

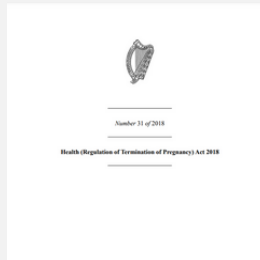


# Termination of pregnancy for fetal anomalies

Generating evidence to support the implementation of legislation in Ireland and enhance termination of pregnancy care experiences

## The Challenge

Termination of pregnancy for fetal anomaly (TOPFA) was introduced in Ireland in 2019. Section 11 of the Health (Regulation of Termination of Pregnancy) Act 2018 allows termination of pregnancy to be provided following a diagnosis of a fetal condition likely to lead to death in utero or within 28 days of birth.



The term fatal fetal anomaly (FFA) is used to describe congenital anomalies that will likely lead to fetal or neonatal death and is used interchangeably with the words lethal and life-limiting. FFA is not a medical term, but it gained popularity in Ireland during its use in the political campaigns to repeal the Eight Amendment of the Irish Constitution.

Approximately 2% of pregnancies are diagnosed with a congenital anomaly each year. A proportion of these anomalies will be lethal or fatal, and congenital anomalies remain the leading cause of fetal death and infant mortality.

A diagnosis of major fetal anomaly in pregnancy is usually unexpected, and causes grief and distress, which can be exacerbated by inadequate care and support. Following the antenatal confirmation of a FFA, parents are faced with decisions concerning the remainder of the pregnancy, continuing the pregnancy and preparing for the birth of their baby, or choosing termination of pregnancy. Parents require accurate information in an empathetic and balanced way to make an informed decision. Research was needed to inform the implementation of the legislation around TOPFA in Ireland.

## Our Work

Members of the Pregnancy Loss Research Group (PLRG) have led a range of studies exploring different aspects of TOPFA.

- Analysis of perinatal deaths reported to the National Perinatal Epidemiological Centre during 2011-2018, led by Dr Stacey Power Walsh, identified that only 42% of perinatal deaths could be classified as a FFA in accordance with the Health (Regulation of Termination of Pregnancy) Bill 2018, highlighting the complexity of these cases/multiorgan system anomalies.
- A critical discourse analysis of media commentary on FFA in Ireland led by Dr Stacey Power Walsh highlighted the influential nature of language and misrepresentations in the information being delivered to the public. It identified the need for healthcare professionals to expand their media literacy and to have knowledge of the information available to women and families who receive a diagnosis of FFA.
- An assessment of the general public's knowledge of fatal fetal anomalies led by Dr Stacey Power Walsh found that there is a lack of accurate knowledge on FFA, its classification, diagnosis, survival, and supports available following a diagnosis of FFA.
- An assessment of UCC students' knowledge of FFA and TOPFA led by Dervla Devine highlighted a gap in university student knowledge in FFA and TOPFA.
- A qualitative exploration of the experiences of volunteers supporting parents following a FFA diagnosis, led by Dr Stacey Power Walsh, found



Supporting references and links for this impact case study are available on our website



that volunteers felt comfortable in their peer support role to bereaved parents. However, there is a need for education and collaborative working between health care professionals and volunteers to assist them in supporting bereaved parents.

- A qualitative interview study examining fetal medicine specialist experiences of providing a new service of TOPFA, led by Dr Stacey Power Walsh, highlighted the challenges that Fetal Medicine Specialists faced with the introduction of TOPFA, particularly in the absence of institutional support and lack of additional resources. They feared getting a diagnosis of a FFA wrong because of media scrutiny and the criminal liability attached to the legislation. The legislation was a challenge for them as it was unclear and open to interpretation regarding what constitutes FFA.
- A qualitative interview study, led by medical student Peter Jackson towards the award of a Masters in Public Health, highlighted parents' need for consistent, well communicated, and comprehensive care, which encourages an individualised perinatal palliative care approach to meet parental needs following the legalisation of termination of pregnancy in Ireland.



### Our Impact

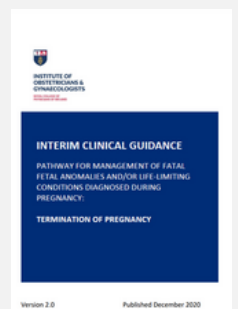
#### Informing training and education of health professionals

- Dedicated session on TOPFA included in TEARDROP - Teaching, Excellent, pArent, peRinatal, Deaths-related, inteRactions, tO, Professionals, a half-day workshop designed to address the educational needs of health professionals involved in maternity and newborn care in managing perinatal death and pregnancy loss. Delivered since 2018. Read separate impact case study on TEARDROP.
- In April 2022, Professor O'Donoghue presented on 'Termination of Pregnancy for Life-Limiting Conditions' at a study day webinar on Termination of Pregnancy, hosted by the Institute of Obstetricians & Gynaecologists and Royal College of Physicians of Ireland.

- In March 2023, Professor O'Donoghue presented the latest research on TOPFA, outlining current challenges and future directions during a UCC Medical Graduates Association webinar on pregnancy loss delivered by the Pregnancy Loss Research Group.

#### Influencing policy and clinical guidelines

- Professor O'Donoghue is a member of the National Women and Infants Health Programme TOP Clinical Advisory Forum since 2020.
- Professor O'Donoghue authored 'Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy - Termination of Pregnancy', on behalf of the Institute of Obstetricians and Gynaecologists; published in 2020. PLRG research informed this guideline.
- Professor O'Donoghue addressed the Oireachtas All Party Group on Sexual and Reproductive Health Rights in January 2021.
- Professor O'Donoghue addressed the National Screening Advisory Committee on antenatal screening for fetal anomaly in Ireland in May 2021.
- During discussions of the Review of the Operation of the Health (Regulation of Termination of Pregnancy) Act 2018 by the Joint Committee on Health debate in April 2022, the "important research coming out of University College Cork by Professor Keelin O'Donoghue and Dr Stacey Power Walsh" was noted by a representative of the Irish Family Planning Association.
- Work on TOPFA integrated into the revised National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, published in 2022.
- Policy brief titled "Termination of pregnancy: Training and clear guidance can have a meaningful impact on services" published in October 2022.
- Research informed the Department of Health-led review of the Health (Regulation of Termination of Pregnancy) Act 2018 legislation and the Health Service Executive-led review of Section 11; both due to be published in 2023.
- The research is also informing a new clinical guideline on the management of TOPFA.



### Increasing public awareness – media coverage

- What is needed for prenatal diagnosis. Professor Keelin O’Donoghue and Professor Noirin Russell, Irish Times (25/07/2016)
- We need to talk about what would replace 8th Amendment, says maternity expert. Professor Keelin O’Donoghue, Irish Examiner (18/09/2016)
- Four families explain the importance of the 20-week fetal anomaly scan. Special Report by Catherine Shanahan, Irish Examiner (06/03/2017)
- No longer alone in calling for fetal anomaly scans for all. Professor Keelin O’Donoghue, Irish Examiner (06/03/2017)
- Only seven out of 19 Irish maternity units offer ultrasound scans to all. Mark Hilliard , Irish Times (24/11/2017)
- A caring service for those who lose a baby. Catherine Shanahan, Irish Examiner (28/02/2019)
- Doctors left high and dry after repeal of Eighth Amendment. Professor Keelin O’Donoghue, Business Post (07/07/2019).

### Awards

Research led by Peter Jackson around parents’ experiences of pregnancy following a diagnosis of fetal fatal anomaly has won awards at several conferences:

- 5th All Island Children’s Palliative Care Conference, Belfast, September 2022
- UCC College of Medicine and Health Research Conference “from Molecules to People”, Cork, September 2022
- Junior Obstetrics and Gynaecology Society Meeting, Dublin, November 2022.



Peter Jackson receiving prize for his oral presentation from Professor Liam Fanning, at “from Molecules to People”, Devere Hall, UCC on 22nd September 2022.

Dr Stacey Power Walsh was awarded her PhD for her thesis “Experiences of pregnancy with major fetal anomalies” from UCC in July 2021. Stacey also received prizes for her PhD work:

- Best Oral 5 Minute Rapid Round: Society for Social Medicine Annual Scientific Meeting, Glasgow, September 2018. Paper: Critical discourse analysis on the influence of media commentary on FFA in Ireland
- Best Poster Presentation: University College Dublin Children’s Research Network PhD Symposium, September 2018. Paper: An assessment of the general public’s knowledge of fatal fetal anomalies.



Dr Stacey Power Walsh graduating with her PhD, July 2021



“Research from our Group highlights key areas for action for Termination of Pregnancy legislation reform, for healthcare policy and for improved clinical practice alongside enhancing training and education of health professionals.

Our research continues to actively inform legislation reviews, clinical guidelines, staff training and education, and public awareness, making an impact to ultimately enhance termination of pregnancy care experiences for parents with a diagnosis of a FFA.

**Professor Keelin O’Donoghue, Lead, Pregnancy Loss Research Group**