**Participant Information Sheet**

**A Survey of Irish Health Care, Social Care, and Education Professionals Knowledge, Attitudes and Experience of Foetal Alcohol Spectrum Disorders (FASD)**

**Dear Colleague**

We are keen to get your views on Foetal Alcohol Spectrum Disorders (FASD). Pregnancy needs to be alcohol free to prevent cases of Foetal Alcohol Spectrum Disorder.

**Why is this study needed?**

Drinking alcohol during pregnancy can cause foetal alcohol spectrum disorders (FASD). It is estimated that 600 babies are born each year in Ireland with Foetal Alcohol Syndrome (FAS) – the more severe end of the spectrum and that another 9-10 times this number are born with a (non-FAS) Foetal Alcohol Spectrum Disorder. These numbers are reflected in referrals to CAMHS, in school SNA numbers, and in the number of school leavers each year seeking rehabilitation training and day service places.

There is an absence of service for the diagnosis and treatment of FASD in Ireland. This survey is the first step of a needs assessment around FASD in Ireland. Public awareness of the dangers surrounding alcohol consumption during pregnancy is limited. Amongst healthcare, social care, and education professionals themselves there is not a consensus on how to address this matter. Foetal alcohol spectrum disorders (FASD), including Foetal Alcohol syndrome (FAS) are often little understood even amongst staff who regularly interact with pregnant women or with persons with FASD. Pregnant women do not consistently receive timely maternity care or support for their alcohol & drug issues. Health, social care, and education professionals do not consistently provide information on the risks of drinking during pregnancy or routinely screen for alcohol issues. Most clinicians lack the capability to diagnose FASD. Families of people with FASD struggle to access appropriate support and report a lack of understanding from services, professionals and even other family members.

The United States Institutes of Medicine (IOM) declared alcohol to be a teratogen in 1996, that alcohol may cause malformation of an embryo. “Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects on the foetus”.

**What are the aims of this study?**

* To assess knowledge and attitudes of key health, social care, and education professionals in Ireland towards Foetal Alcohol Spectrum Disorders (FASD), FASD prevention and response to persons with FASD
* Explore FASD service needs and staff training needs in Ireland through a survey of paediatricians, general practitioners, child and adolescent psychiatry teams, social workers, educators (principals, resource teachers, and primary school teachers) and educational psychologists (NEPS).
* To identify key staff requiring education and training to a level of competency that enables them to provide information and interventions to pregnant women and their partners.
* Further training is required to support families impacted by a son/daughter with FASD so that they receive a diagnosis and an assessment of their strengths and the right intervention to help them address and cope with their difficulties.
* Raise awareness of FASD

We would very much appreciate if you would complete the short anonymous survey monkey questionnaire. We estimate that it will take 10-20 minutes to complete the questionnaire. There is no risk to participants.

Results will be analysed by the research team to produce:

* a report for the HSE National FASD Expert Advisory Group; and the HSE Alcohol Programme Alcohol Implementation Group;
* the results will be used as a basis to inform the organisation of future training; and
* a peer-reviewed paper

**Will this be confidential?**

The information and data provided to this study will only be accessed by the research team and will only be reported at an anonymous level

**Is this study approved by an Ethics Committee?**

Yes, ethical approval for this study was granted to us from both the University of Limerick, Tusla Research Ethics Committee, and the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC). If you have any concerns about this study and wish to contact someone independent you may contact the Clinical Research Ethics Committee at crec@ucc.ie Tel: +353-21-4901901.

If you have any questions please do not hesitate to contact Dr Mary T O’Mahony, Co-Principal Investigator.

Thank you in advance for your support with this.

Best wishes,

* Dr Barry Coughlan, Director of Clinical Psychology, Department of Psychology, Faculty of Education & Health Sciences, University of Limerick Ireland.
* Dr Mary T O’Mahony, (Co-PI) Specialist in Public Health Medicine, HSE Health and Wellbeing National Alcohol Programme Lead for Prevention of Foetal Alcohol Spectrum Disorder (FASD), Department of Public Health HSE-South [maryt.omahony@hse.ie](mailto:maryt.omahony@hse.ie) Tel: +353-21-4927601.