for T13 and T18 which are therefore considered to be 'fatal fetal abnormalities'. When a fetus is affected by T13 or T18 (3-7 per 10,000 births), 7 in 10 pregnancies over 12 weeks' gestation result in miscarriage or stillbirth. If the pregnancy goes to

term, 9 out of 10 infants will die in their first year (NHS). When a fetus is affected by T21 (26 per 10,000 births), 3 in 10 pregnancies over 12 weeks' gestation will end in miscarriage or stillbirth; and if the pregnancy goes to term, 1 in 20 infants will die in their first year (UK Office for Health Improvement and Disparities, 2026). Evidence highlights that miscarriage, stillbirth, neonatal and infant mortality cause significant levels of trauma, stress, anxiety, grief and depression amongst women (Herbert et al. 2022; Quenby et al. 2021). Men are also significantly affected by pregnancy and baby loss, including in the context of fetal abnormalities (Kecir et al., 2021; Obst et al., 2020).

When they do not lead to a fatal outcome, T13, T18 and T21 often result in disabilities likely to require additional ongoing care for the child, a position most often held by women who represent 59% of all carers of working age in NI (Carers NI and Women's Regional Consortium 2024). In the UK, the UK Carer's Allowance is subject to stringent eligibility conditions and amounts to £83.30 per week in 2025-2026 (UK Government, 2026); despite carers being more likely to be unemployed, live in poverty or experience ill-health than non-carers (Carers UK, 2025).

Absence of NHS-funded first trimester antenatal screening in Northern Ireland

While all pregnant women/persons in England, Scotland and Wales are offered FTS between 11 and 13 weeks' gestation, this service is not routinely offered in NI as part of maternity care. As a result, most fetal abnormalities in NI are identified at the anomaly scan during the second-trimester of pregnancy, or in some cases after birth. All pregnant women/persons in NI are offered fetal anomaly screening at around 18-20 weeks' gestation through an ultrasound scan carried out by a trained sonographer (NI Direct). If the result of the scan warrants further investigation, women are referred for more specialist care, usually to the Regional Fetal Medicine Unit based at the Royal Victoria Hospital in Belfast; and for many

families, this means waiting a further 3-4 weeks for a confirmed diagnosis. For some families the diagnosis is not made until after birth. Testing is available from private providers from 10-11 weeks' gestation, but the cost is high (£400 on average), not subject to regulation, and it does not have an established referral pathway into mainstream maternity and fetal medicine services.

Following freedom of information requests to all Health and Social Care Trusts in NI, responses confirmed that none routinely offer or fund NIPT as part of universal maternity care. However, two Trusts disclosed taking blood samples and sending them to laboratories in certain cases, with one reporting doing so for approximately 50 patients per year over the past 5 years. It remains unclear how many pregnant women and persons access NIPT privately in NI, as most private laboratories did not respond to our enquiries for information (which fall outside the scope of freedom of information legislation). Despite global and national expert guidelines recommending FTS, ongoing medical professional support in NI, and the NI Health Committee showing interest when we met them in January 2025, there has been no progress from the NI government towards the implementation of a publicly-funded programme.

Experience of families

Timing of diagnosis

None of the mothers we spoke to had been offered publicly-funded FTS or had accessed privately funded FTS. Amongst those, some were offered screening or diagnostic tests in the second trimester of their pregnancies due to their age (i.e., 37+) or due to the existence of "markers" (often identified during the anomaly scan at 18-20 weeks), but most refused. Most participants therefore learned of their child's diagnosis either after birth or late in pregnancy following the anomaly scan.

For those women who had a child with T21, all learned of the diagnosis post birth as no concerns were raised during pregnancy. For those who had a diagnosis of T13 or T18, all had been informed of the existence of concerns during pregnancy, most at the anomaly ultrasound scan. This stands in stark contrast to the timing of diagnosis in England, with NHS-funded FTS allowing cases of Trisomy 13, 18 and 21 to be mostly detected before birth rather than after, with antenatal detection rates of 61.4% (T13), 71.7% (T18) and 60% (T21) (NCARDRS, 2025).

Various participants were offered second-trimester screening but some refused on the basis that “it wouldn’t have made a difference because I would have carried on” (T21); or because they feared their baby would not access care if there was a positive result and that a “do not resuscitate’ would be activated” (T13/T18). This fear was a reality for one participant who reported that after a positive diagnosis during pregnancy, “my baby wasn’t treated as a human but as his ‘diagnosis’. They just stopped monitoring him” (T13). This correlates with wider research on parents reporting fear of withheld care in cases of antenatally diagnosed fetal anomalies (Ritchie et al., 2024; Winn et al., 2018).

Communication of diagnosis

Participants described communication of diagnosis as having a lasting impact, one said, “the first tell (...) is life lasting, (...) so impactful” (T21). Positive experiences were characterised by the compassion of staff, acknowledgement of the baby as an individual and balanced information. Negative experiences often involved perceptions of pressure, lack of empathy or overly directive counselling. These findings mirror previous research highlighting the importance of communication skills when discussing fetal anomalies and chromosomal diagnoses (Berry and Colorafi, 2019; Lou et al., 2020).

“The paediatrician was lovely, the first thing he said was congratulations (...) he didn’t say ‘I am sorry’. He said ‘he might not be the baby you expected but he is still a baby (who) needs the same love’.” (T21)

“The consultant had zero bedside manners. (...) my baby wasn’t treated as a human but as his diagnosis.” (T13)

Reactions to diagnosis

Mothers we spoke to all reported reacting to the diagnosis of Trisomy with a wide range of emotions: shock, disbelief, anger, fear, isolation and grief. They were all emotional sharing their stories. This strongly aligns with wider research on maternal and parental reactions to Trisomy diagnoses (Lukowski and Bohanek, 2025; Thompson et al., 2024; Clark et al., 2020). On reflecting about the time when they were given a diagnosis, participants said:

“When they told me, I was upset, roaring, it’s not what you expect. (...) your mind is running ahead to 20 / 30 years, you can’t focus” (T21 diagnosis at birth).

“I got a call telling me he had Trisomy 13 and my world fell apart, I was in complete and utter shock” (T13 diagnosis during pregnancy).

Perspectives on first-trimester antenatal screening

When asked if they were supportive of an NHS-funded FTS programme routinely offered to all pregnant women/persons in NI, all mothers we spoke to responded favourably, viewing screening as a mechanism for informed choice, preparation and access to support. Some participants specified that having information early in the pregnancy could also remove the trauma of late diagnoses.

“If we’d had first trimester screening, it would have given us time to prepare ourselves, (...) it would have removed a lot of the trauma of finding out so late” (T13).

Participants often ended up reflecting on their personal journeys. Some were unsure whether they would have opted for FTS had it been offered, while others wished they had been offered FTS and subsequently chose to access it privately in later pregnancies.

“I would have had time to prepare to make informed decisions and think about the impact on the family (...) I wouldn’t want anyone to think I don’t love my child, I do, but I would like to be better informed” (T21).

Many participants, however, stressed that healthcare professionals should not repeatedly offer screening to parents who refuse it, and that families unsure about screening should not feel obliged to make a decision on the day it is offered. This reflects wider studies indicating that when healthcare professionals repeatedly offer tests or present them as routine care, parents can feel pressure to comply (Warton and Vears, 2025).

“It’s an invitation, it’s not a summons, you don’t have to do it” (T13).

Participants also distinguished between access to screening and the personal decisions that follow, highlighting the importance of information, consent, support, and a clear care pathway for whatever decision parents make. Parents of children with T21 emphasised that supporting screening on one hand and being pro-choice on the other can co-exist with strong commitments to disability rights and inclusion. However, they expressed concern that families receiving a positive T21 screening result may choose to end pregnancies due to negative societal views on disability and a lack of comprehensive information. Some feared that increased screening could lead to higher rates of termination of T21 pregnancies.

“I would worry that a lot of people would choose to terminate and that people like my son end up being wiped out. Are their lives not as important as others”? (...) people should have a choice (but) we need to look at wider societal views, what these children can contribute to society.” (T21)”.

Some participants reported that certain groups in the Down’s syndrome community can be anti-screening, anti-termination and “defensive”, and that it can be hard to have “open and honest conversations” on these topics, or to say “I don’t know what I would do” without being “judged” (T21).

This correlates with wider studies indicating that strong peer support network environments can advertently or inadvertently prioritise unwavering advocacy and lead to defensive postures against prenatal screening or termination discussions (Denneny, 2026; van Schendel et al. 2017).

Information and support needs

All mothers we spoke to stressed the importance of comprehensive and relevant information, highlighting that information needs may differ, including depending on whether a diagnosis is made before or after birth. Participants stated that information should be available in multiple formats (e.g., videos, books, leaflets), include contact details for support networks, show children at different ages to illustrate what lies ahead, be tailored to families’ needs, and be readily accessible for whenever parents feel ready.

“The more information and balanced information people can have, the better it is for them to make decisions” (T21).

“At the start, I didn’t feel ready to talk to anyone. It took me a long time (...) to avail of support.” (T21).

All mothers we spoke to emphasised the importance of combining professional and peer support following a diagnosis of Trisomy 13, 18 or 21. Participants valued healthcare professionals for their clinical expertise, objective information and ability to explain complex medical issues. Several mothers also highlighted the importance of midwives, often perceived as providing compassionate and holistic support alongside consultant-led care. However, some participants reported being unable to access specialist midwifery or health visiting support and described feeling unsupported following diagnosis or birth.

“I remember my health visitor saying when I got out the red book ‘there is no point filling that out’” (T18).

Alongside professional support, participants consistently highlighted the importance of peer-support networks, describing it “a lifeline” and a crucial source of emotional support, practical advice and information. Participants valued sharing lived experiences of navigating healthcare services, family life and day-to-day challenges, while acknowledging differences in parenting approaches. Participants also stressed the importance of including partners in offers of information and support (e.g., Mencap) because “dads are forgotten about, in the middle of it all” (T18)”. These findings echo wider literature demonstrating the importance of both professional and peer support following an antenatal or postnatal diagnosis, as well as the need for family-centred approaches recognising the experiences of partners and wider family members (Rutter et al., 2025; Craig et al., 2023; Sheets et al., 2011).

Views of healthcare professionals and stakeholders

Unanimity in favour of a first-trimester antenatal screening programme in NI

There was unanimous support amongst healthcare professionals and stakeholders for introducing FTS as part of routine maternity care. They raised the following key points:

Inter-disciplinary approach: Participants acknowledged that implementing a FTS programme will have implications for a range of other services, which requires an interdisciplinary approach during both the design and implementation stages. They also suggested that FTS allows other diagnoses to be established if needed, e.g., inherited blood disorders.

Staff training: Participants identified the need for adequate resources such as education, information and training to successfully implement FTS, and recommended that these should be provided on a regional basis to reduce variability between different settings.

Public awareness: Participants highlighted the importance of public awareness of FTS at population-scale, and reflected upon the need to let patients know in the interim about the availability of NIPT in the private sector. They also raised the importance of educating politicians about this service. Finally, they discussed when information about screening should be provided to women, reflecting upon the need to inform patients before booking an appointment as the first appointment is often overloaded with information.

Programme tailored to the needs of population: Participants stressed the importance of services tailored to the needs of particular subgroups, such as individuals for whom English is not their first language or individuals who need easy-to-read material.

Concerns about the absence of first-trimester antenatal screening in NI

There was widespread concern about the absence of FTS amongst healthcare professionals and stakeholders. They raised the following key points:

Lack of strategic progress: Participants were frustrated by the lack of action from the Department of Health regarding FTS in NI, despite longstanding professional support: “we know what needs to happen, but progress is stalled”. There was a strong perception that abortion stigma is prevalent in professional discussions and is obstructing political decisions regarding FTS.

Delayed diagnosis – impact on families: All participants agreed that a FTS programme is needed to ensure that families are aware of the diagnosis early and that their decision-making process is not time-pressured. All participants agreed that families need more support after the diagnosis, to reduce the isolation many experience.

Impact on clinical services: Some healthcare professionals highlighted the implications of the absence of FTS for clinical care, particularly where a fetal condition is not identified until later in pregnancy. They noted that clinical guidance recommends that “*feticide should be performed before medical abortion after 21 weeks and 6 days gestation to ensure there is no risk of a live birth*” (RCOG, 2011). Feticide involves an injection to induce fetal demise. At the Regional Fetal Medicine Unit, a significant proportion of feticide procedures or late terminations are undertaken following diagnoses of conditions that could potentially have been identified through FTS, including Trisomies 13, 18 and 21 (Mone, 2026). Participants therefore suggested that earlier identification through FTS could reduce the number of feticide procedures, which many families report as extremely distressing.

Impact on staff: Healthcare professionals described the emotional and professional impact of the absence of a FTS programme. This included the emotional burden associated with communicating diagnoses later in pregnancy or following birth, and the emotional burden of providing care to women undergoing later termination procedures. While staff emphasised their willingness to provide this care, they acknowledged the emotional impact it could have on them. Sonographers also described feeling under pressure to undertake anomaly scans before 19 weeks’ gestation where possible, in order to facilitate earlier diagnosis and reduce some of the distress caused by later identification.

Private sector inequalities: Participants expressed concern about FTS being only accessible to individuals able to pay for it privately, as it reflects a two-tier system with inequitable access to information and healthcare. They also expressed concern about the quality of testing in private settings (especially when a positive result is identified and communicated to families) and the absence of a referral process into the healthcare system and/or for support services.

Inconsistency across HSC trusts: Participants noted variability in screening services across Trust areas and in how their availability is communicated to families, including a lack of transparency regarding reliability (e.g., the limitations of the quadruple test) and eligibility criteria (e.g., which age groups are offered screening).

Human rights implications

As outlined in the 2024 policy briefing, the absence of NHS-funded FTS as part of routine maternity care raises a number of potential issues regarding the UK’s legal obligations under international and European human rights law. Discussions with families who had diagnoses of severe or fatal fetal abnormalities and who either continued or ended their pregnancy informed our legal analysis.

Firstly, the absence of FTS in NI prevents all pregnant women/persons from gaining information and/or seeking reassurance early in the pregnancy as to whether the fetus they carry may be affected by one of the most common fatal or severe fetal abnormalities in the UK, despite available technology in the country.

Secondly, the absence of FTS in NI exposes pregnant women/persons whose fetus may be affected by Trisomy 13, 18 or 21 to diagnoses being communicated either later in the pregnancy (fetal abnormalities are often identified during the anomaly scan at 18-20 weeks’ gestation and later confirmed through diagnostic testing) or at birth (anomaly scans do not always identify such conditions), causing significant trauma to pregnant women and their families. On the one hand, for women who may decide to continue their pregnancies, the absence of FTS impedes their ability to prepare for the arrival of a baby with a disability both at birth and afterwards, and, in some cases, to prepare for the possible death of their baby. More specifically, it curtails their ability to plan their babies’ care, access psychological and peer support, and make family or work adjustments as early as possible. On the other hand, for women who may decide to terminate their pregnancies,

the absence of FTS impedes their ability to make an informed and timely decision, thereby compromising the realisation of their rights under Section 7 of the Abortion (NI) Regulations 2020, which allows termination of pregnancies on the ground of severe or fatal fetal abnormalities. More specifically, it limits women's access to timely information and support, increases the likelihood of requiring a feticide procedure (typically after 22 weeks' gestation), and curtails their ability to maintain privacy, given pregnancies may have been announced or become visible by that stage.

The UK (including NI) is legally bound to respect a number of human rights relevant to the situations highlighted above: the freedom from cruel treatment, the right to private and family life, the right to health and the right to be free from gender discrimination. Those rights are protected in the following legal instruments: the International Covenant on Civil and Political Rights 1966, the International Covenant on Economic, Social and Cultural Rights 1966, and the Convention on the Elimination of Discrimination Against Women 1979 (United Nations); the European Convention on Human Rights 1950 and the European Social Charter 1961 (Council of Europe); and the Human Rights Act 1998 (UK). As discussed in our previous policy briefing, both international and European human rights law require that States provide adequate maternal care and information, including resources necessary to act on that information (UN Committee on Economic, Social and Cultural Rights, 2000 and 2016); this includes free and regular consultation and screening for pregnant women throughout the country (European Committee of Social Rights, 2021). It also requires that States protect women's right to make an informed and timely decision on whether or not they wish to continue their pregnancies, including in cases of severe and fatal fetal abnormalities (e.g., European Court of Human Rights: *Tysiac v Poland* 2007 and *R.R. v Poland* 2011; UN Human Rights Committee: *Amanda Mellet v Ireland* 2016).

Gaps in knowledge

Despite evidence regarding the benefits of FTS and its availability elsewhere in the UK, gaps remain in understanding the implications of its absence in NI.

Data on antenatal detection dates for T13, T18 and T21: Unlike other UK jurisdictions, NI does not routinely publish data on antenatal detection rates for Trisomy 13, 18 or 21, making it difficult to fully assess the scale of potentially avoidable late diagnoses in NI.

Use of private sector: Little is known about the number of women in NI accessing privately funded FTS, how socioeconomic status influences uptake, or how women experience care, particularly when given a high chance result. Further research is needed to understand the extent to which private provision may be contributing to inequalities in access to information, choice and healthcare.

Experiences of minority and underrepresented groups: The experiences of ethnic minority communities, migrants, those with limited English, individuals with a disability and individuals from the LGBTQIA+ community remain largely absent from existing evidence. Further research is needed to understand how information about screening and diagnosis can be delivered in an appropriate and accessible way for all.

Impact on healthcare professionals: Although healthcare professionals described significant emotional and professional challenges associated with delayed diagnosis, there is limited evidence detailing the impact of the current system on staff wellbeing, morale, stress, training needs and workforce retention.

Economic implications of screening: There is currently limited NI specific evidence regarding the economic implications of introducing a publicly funded FTS programme, including its impact on specialist fetal medicine services, maternity services and longer-term healthcare provision. Research is currently underway at Queen's University Belfast to explore the economic implications of introducing FTS in NI; for further details contact Dr Fionnuala Mone: f.mone@qub.ac.uk

Attitudes towards antenatal screening: While this policy briefing highlights the views of families affected by Trisomy 13, 18 and 21, less is known about the views of the wider pregnant population in NI towards FTS, informed choice and reproductive decision making. Research is currently underway at Queen's University Belfast to explore the attitudes towards antenatal screening amongst pregnant people in NI; for further details contact Dr Fionnuala Mone: f.mone@qub.ac.uk

Policy recommendations

- 1: Introduce a comprehensive universal publicly funded first-trimester antenatal screening programme across all Health and Social Care Trusts in NI.
- 2: Develop standardised regional information resources that support informed decision making and present balanced information about Trisomy 13, 18 and 21.
- 3: Establish clear referral pathways to specialist healthcare, bereavement services, disability services and peer support organisations.
- 4: Provide regional training for healthcare professionals involved in offering screening and communicating diagnoses.
- 5: Develop a public awareness strategy regarding antenatal screening and informed choice.
- 6: Establish a regional monitoring and evaluation framework, supported by routine data collection and reporting to ensure equity, consistency and quality of service provision.
- 7: Monitor the realisation of human rights of pregnant women/pregnant persons living in NI, including access to antenatal screening.

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