

Antenatal screening in Northern Ireland and Women's Rights

Claire Lougarre, Suzie Heaney and Fiona Bloomer

Introduction

Abortion was decriminalised in Northern Ireland (NI) in October 2019, following the introduction by the United Kingdom (UK) government of the *Northern Ireland Executive Formation Act 2019* (Aiken and Bloomer, 2019). The NI Abortion Regulations introduced in March 2020, allowed abortion services to be provided under a broad set of conditions, including in cases of 'severe fetal impairment or fatal fetal abnormality' (Regulations, Section 7). Following a delay in the commissioning of services, interim services were eventually provided, but these were focused on early medical abortions (up to 10 weeks' gestation), using medication. Some terminations due to diagnoses of severe or fatal fetal abnormality took place during that period, but monitoring data on gestations, and method of abortion have not been published. Beyond these criteria and parameters, abortion seekers were required to travel elsewhere to access services including some cases of severe or fatal fetal abnormality (Kirk et al., 2021). As of 24 October 2022, the Northern Ireland Office (NIO) has led commissioning, with full implementation

of services enacted in late 2023. The adoption of the *NI Abortion Regulations 2020*, with its Section 7 allowing terminations on the ground of severe or fatal fetal abnormality, has brought into sharp focus access to antenatal screening, specifically during the first trimester. Unlike the rest of the UK, this screening is not routinely offered in NI and as a result, most fetal abnormalities are diagnosed following the anomaly scan which typically occurs at around 18-20 weeks' gestation.

This policy briefing has been informed by two expert roundtables held in January 2024. The first roundtable was attended by families bereaved following diagnoses of severe or fatal fetal abnormalities and a representative from the Regulation and Quality Improvement Authority (RQIA), the regulator for health and social care in NI. The second roundtable was attended by health professionals involved in the delivery of maternity and fetal medicine services in NI, as well as academics and support organisations.

Background on First Trimester Antenatal Screening

First trimester antenatal screening allows the detection of three conditions: Trisomy 13, Trisomy 18 and Trisomy 21 (respectively known as Patau’s syndrome, Edwards’ syndrome, Down’s syndrome). In England in 2019, 2,134 babies were born with either Trisomy 13, 18 or 21, representing 16% of the total number of babies born with a congenital anomaly that year (13,306) (Public Health England, 2021). First trimester antenatal screening is routinely offered to all pregnant women in England, Wales and Scotland, but not in NI (see table 1, below). In the parts of the UK where testing takes place, when the screening test (a scan and a blood test called the ‘Combined Test’) indicates a high likelihood for the fetus to be affected by one of those three conditions, women

are offered either: a) a further screening test (a blood test called the ‘Non-Invasive Prenatal Testing’ or NIPT, with accuracy over 99%); or b) an invasive diagnostic test (called the ‘CVS’ if below 14 weeks’ gestation or ‘Amniocentesis’ if above 15 weeks’ gestation, with accuracy of 100% but a 0.5% risk of miscarriage (NHS, 2024)); or c) no further testing. In NI, women over 36 years old may be offered a screening test (a blood test called ‘Quadruple Test’) in their second trimester, which presents a lower accuracy and only detects Trisomy 21. Statistics in the UK indicate that most cases of Trisomy 13, 18 and 21 are diagnosed antenatally, with approximately 86-88% of these pregnancies ending in termination (Public Health England, 2021).

Table 1: Antenatal screening in the UK before the ‘anomaly scan’ (18-20 weeks)

Region	Publicly funded antenatal screening	Type of screening	Conditions detected	Accuracy	Comments
Northern Ireland	Screening test sometimes offered to pregnant women at weeks 14-20 (some Trusts charge for this)	Quadruple test (blood test)	Trisomy 21 only (not Trisomy 13 or Trisomy 18)	80%	Maternal age appears to be the main criteria, however there is inconsistent practice across Trusts. Referral for amniocentesis possible
Rest of the UK	Screening test offered at weeks 11-13	Combined test (scan + blood test) (free)	Trisomy 13, Trisomy 18, Trisomy 21	90-95%	Offered to all pregnant women. Referral for NIPT/ amniocentesis/ CVS possible

Trisomies 13, 18 and 21 all lead to higher incidences of miscarriages, stillbirth, neonatal and infant mortality, with particularly high incidences for Trisomy 13 and Trisomy 18 which are thus, considered to be ‘fatal fetal abnormalities’. Indeed, when a fetus is affected by Trisomy 13 or 18 (3-7 per 10,000 births), 7 in 10 pregnancies over 12 weeks’ gestation will end in miscarriage or stillbirth; and if the pregnancy goes to term, 9 in 10 children will die in their first year (NHS). When a fetus is affected by Trisomy 21 (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, 0.5 in 10 children will die in their first year (UK Office for Health Improvement and Disparities, 2022). Miscarriage, stillbirth, neonatal and infant mortality cause significant levels of trauma, stress, anxiety, grief and depression amongst women, with a risk of increasing trauma for women as the pregnancy progresses and/or when or after the child is born (Kukulskienė & Žemaitienė 2022; Quenby et al. 2021). Men are also significantly affected by pregnancy and baby losses, including in the context of fetal abnormalities (Kecir et al., 2021; Obst et al., 2020).

When they do not lead to fatal outcomes, Trisomy 13, Trisomy 18 and Trisomy 21 result in disabilities likely to require regular care, a position held most often by mothers. Indeed, carers for disabled children are predominantly women (>65%); and women carers are more likely to be unemployed, to be in low paid/ low skilled employment, or to work part-time; with 1/4 of women carers for disabled children being lone parents (Carers UK, 2021). While parent carers of disabled children report on a wide range of positive outcomes (Beighton and Wills, 2019), they also face various challenges, and these predominantly affect women. Carers are also more likely to live in poverty, with the Carers Allowance in the UK amounting to £76.75 per week in 2023/24 (Joseph Rowntree Foundation, 2022). Furthermore, carers are more exposed to ill-health: indirectly, since poverty is evidenced with lower levels of health (WHO, 2024); and directly, since carers report long-term health conditions or disabilities more often than non carers (Carers UK, 2022).

Antenatal screening and human rights law

The absence of first trimester antenatal screening universally offered and funded by the NHS in NI raises a number of potential issues regarding UK’s legal obligations under human rights law.

Firstly, it prevents all pregnant women from gaining information and/or seeking reassurance until 18-20 weeks gestation on whether or not the fetus they carry is affected by one of the most common fatal or severe fetal abnormalities in the UK, despite available technology in the UK. Secondly, the absence of NHS first trimester antenatal screening in NI prevents women whose fetus may be affected by Trisomy 13, 18 or 21, from making an informed and timely decision on whether or not they wish to continue their pregnancies. In NI, women wishing to end their pregnancies in such circumstances must typically make decisions at 18-20 weeks’ gestation or more (and cannot avail of their right under Abortion Regulations NI, Section 7 until then). This contrasts with England and Wales, who have embedded universal antenatal screening and where 67% of abortions carried out in cases of an anomaly diagnosis are done so at under 20 weeks’ gestation, with 25% carried out at 13-14 weeks gestation (Office for Health Improvement and Disparities, 2023). Furthermore, women wishing to continue their pregnancies in such circumstances are unable to prepare themselves for the possibility of pregnancy/baby loss, infant death, or becoming a carer for a disabled child, until 18-20 weeks’ gestation or more in NI. In cases where women choose to continue their pregnancy this also delays access to specialist support through the NI Antenatal Palliative Care Pathway (Regional Paediatric Palliative Care Network, 2022).

The UK (including NI) is legally bound to respect a number of human rights relevant to such situations: the freedom from ill-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: *International Covenant on Civil and Political Rights 1966*, *International Covenant on*

Economic, Social and Cultural Rights 1966, and *Convention on the Elimination of Discrimination Against Women 1989* (UN); *European Convention on Human Rights 1950* and *European Social Charter 1961* (Council of Europe); *Human Rights Act 1998* (UK). International and European human rights law require that States (including the UK) 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*). It also requires 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).

Policy and Service provision of NIPT – national and international perspectives

First trimester antenatal screening policies are 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). Public Health England (PHE) (2023) have published specific guidance and recommendations on NIPT, and with RCOG (in prep) jointly consulting, with the British Maternal and Fetal Medicine Society, on new guidance on care after NIPT.

NIPT is available as part of antenatal care around the world, including Belgium, Canada, Denmark, France, England, Scotland, Wales, the Netherlands and Singapore. In the USA, Israel and Australia, it is typically available through commercial providers (Bunnick et al., 2022). In places where it is fully publicly funded, the uptake is high (Denmark, 90%; Belgium 80%). In contrast, when it is provided at cost to the pregnant woman the uptake is typically

lower, (approximately 30%), impacting on those in lower socio-economic groups (Bunnick et al., 2022; van der Meij et al., 2021).

The use of NIPT significantly reduces the need for invasive procedures such as CVS and amniocentesis, with one study conducted by Public Health Wales documenting that such procedures dropped from an annual average of 229 to 27 procedures after NIPT implementation throughout Wales (UK) (Bowden et al., 2022). Testing has not impacted on the annual live birth rate of those with Trisomy 21 (Down's syndrome) (UK) (Bowden et al., 2022). The importance of providing NIPT is set within a context where the immediacy of fetal abnormality diagnosis at prenatal scan (18-20 weeks+) can be very distressing for women and sonographers. Thus, providing tests earlier, and allowing time to prepare for giving results is recommended (UK) (Cantlay, 2011).

Further key findings in a review of evidence focusing on pregnant women included:

- A small minority were concerned about pressure to test (Canada) (Ravitsky et al., 2021).
- Culturally competent educational resources are needed to ensure informed decision making for those from ethnic minority communities (Netherlands) (Peters et al., 2017).
- Concerns about a lack of information, costs of tests, decisions impacted by relations with family, kinship and community (India) (Gupta, 2010).
- Informed choice is problematic if decision-making is limited by concerns regarding insufficient resources to support people with disabilities (Canada) (Haidar et al., 2016).
- Adequate time is needed for pre- and post-test counselling (Canada) (Haidar et al., 2016).
- Communication of results was problematic for some women, with medics relying on medical terms or in contrast euphemisms (UK) (Littlemore et al., 2019).

Antenatal screening: service provision in Northern Ireland

NI follows guidance from the National Institute for Health and Care Excellence (NICE) and offers specific screening programmes for fetal anomalies, infectious diseases in pregnancy, and sickle cell and thalassaemia screening (NICE, 2021). As highlighted above, NI does not offer combined screening or NIPT as part of universal maternity care (NI Direct 2021; Public Health England, 2021a). NIPT can be accessed from private providers in NI (average cost of £400) but it is not routinely signposted by health professionals. Women may be offered a quadruple test between weeks 14-20 but this seems to be at the discretion of health professionals. In line with NICE guidelines, all pregnant women in NI are offered fetal anomaly screening for 11 physical conditions (NI Direct, 2021; NICE, 2021; Public Health England, 2021b). These conditions include: anencephaly; open spina bifida; cleft lip; diaphragmatic hernia; gastroschisis; exomphalos; serious cardiac abnormalities; bilateral renal agenesis; lethal skeletal dysplasia; Edwards syndrome (trisomy 18); Patau syndrome (trisomy 13). This is carried out at around 18-20 weeks' gestation in line with the NHS Fetal Anomaly Screening Programme (FASP).

View from the Expert Roundtables

This policy overview was discussed and endorsed by roundtable experts, including families bereaved following diagnoses of fatal or severe fetal abnormalities, healthcare professionals involved in the delivery of maternity and fetal medicine services in NI, and academics in law, midwifery and social policy. There was consensus that the absence of first trimester antenatal screening discriminated against women living in NI and that it was combined with a lack of transparency around screening and diagnosis. Participants agreed that and that these deficiencies in service provision needed to be addressed by planning and introducing a new service from scratch. The following points provide a summary of the justification for this:

- Discrimination against women living in NI: both groups felt that the failure to offer first trimester antenatal screening to women in NI was not aligned with abortion law in NI. Participants highlighted that the absence of such services exposed women to preventable mental and physical harm related to late diagnoses of fetal abnormalities (increased risk of trauma and complicated grief; increased risk of amniocenteses; limited choice on the method and timing of termination – e.g., induced medical labour over surgical procedure; heavy decisions around feticide and palliative care, possibility of having to travel to other jurisdictions to access care etc.), with limited emotional support available such as counselling. Families felt that having late diagnoses also forced them to disclose personal details to persons aware of the pregnancy by then (they felt “the pressure of the world observing”, the fear of judgment given “the stigma around abortion in NI” and having “no right to private and family life”). Finally, families and clinicians highlighted that late diagnoses of fetal abnormalities unnecessarily rushed parents during life-changing and often devastating decisions, whether to continue or terminate the pregnancy. Both groups stressed that this amounted to treating women like “second class citizens” in accessing what is “essentially healthcare”, and felt a stark contrast with what was offered to women (and parents) in the rest of the UK. Families stated “this is not respectful of our time, our emotional and physical wellbeing”.
- Lack of transparency: both groups felt that the failure to offer first trimester antenatal screening to women in NI was combined with a lack of information and care pathway regarding antenatal screening and diagnosis. Some parents reported not knowing at the time that first trimester antenatal screening was available in the rest of the UK or that the NIPT was a (private) alternative in NI. Parents highlighted being confused about the fetal abnormalities they received diagnoses for

(some were told “not to Google”), and meeting with staff “unsure” what to do or tell them about alternatives following such diagnoses. Some parents felt that information was ‘withheld’ from them without anyone being accountable for it. Health professionals stressed the need to provide adequate information to families and make sure it was understood. Both groups called for immediate action in the interim: informing pregnant women of the situation in NI (some health professionals calling it an “obligation”) and signposting them to options such as the NIPT, despite the challenges raised by private healthcare (i.e., insufficient audits and disparities of access).

- A unique opportunity to coordinate optimal service: both groups highlighted the cost and commissioning of first trimester antenatal screening as a major barrier to its design and implementation. Healthcare professionals stressed that planning and training had to be thought through. Both groups highlighted the possibility to create “gold standard” care for antenatal screening in NI by starting from scratch, and they enthusiastically supported the possibility to “get it so right” and “turn equity on its head”. There was a call to bring together experts in this area and get “the right people to hear what needs to be done, people listening to us, properly working with us”, rather than “personal [political] views influencing” healthcare. Health professionals favoured the option of offering NIPT to pregnant women over the combined test, due to the situation in NI.

Gaps in knowledge

There is limited published research on antenatal screening in NI, and findings are not recent. One study which reviewed clinical documents identified “*variation in service provision across maternity units; a lack of training opportunities for health professionals and no common information system employed*” (Lynn et al., 2010, pp.12). Another study which comprised a survey of pregnant and non-pregnant women reported that

both groups preferred screening tests offering more accurate results over no risk of miscarriage (Reid et al, 2014). There is no congenital anomaly register in NI, thereby, limiting knowledge in this area as surveillance data including incidence and outcomes regarding pregnancies affected by an anomaly diagnosis are unknown, including those pregnancies that end in abortion (DoH NI, 2023; McCullough and Dolk, 2017). England and Wales, in contrast, have congenital anomaly registers: the National Congenital Anomaly and Rare Disease Registration Service in England; and the Congenital Anomaly Register and Information Service in Wales (NCARDRS, 2021; Public Health Wales, 2022).

Policy Recommendations

- First trimester antenatal screening should be offered to all pregnant women in NI in order to make NI Abortion Regulations 2020 Section 7, effective; and in order to prevent the significant harm caused by late diagnoses of fetal abnormalities for pregnant women.
- An expert group on first trimester antenatal screening should be established to advise, research and plan the design and delivery of such services in NI.
- Interim public information on antenatal screening should be made available to all pregnant women in NI as a priority, as well as to key healthcare providers involved in early stages of pregnancy.
- There is a need for more research on this topic; data should be collected and monitored on prenatal diagnosis and its outcomes in NI, including gestation detected and outcome of pregnancy. The views and experiences of women of reproductive age, families who have had a prenatal diagnosis and healthcare providers should also be gathered.

References:

- Aiken, A. and Bloomer F. (2019)** Abortion decriminalised in Northern Ireland. *Bmj*, 367: l6330.
- Beighton, C., & Wills, J. (2019)** How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, 32 (5), 1255-1279.
- Bowden, B. de Souza, S., Puchades, A., Williams, K., Morgan, S., Anderson, S., Tucker, D., Hillier, S. (2022)** Implementation of non-invasive prenatal testing within a national UK antenatal screening programme: Impact on women's choices, *Prenatal Diagnosis*, 42(5), pp. 549–556.
- Cantlay, N. (2011)** *Sonographers' experiences of breaking bad news in prenatal ultrasound: A phenomenological analysis*. University of Cumbria.
- Carers UK (no date)** *Key facts and figures about caring*, <https://www.carersuk.org/policy-and-research/key-facts-and-figures/>
- Carers UK (with ACE, EU European Social Fund, University of Leeds), (2021)** *Managing More than Most: A statistical analysis of families with sick or disabled children*, p5, <https://contact.org.uk/wp-content/uploads/2021/03/caringforsickanddisabledchildren2006appendix.pdf>
- Carers UK, (2022)** *State of Caring 2022: A snapshot of unpaid care in the UK*, <https://www.carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf>
- Council of Europe (1950)** European Convention on Human Rights
- Council of Europe (1961)** European Social Charter
- Council of Europe European Court of Human Rights (2007)** *Tysiack v. Poland* Judgment, Application No. Application no. 5410/03
- Council of Europe, European Court of Human Rights (2011)** *R.R. v. Poland* Judgment, Application No. 27617/04
- Department of Health NI (2023)** *Northern Ireland termination of pregnancy statistics 2021/22*, <https://www.health-ni.gov.uk/publications/northern-ireland-termination-pregnancy-statistics-202122>
- Gupta, J.A. (2010)** 'Exploring women's reproductive decision-making regarding prenatal testing', *Culture, Health & Sexuality*, 12(2), 191–204.
- Haidar, H., Dupras, C., Ravitsky, V. (2016)** Non-invasive prenatal testing: Review of ethical, legal and social implications, *BioethiqueOnline*, 5, 1-14.
- Joseph Rowntree Foundation (2022)** *UK Poverty 2022: The essential guide to understanding poverty in the UK* (full report), pp. 57-63 <https://www.jrf.org.uk/report/uk-poverty-2022>
- Kecir, K. A., Rothenburger, S., Morel, O., Albuissou, E. and Ligier, F. (2021)** Experiences of fathers having faced with termination of pregnancy for foetal abnormality, *Journal of Gynecology Obstetrics and Human Reproduction* 50 (1), 101818, 1-5

Kirk, S., Morgan, L., McDermott, S., McLaughlin, L., Hunter, C., and Farrington, T. (2021) Introduction of the National Health Service early medical abortion service in Northern Ireland—an emergency response to the COVID-19 pandemic. *BMJ Sexual and Reproductive Health*, 47(4), 293-295.

Kukulskienė M, Žemaitienė N. (2022) Experience of Late Miscarriage and Practical Implications for Post-Natal Health Care: Qualitative Study. *Healthcare* 10(79), 1-16

Littlemore, J. Fuller, D. McGuinness, S. Kuberska, K. Turner, S. (2019) Death before birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination and stillbirth, *NILQ* 70(1),131–153.

Lynn, F., McNeill, J., Alderdice, F. (2010) Current trends in antenatal screening services: Results from a regional survey, *The Ulster Medical Journal*. 79(1),12–15.

McCullough, N. and Dolk, H. (2017) *Prevalence and primary prevention of congenital anomalies in Northern Ireland*, Ulster University.

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) (2021) Congenital anomaly statistics 2019, Public Health England, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1021335/NCARDRS_congenital_anomaly_statistics_report_2019.pdf, [Accessed on: 22/02/2024]

National Institute for Health and Clinical Excellence [NICE] (2010) NICE Clinical Guideline 62. Antenatal Care: Routine Care for the Healthy Pregnant Woman. /www.fetalanomaly.screening.nhs.uk/consentS

NHS (2021) 20-week screening scan, available from, <https://www.nhs.uk/pregnancy/your-pregnancy-care/20-week-scan/>

NHS, ‘Overview: Amniosynthesis’ <https://www.nhs.uk/conditions/amniocentesis/>

NHS, ‘Screening tests in pregnancy’ <https://www.nhs.uk/pregnancy/your-pregnancy-care/screening-tests/>

NHS, ‘Down’s Syndrome (Trisomy 21)’ <https://www.nhs.uk/conditions/downs-syndrome/>

NHS, ‘Edwards Syndrome (Trisomy 18)’ <https://www.nhs.uk/conditions/edwards-syndrome/> See also <https://www.nhsinform.scot/illnesses-and-conditions/chromosomal-conditions/edwards-syndrome>

NHS, ‘Patau Syndrome (Trisomy 13)’ <https://www.nhs.uk/conditions/pataus-syndrome/> See also <https://www.nhsinform.scot/illnesses-and-conditions/chromosomal-conditions/pataus-syndrome>

NI Direct (2021) *Scans, screening tests and check – ups*, <https://www.nidirect.gov.uk/articles/scans-screening-tests-and-check-ups>

NICE (2021) *Antenatal Care: Quality statement 10: Screening – national fetal anomaly screening programmes*, <https://www.nice.org.uk/guidance/qs22/chapter/quality-statement-10-screening-national-fetal-anomaly-screening-programmes>

NIACT (2021) *Report on Sexual and Reproductive Health in Northern Ireland*, <https://www.fsrh.org/documents/niact-full-report-31st-march-2021/>

Northern Ireland Office (NIO) (2020). Abortion (Northern Ireland) Regulations, 2020, <https://www.legislation.gov.uk/ukSI/2020/345/contents/made>

Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020) Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. *BMC pregnancy and childbirth*, 20(1), 1-17

Office for Health Improvement and Disparities (UK), (2022) *Guidance: Down's syndrome, Edwards' syndrome and Patau's syndrome*, <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby/downs-syndrome-edwards-syndrome-and-pataus-syndrome-combined-or-quadruple-test-taken-on-or-after-1-june-2021#about-these-conditions>

Office for Health Improvement and Disparities (2023) National statistics. Abortion statistics for England and Wales: 2021, <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2021>

Peters, I.A., Posthumus, A.G., Reijerink-Verheij, J.C.I.Y., Van Agt, H.M.E., Knapen, M.F.C.M. and Denktas, S., (2017) Effect of culturally competent educational films about prenatal screening on informed decision making of pregnant women in the Netherlands, *Patient Education and Counseling*, 100 (4),776-782.

Public Health England (2021) *National congenital anomaly and rare disease registration service: Congenital anomaly statistics 2019*, https://assets.publishing.service.gov.uk/media/61533beb8fa8f5610d9a1844/NCARDRS_congenital_anomaly_statistics_report_2019.pdf

Public Health England (2021a) *Guidance: Down's syndrome, Edwards' syndrome and Patau's syndrome*, <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby/downs-syndrome-edwards-syndrome-and-pataus-syndrome-combined-or-quadruple-test-taken-on-or-after-1-june-2021>

Public Health England (2021b) *NHS Fetal Anomaly Screening Programme (FASP): programme overview*, <https://www.gov.uk/guidance/fetal-anomaly-screening-programme-overview#screening-test>.

Public Health England (PHE) (2023) Screening in the UK: making effective recommendations 1 April 2021 to 31 March 2022, <https://www.gov.uk/government/publications/uk-national-screening-committee-annual-report-2021-to-2022/screening-in-the-uk-making-effective-recommendations-1-april-2021-to-31-march-2022>

Public Health Wales (2022) (CARIS) *Congenital Anomaly Register and Information Service*, <https://phw.nhs.wales/services-and-teams/caris/#:~:text=CARIS%20is%20a%20programme%20which,Division%20of%20Public%20Health%20Wales.&text=CARIS%20collects%20information%20about%20any,of%20the%20end%20of%20pregnancy>

Quenby, S., Gallos, I.D., Dhillon-Smith, R.K., Podeseck, M., Stephenson, M.D., Fisher, J., Brosens, J.J., Brewin, J., Ramhorst, R., Lucas, E.S. and McCoy, R.C (2021) Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. *Lancet*. 397(10285):1658-1667.

Ravitsky, V., Birko, S., Le Clerc-Blain, J., Haidar, H., Affdal, AO., Lemoine, M., Dupras, C., Laberge, A. (2020) Noninvasive prenatal testing: Views of Canadian pregnant women and their partners regarding pressure and societal concerns, *AJOB Empirical Bioethics*, 12(1),53–62.

Regional Paediatric Palliative Care Network (2022) *Northern Ireland Antenatal Palliative Care Pathway*, <https://online.hscni.net/partnerships/regional-paediatric-palliative-care-network/northern-ireland-antenatal-palliative-care-pathway-user-guide/>

Reid, B., Sinclair, M., Barr, O. Dobbs, F., Crealey, G. (2014) Women’s preferences for antenatal screening for Down syndrome in Northern Ireland: a choice experiment, *Evidence Based Midwifery*, 12(4),112-120.

Riches, NO., Johnson, EP., Subramaniam, A., Vora, NL. ,Hardisty, E., LaRiviere, K., Rothwell, E. (2023) Understanding the experiences and perspectives of prenatal screening among a diverse cohort, *Prenatal Diagnosis*, 43(5),605–612.

Royal College of Obstetricians and Gynaecologist (RCOG) (2010) *Guidance: Termination of Pregnancy for Fetal Abnormality*, <https://www.rcog.org.uk/guidance/browse-all-guidance/other-guidelines-and-reports/termination-of-pregnancy-for-fetal-abnormality-in-england-scotland-and-wales/>

RCOG (in prep) *Care after non-invasive pre-natal testing*, *Green-top Guideline No. 76*, <https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/care-after-non-invasive-pre-natal-testing-green-top-guideline-no-76/>

UN Committee on Economic, Social and Cultural Rights, (2000) General Comment No. 14: The right to the highest attainable standard of health.

UN Committee on Economic, Social and Cultural Rights (2016) General Comment No. 22: The right to sexual and reproductive health.

UN Human Rights Committee (2016) *Amanda Mellet v. Ireland* Communication No. 2324/2013

van der Meij, KRM., Kooij, C., Bekker, MN., Galjaard, RH., Henneman, L., **Dutch NIPT Consortium (2021)** Non-invasive prenatal test uptake in socioeconomically disadvantaged neighborhoods, *Prenatal Diagnosis*, 41(11),1395–1400.

World Health Organization, Social determinants of health https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

World Health Organisation (2016), *WHO recommendations on antenatal care for a positive pregnancy experience*, <https://www.who.int/publications/i/item/9789241549912>.

About the authors:

Dr Claire Lougarre is Lecturer in Law at the School of Law, Ulster University, specialising in human rights law and reproductive health.

Dr Suzie Heaney is NI Co-ordinator at Antenatal Results and Choices. Her PhD was on the experiences of families from Ireland and Northern Ireland who ended a pregnancy following an antenatal anomaly diagnosis.

Dr Fiona Bloomer is Senior Lecturer in Social Policy at the School of Applied Social and Policy Sciences, Ulster University, specialising in abortion policy.



**QUEEN'S
UNIVERSITY
BELFAST**

T. 028 9097 3034 E. info@ark.ac.uk



T. 028 9036 6339wE. info@ark.ac.uk