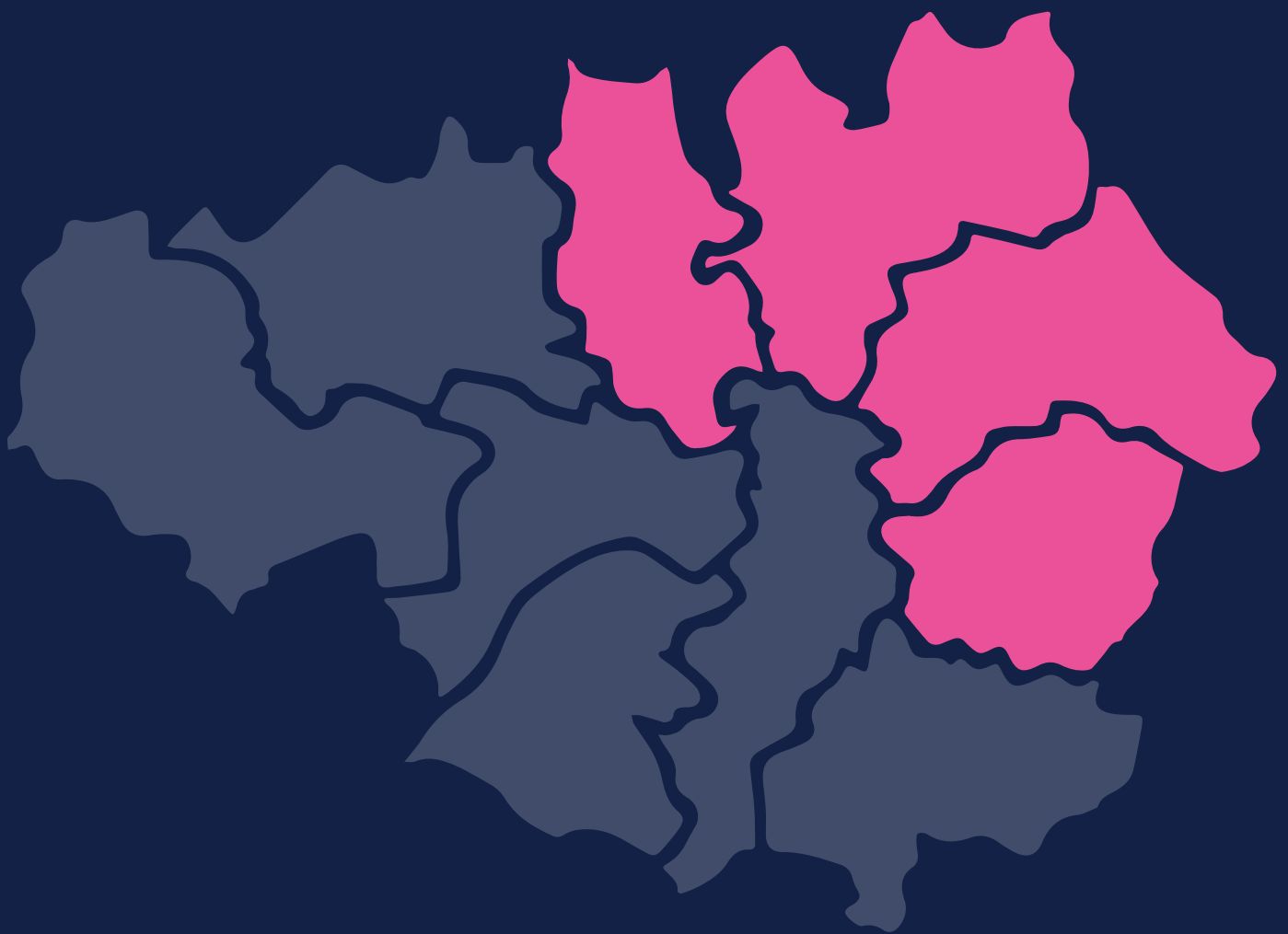


# GREATER MANCHESTER ALCOHOL EXPOSED PREGNANCIES PROGRAMME: EVALUATION





“

The Greater Manchester Health and Social Care Partnership (GMHSCP)'s Alcohol Exposed Pregnancy (AEP) Programme has been vast, having a very positive and rapid influence on change for the AEP and FASD agenda in local places across Greater Manchester. Parental engagement has been an integral part of the work undertaken and the journey so far.

The impacts have extended beyond the original scope of the programme with one of the biggest changes being how the work has extended beyond the boundaries of the health sector, into education. This has accelerated the involvement throughout localities, and we are now hopeful of a Greater Manchester-wide response to AEP that brings together the collective energies of the health and social care and education sectors (SEND) as well as local authorities. This larger scale, more co-ordinated engagement is welcomed and has happened much more quickly than we as parents and carers have previously been able to influence.

It is the benefits to families which are most important to us and it is pleasing families are starting to report more awareness and understanding of FASD amongst professionals, so the impact has already started to filter down to some families.

This work has been ground-breaking, and we look forward to seeing how the learnings from the pilot shape further developments now.

”

**Susan McGrail**  
FASD Greater Manchester

# CONTENTS

<b>ACKNOWLEDGEMENTS</b>	4
<b>EXECUTIVE SUMMARY</b>	5
<b>INTRODUCTION</b>	8
<b>PROGRAMME OVERVIEW</b>	9
<b>FINDINGS</b>	11
Impact 1: Fewer alcohol exposed pregnancies within pilot areas	11
Impact 2: Alcohol screening in pregnancy as standard across pilot area maternity services	14
Impact 3: Clear and consistent messaging from professionals regarding alcohol and pregnancy in pilot areas	22
Impact 4: Increased public understanding and awareness of the risk of alcohol use in pregnancy and FASD as a hidden disability	26
Impact 5: Families affected by FASD in GM having more support	31
Impact 6: Understanding of FASD Prevalence	37
Unintended impacts	39
<b>CONCLUSIONS</b>	40
<b>RECOMMENDATIONS</b>	42
<b>REFERENCES</b>	44
<b>FIGURES</b>	
Figure 1: The Approach	10
Figure 2: Prevention Cohorts, January 2020 to December 2020	13
Figure 3: PAHT & TGICFT – Total Numbers Screened	16
Figure 4: Total number being flagged by Audit C or TWEAK	16
Figure 5: Scoring +3 Audit C or +2 TWEAK – July 2019 to February 2021	17
Figure 6: Total numbers of people entering TGICFT – July 2019 to February 2021	18
Figure 7: PAHT, December 2019 to May 2020	19
Figure 8: Pre and post knowledge evaluation	24
Figure 9: Images from Birthday Production	27
Figure 10: #DRYMESTER Phase 1 Analysis	28
Figure 11: #DRYMESTER Summary	29
Figure 12: Hitting the headlines nationally and globally	30

# ACKNOWLEDGEMENTS

## Report Authors:

- **Rachael Nielsen**, Project Manager, GMHSCP
- **Róisín Reynolds**, Senior Advisor, GMHSCP
- **Ian Jones**, Population Health Analyst, Greater Manchester Combined Authority
- **Jessica Smith**, Principal Researcher – Population Health, Greater Manchester Combined Authority

## Report Contributors:

- **Helen-Louise Smith**, Communications Manager, GMHSCP
- **Professor Penny Cook**, Professor of Public Health, University of Salford
- **Dr Alan Price**, Research Fellow, University of Salford
- **Robyn McCarthy**, Research Assistant, University of Salford

With thanks to the commissioners and providers in Oldham, Rochdale, Bury and Tameside for their commitment to preventing Alcohol Exposed Pregnancies.

Thanks to Dr Raja Mukherjee, Consultant Psychiatrist, National Clinic for FASD, Dr Cassie Jackson, Clinical Psychologist, The Centre for FASD, Sandra Butcher, Chief Executive, The National Organisation for FASD, Joanna Buckard, Director, Red Balloon Training and Consultancy, Dr Jennifer Shields, Clinical Psychologist, NHS Ayrshire and Arran and Dr Sarah Brown, Consultant Paediatrician, NHS Ayrshire and Arran, who have provided their support, guidance and expertise throughout the programme.

And finally, with special thanks to the programme's Parents as Partners Group who have given their time and shared personal insights to shape and enhance the programme.

# EXECUTIVE SUMMARY

**In 2018, the Greater Manchester Health and Social Care Partnership (GMHSCP) committed £1.6m in non-recurrent transformation funding towards an initial ‘proof of concept’ programme to reduce Alcohol Exposed Pregnancies (AEP) and progress towards an ambition of ending new cases of Fetal Alcohol Spectrum Disorder (FASD). There is increasing recognition that FASD is a significant public health issue in the UK, where prevalence of prenatal alcohol exposure is estimated at 41%.**

This report provides findings and reflections from an evaluation of the Greater Manchester Health and Social Care Partnership (GMHSCP)’s Alcohol Exposed Pregnancy Programme. The original aims of the evaluation were to: demonstrate the impact of the programme; and to capture learning from delivering the programme. This evaluation, therefore, focuses on the extent to which the programme achieved the following intended impacts:

## IMPACT 1: FEWER ALCOHOL EXPOSED PREGNANCIES WITHIN PILOT AREAS

To prevent alcohol exposed pregnancies, the programme recognised the need to deliver pre-pregnancy prevention interventions to people and partners. Between July 2019 to February 2021, over 1,000 people were identified as being at risk of an AEP, with 67% going on to engage with a prevention intervention. Of those who were identified as at risk, 18% reduced alcohol consumption. Based on these findings it can be concluded that the programme was successful in both identifying and reducing the risk of an AEP for a significant number of people.

However, uptake of Long Acting Reversible Contraceptive (LARC) was low, and it is acknowledged that it is not the preferred choice of contraception for all, therefore some women identified at risk were supported to access alternative forms of contraception. Most significantly, this programme intervention was impacted by COVID-19, with community sexual health services pausing the offer of LARC for a period of time.

## IMPACT 2: ALCOHOL SCREENING IN PREGNANCY AS STANDARD ACROSS PILOT AREA MATERNITY SERVICES

The AEP programme aimed to further develop existing pathways at Tameside and Glossop Integrated Care Foundation Trust (TGICFT) and introduce a similar AEP maternity pathway at Pennine Acute Hospital Trust (PAHT). Between July 2019 and February 2021, over 98% of people entering services were asked about alcohol consumption and of those that went on to be formally assessed via Audit C or TWEAK, just over 11% went on to score +3 or +2 respectively indicating pregnancies at a higher risk of an AEP.

A qualitative study<sup>1</sup> found, from the sample of midwives interviewed, that routine alcohol screening had been successfully embedded at both Trusts with clear referral pathways and dedicated specialised teams giving midwives the confidence to screen and deliver Brief Interventions.

1. Morrello, R., Midwives’ perspectives on their role in the Greater Manchester Health and Social Care Partnership’s programme to Reduce Alcohol Exposed Pregnancies, Unpublished dissertation, University of Salford, 2021

# EXECUTIVE SUMMARY

## IMPACT 3: CLEAR AND CONSISTENT MESSAGING FROM PROFESSIONALS REGARDING ALCOHOL AND PREGNANCY IN PILOT AREAS

Prior to the AEP programme AEP/FASD training was not readily available to professionals in GM. To equip health and social care staff with the correct knowledge and skills to raise awareness of the harms of alcohol use in pregnancy and FASD, a comprehensive training package was required.

A contract was awarded to Red Balloon Training to create a bespoke, Continuing Professional Development (CPD) accredited, training session that could be delivered to all staff involved in the delivery of the programme. The programme also delivered FASD/AEP awareness training to professionals within their locality areas. Additionally, to sustain the availability of FASD workforce training, the programme commissioned NOFAS UK and Red Balloon training to develop an interactive, CPD accredited and expertly reviewed eLearning course.

Training was consistently well received by professionals. Most who attended the training had received no, or little, previous training relating to AEP and FASD. Practitioners who attended the training frequently commented that, with their new knowledge of FASD, they believed they may have been supporting people with undiagnosed FASD throughout their careers.

## IMPACT 4: INCREASED PUBLIC UNDERSTANDING AND AWARENESS OF THE RISK OF ALCOHOL USE IN PREGNANCY AND FASD AS A HIDDEN DISABILITY

The programme identified there was limited accurate, non-judgmental, accessible information for the public and parent-to-be. Two activities are evaluated in this report, the targeted digital public marketing campaign #DRYMESTER developed by C21, and the interactive performance and educational workshop 'Birthday' created by Oldham Theatre Workshop (OTW).

The #DRYMESTER campaign was delivered in two phases via a range of social media platforms; in phase 1, awareness was established in the four pilot areas (May to June 2019). After an evaluation, phase 2 focused on building community ownership and participation across GM. Analysis of phase 1, carried out by Bluegrass Research, showed a strong reach, 4.5 million views, among the primary audience of would-be-mums, but also found promising engagement from male partners. Phase 2 of the campaign was not independently evaluated but intelligence provided by C21 showed increased reach and engagement.

Over 5,000 young people saw the Birthday production. Of those submitted survey responses, over 93% of respondents felt what they had learned during the performance/workshop would inform their future choices. The number who understood the terms FASD and AEP increased to over 93% as did the number who knew that you should consume no alcohol during pregnancy, which increased from 49% to 97%. Following the successful evaluation of Birthday, it has been adapted into a short film to increase access and reach to young people.

# EXECUTIVE SUMMARY

## IMPACT 5: FAMILIES AFFECTED BY FASD IN GM HAVING MORE SUPPORT

The programme sought to meet this aim by providing small grants to voluntary organisations to fund FASD-related activities. Further, the programme sought to involve parents affected by FASD in its design and delivery (via a 'parents as partners' group) with the aim of ensuring the programme was meeting the needs of parents, families, and carers affected by FASD. Semi-structured interviews with organisations that have received grant funding found that the grants received as part of the AEP Programme have helped to establish new activities and, in the case of FASD Greater Manchester, improve a support group that already existed. Feedback, from the organisations, suggests that these activities have helped to provide support to parents and carers affected by FASD and have increased awareness of FASD.

Parents involved in the development and delivery of the AEP programme that responded with feedback were positive about their involvement, believing their knowledge and experience had been drawn upon and they suggested that the programme had helped raise awareness of FASD. Involving parents in procurement processes and programme design has been fundamental to the success of the AEP programme and it is recommended that a co-production approach continues in any future developments.

## IMPACT 6: INCREASED UNDERSTANDING OF THE PREVALENCE OF FASD IN GREATER MANCHESTER

When the programme began there was limited knowledge regarding FASD prevalence in GM as there had been no UK FASD prevalence studies. However, it was known that the UK has the fourth highest drinking rate in pregnancy in the world, and whilst an international modelling study suggested 3.24% of young people in the UK have FASD, it was recognised that FASD is difficult to diagnose and is under-diagnosed<sup>2</sup>. A decision was therefore made to commission the first UK FASD prevalence study, which took place between May 2019 and March 2020 in three mainstream primary schools in Greater Manchester. This research was led by Professor Penny Cook from the University of Salford. The project was a collaboration with the National FASD Clinic, led by leading UK FASD expert Dr Raja Mukherjee, the University of Manchester and the University of Liverpool and Greater Manchester parents.

The study found that the prevalence of FASD in the three schools was 1.8% and when possible cases of FASD were included, the prevalence was 3.6%. None of these children had previously identified with a neurodevelopmental diagnosis. Although it is difficult to apply the findings to the whole of Greater Manchester, since only three schools were used, if the prevalence was representative there would be between 619 and 1,238 affected live births each year and a similar number of affected children will be starting school in Greater Manchester each year. It is also worth bearing in mind that these results may be an underestimate as many children, considered most at risk, were not available to be assessed.

## SUMMARY OF CONCLUSIONS

**The above leads this report to conclude that the Alcohol Exposed Pregnancy Programme has made important progress and, in some cases, exceeded the ambitions set out in the impact areas. However, there is much more to be done to prevent alcohol harm in pregnancy and FASD in Greater Manchester, this report also lists recommendations based on the findings of this evaluation which can be found on page 42.**

# INTRODUCTION

This report provides findings and reflections from an evaluation of the Greater Manchester Health and Social Care Partnership (GMHSCP)'s Alcohol Exposed Pregnancy Programme. The original aims of the evaluation were to: demonstrate the impact of the programme; and to capture learning from delivering the programme. This evaluation is separate to that of the Rapid Review, conducted by an external consultancy (SQW), between February and July 2020. In brief, the review found that the Alcohol Exposed Pregnancy Programme had, at that point, made demonstrable progress in achieving its outcomes. The involvement of parents in the programme design, and the communications and marketing were highlighted as some of the programme's achievements at that stage. Whilst the Rapid Review focused on how the programme was being delivered, this report focuses on what impact the programme has had.

This evaluation, therefore, focuses on the extent to which the programme achieved the following intended impacts:

- **Impact 1:** Fewer alcohol exposed pregnancies within pilot areas
- **Impact 2:** Alcohol screening in pregnancy as standard across pilot area maternity services
- **Impact 3:** Clear and consistent messaging from professionals regarding alcohol and pregnancy in pilot areas
- **Impact 4:** Increased public understanding and awareness of the risk of alcohol use in pregnancy and FASD as a hidden disability
- **Impact 5:** Families affected by FASD in GM having more support
- **Impact 6:** Increased understanding of the prevalence of FASD in Greater Manchester

Following a brief history of the programme and overview of the programme's approach, the report considers each impact in turn.

It is important to note that this report has been written by colleagues involved in the programme, both in its design and delivery and in the provision of data and analysis support over the course of the programme. The report is not, therefore, an independent evaluation of the programme. However, alongside analysis of programme data and primary research (including with groups that received grants as part of the AEP Programme), the report draws on key findings from other evaluation activity that has been conducted, independently, during the programme. The report has also been reviewed by Professor Penny Cook, Dr Alan Price and Robyn McCarthy from the University of Salford, who provided feedback and suggestions; it is hoped that this went some way in mitigating potential bias. It is outside the scope of the evaluation to consider the impact of the COVID-19 pandemic on the programme.



# PROGRAMME OVERVIEW

**A broad overview of the programme has been published in the journal *Perspectives in Public Health* (Reynolds et al., 2021).<sup>3</sup> In 2018, the Greater Manchester Health and Social Care Partnership (GMHSCP) committed £1.6m in non-recurrent transformation funding towards an initial ‘proof of concept’ programme to reduce alcohol exposed pregnancies (AEP) and progress towards an ambition of ending new cases of Fetal Alcohol Spectrum Disorder (FASD). The pilot phase of the programme commenced delivery in May 2019 and concluded in March 2021. Two strands of the programme (the FASD prevalence study and Acorn enhanced support) paused for periods of time in response to the COVID-19 pandemic.**

The programme focused upon prevention, early intervention and awareness raising, and was tested across two Greater Manchester (GM) Foundation Trust footprints: Pennine Acute Hospital Trust (PAHT) and Tameside and Glossop Integrated Care Foundation Trust (TGICFT); and four of the 10 GM localities: Bury, Oldham, Rochdale, and Tameside.

The aim of the programme was to add to an ambition within the Greater Manchester Drug and Alcohol Strategy to reduce the harm experienced by children and young people in Greater Manchester as a result of parental substance misuse, and additionally contributes to the ‘Start Well’ domain of the GM Population Health Plan and GM ambitions relating to giving every child the best start in life.

*“FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than 400 conditions can co-occur, FASD is at its core a lifelong neurodevelopmental condition.”<sup>4</sup>*

Greater Manchester has some of the highest levels of alcohol consumption and alcohol-related harm in England and although the true extent of the harm from alcohol to children in GM is unknown, it was estimated prior to the programme’s implementation that of the 564,500 under-16s living in Greater Manchester in 2016, at least:

- 164,269 (29.1%) lived with at least one binge drinking adult
- 46,289 (8.2%) lived with at least two binge drinking adults
- 33,306 (5.9%) lived with a dependent alcohol user

There is increasing recognition that FASD is a significant public health issue in the UK where prevalence of prenatal alcohol exposure is estimated at 41%. The GM prevalence study commissioned as part of this programme has found that FASD is thought to be present in at least 1.8% of the GM population. This will be covered in more detail in section 3.

3. Reynolds, R., McCarthy, R. & Cook, P.A. We do things differently here: the Greater Manchester approach to preventing alcohol-exposed pregnancy. *Perspectives in Public Health*. 2021;141(5):252-254. doi:10.1177/1757913920985553

4. Seashell Trust/National FASD, FASD: Preferred UK Language Guide, 2020

# PROGRAMME OVERVIEW

Prior to the programme's implementation there was little policy or guidance driving FASD prevention in England. However, NICE commenced drafting FASD quality standards<sup>5</sup> in May 2019 and this process has run in parallel to the programme, with the programme's senior advisor sitting on the select committee. Publication of these standards is imminent at the time of writing, and the five draft statements set out clear expectations in relation to AEP prevention and FASD diagnosis and care. In addition, Public Health England have produced a document — Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy<sup>6</sup> that cites the programme's approach as good practice.

The six impacts identified in this report directly align with the programme's activities as summarised in the image below. These broadly sit within three categories: Prevention; Support; and Knowledge.

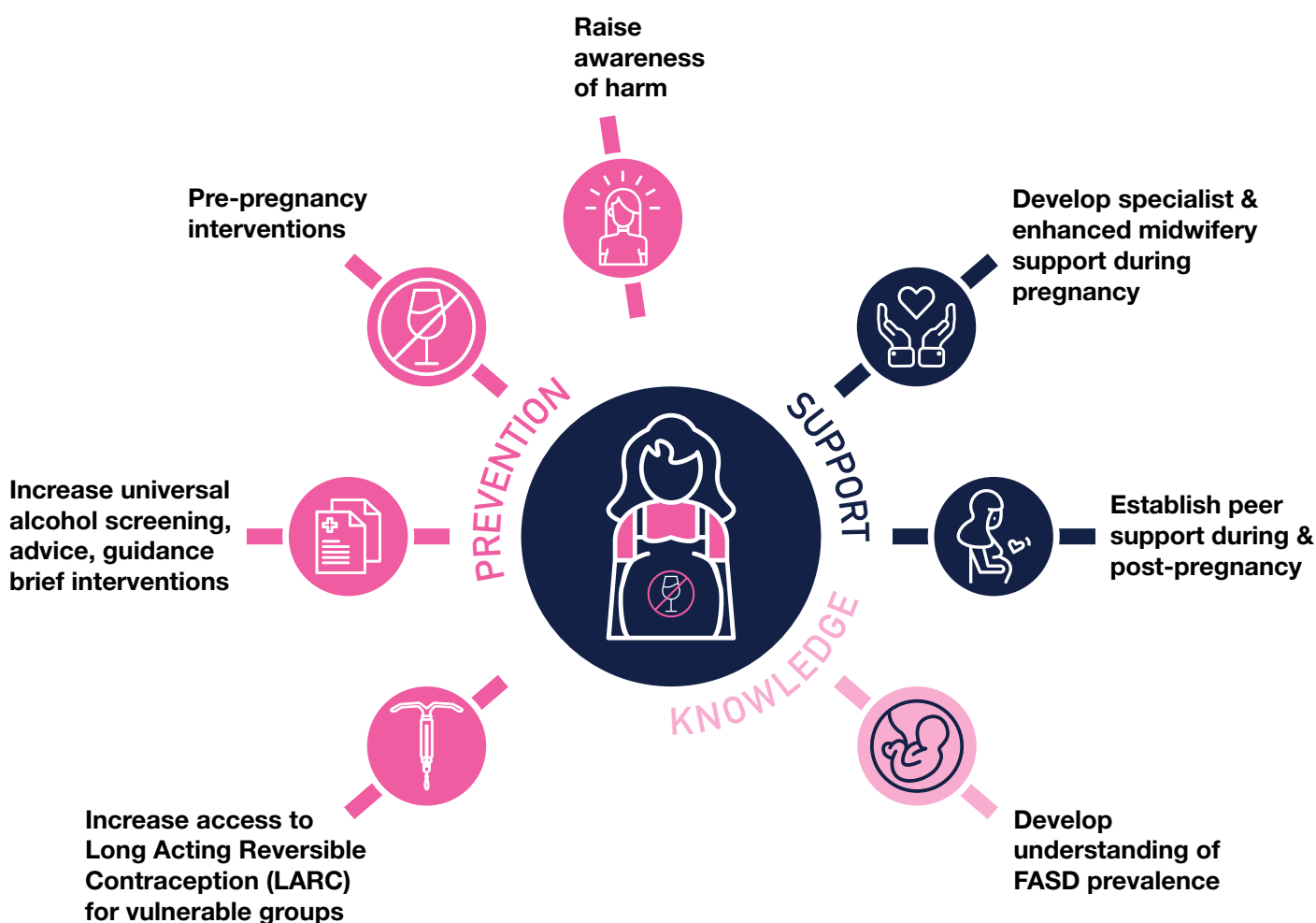


Figure 1: The Approach

5. <https://www.nice.org.uk/guidance/indevelopment/gid-qs10139/documents>

6. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/942477/Maternity\\_high\\_impact\\_area\\_4\\_Reducing\\_the\\_incidence\\_of\\_harms\\_caused\\_by\\_alcohol\\_in\\_pregnancy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_area_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf)

# FINDINGS

This section of the report provides the findings of this evaluation. It is organised around the six intended programme impacts. For each, a brief overview of the activities intended to achieve the given impact is provided, along with a brief methodology of how the impact has been evaluated. Findings from the evaluation are reported, along with a summary statement as to the extent to which the impact was achieved.

## IMPACT 1: FEWER ALCOHOL EXPOSED PREGNANCIES WITHIN PILOT AREAS

### Introduction

To prevent alcohol exposed pregnancies, the programme recognised the need to deliver pre-pregnancy prevention interventions to people and partners who were not necessarily planning a pregnancy. This is because 45% of pregnancies in England are known to be unplanned.

### Overview of activities

To quickly mobilise this element of the programme, AEP prevention interventions were included as contract variations for commissioned services within the localities. The type of provider varied in each locality but included Substance Misuse Services, lifestyle services, early help/early years, sexual health services and women's centres. All staff, within the services identified to deliver the interventions, attended awareness-raising training in AEP and FASD, delivered by an external provider, Red Balloon Training.

With a limited evidence base for interventions to prevent AEP, the localities were encouraged to develop pathways loosely based on the American 'CHOICES' model<sup>7</sup> targeting females aged 16–44, who are sexually active, using alcohol and not using an effective form of contraception. Different approaches were encouraged but all consisted of:

- Assessment and alcohol screening using AUDIT C (see DHSC FASD health needs assessment for a description of Audit C)<sup>8</sup>
- Alcohol Brief Intervention

- Motivational Interviewing interventions regarding alcohol in pregnancy and contraception
- Referral to sexual health services
- Methodology

Outcome metrics were agreed, and commissioners were required to submit their performance against each metric monthly. It was the commissioner's responsibility to collect the data from their individual providers and make one locality submission. The metrics for prevention services were:

- Number of people who have been identified as at risk of an AEP
- % who identified at risk of an AEP who then engage with prevention intervention
- % who identified at risk of an AEP who then reduce alcohol consumption
- % who identified at risk of an AEP who are in receipt of a Long-Acting Reversible Contraception (LARC)<sup>9</sup>

7. Mary M Velasquez et al., A Dual-Focus Motivational Intervention to Reduce the Risk of Alcohol-Exposed Pregnancy, May 2010

8. Department of Health and Social Care (2021), Fetal alcohol spectrum disorder: health needs assessment. Available at <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment> (Accessed September 2021)

9. LARC comes in 4 types: the contraceptive implant, contraceptive injection, the intrauterine contraceptive device (IUCD) and the intrauterine system (IUS).

# FINDINGS

Following early data submissions, it was identified that changes were required to capture the impact of the programme interventions on individuals over time. A new template was developed that captured both monthly reporting figures and 'cohort' data; this was issued to the commissioners. Cohort data processes were designed to allow the tracking and analysis of people by the month they entered the service. For instance, this process enables measurement of the number of people entering a service in January 2020 and then the proportion of this cohort who went on to reduce alcohol consumption. This form of reporting required the providers to have unique identifiers for the people that they supported.

For Acorn, which provided support for people and partners consuming alcohol during pregnancies, the metrics were:

- The number of people referred to service by type (at risk, pregnant or partner/significant other)
- The number of people who commence 1:1 support by type
- The number of people who successfully complete 1:1 support by type
- The number of people who commence Psychosocial Intervention Group Support (PSI) by type
- The number of people who successfully complete Psychosocial Intervention Group Support (PSI) by type
- The number of people who cease alcohol use
- The number of people identified as at risk of a further AEP fitted with LARC
- The number of people successfully discharged and referred on for aftercare including source of support

## Findings

From July 2019 to February 2021, 1,028 people have been identified as being at risk of an AEP, with 67.2% (691) engaging with a prevention intervention. Of those who are identified as at risk, 18.3% (189) reduced alcohol consumption. LARC uptake in prevention services has been at a relatively small level, with 39 people being fitted with LARC throughout the programme. There are a number of reasons identified for this, including LARC not being the preferred choice of contraception but most significantly, this programme intervention was impacted by COVID-19, with community sexual health services pausing the offer of LARC for a significant period of time.

However, as LARC is the most reliable form of contraception to prevent against unwanted pregnancies, these interventions have resulted in 39 people identified at risk who will not go on to have an AEP. For those women identified at risk of an AEP and LARC was not their preferred choice of contraception, they were supported to access alternative forms of contraception.

To eliminate data lags and due to the process of reporting data changing in the autumn of 2019, the table below takes a sample of data from January to December 2020. Note that the Total column refers to the denominator for the metric.

# FINDINGS

Metric	Numerator	Denominator	%	Monthly Avg.
Number of people who have been identified as at risk of an AEP	524	NA	NA	43.7
% who were identified as at risk of an AEP who then engage with prevention intervention	338	524	64.50%	28.2
% who were identified as at risk of an AEP who then reduce alcohol consumption	108	524	20.60%	9
% who were identified as at risk of an AEP who are in receipt of a LARC	5	524	0.95%	0.4

**Figure 2:** Prevention Cohorts, January 2020 to December 2020

With Acorn, 470 people were referred to the service between December 2019 and April 2021. Of those referred, 420 people were pregnant and consuming alcohol, 36 were partners/significant others, and another 14 were people at risk of an AEP. In addition, 330 of the 420 referred were from Pennine Acute Maternity. Of those being referred, 347 entered the service, 340 of whom were pregnant and consuming alcohol.

Of the 340 people who were referred due to continued alcohol use during pregnancy, 129 commenced 1:1 support and 10 commenced Psychosocial Intervention Group Support (PSI). At time of writing, seven people went on to successfully complete 1:1 support although this will increase due to reporting lag. Five people who were identified as at risk of a further AEP were fitted with a LARC.

## Summary:

Based on the findings above it can be concluded that the programme was successful in identifying a significant number of people who were at risk of an AEP. The number of at-risk people who then engaged with the interventions offered, suggests that workforce training has equipped the staff with the skills and knowledge to successfully deliver these interventions. Most of the services involved in this aspect of the programme were providing support to people with alcohol dependence issues and therefore the number of people who achieved changes to their alcohol use is positive. Uptake of LARC was low but was of significant benefit for all those individuals who accessed it. It is acknowledged that this is not the first choice of contraception for many people and therefore people were supported to access suitable alternatives. Attempts to improve this aspect of the programme were hindered by sexual health services withdrawing the offer of LARC due to COVID-19.

## Recommendations:

1. Interventions to prevent AEP should be embedded in universal services across Greater Manchester as AEP risk is not exclusive to those with alcohol dependency issues.
2. AEP prevention interventions should include enhanced support to access all forms of contraception.

# FINDINGS

## IMPACT 2: ALCOHOL SCREENING IN PREGNANCY AS STANDARD ACROSS PILOT AREA MATERNITY SERVICES

### Introduction

The World Health Organisation (WHO) (2014) advises that midwives screen for alcohol use on multiple occasions antenatally using a validated tool and deliver Brief Interventions when alcohol consumption is disclosed. Greater Manchester was already leading the way with this as Tameside and Glossop Integrated Care Foundation Trust (TGICFT) had launched their MAMA pathway in 2016, which was the first maternity alcohol screening pathway in the country. The AEP programme aimed to further develop this pathway and introduce a similar AEP maternity pathway at Pennine Acute Hospital Trust (PAHT).

### Overview of activities

To achieve this impact, key midwifery staff from both TGICFT and PAHT attended the Red Balloon Training. These staff then developed training packages and delivered this within their Trusts to all midwifery staff. This training included information on:

- AEP and FASD
- CMO guidelines
- How to deliver brief interventions
- LARC
- Local referral pathways

Routine alcohol screening was embedded at first contact, booking and 36 weeks at PAHT via the Trusts' preferred alcohol screening tool, Audit C. A dedicated continuity midwifery team was established to carry caseloads that included people with complex needs including AEP. Three midwives were trained to fit LARC and this was offered on the post-natal ward and via outpatients' clinics.

TGICFT extended their MAMA pathway to include screening at 36 weeks and continued to use their preferred screening tool TWEAK. Support was offered to people identified as having an AEP via the Enhanced team. There was a delay in training midwives to fit LARC, so this was offered via consultant obstetricians to people identified as vulnerable.

### Methodology

This strand of the programme was evaluated using both quantitative and qualitative methods. The qualitative research was independent of the programme and carried out by an MSc Public Health student Ruth Morrello (also a Registered Midwife) for her Dissertation Project, Midwives' perspectives on their role in the Greater Manchester Health and Social Care Partnership's programme to Reduce Alcohol Exposed Pregnancies. Ruth Morrello was studying at the University of Salford and was introduced to the programme by Professor Penny Cook.



# FINDINGS

## Quantitative Methodology

Outcomes measures were agreed, and the maternity providers were required to report on these monthly direct to the programme leads. Both Trusts updated their electronic clinical note systems with the alcohol screening questions from their chosen screening tool and data reporting processes were agreed with the individual business intelligence (BI) teams. Establishing these systems, processes and reporting changes presented different challenges in each Trust and, at the time of writing, work is ongoing to fully embed alcohol screening and reporting at 36 weeks for both.

### PAHT metrics:

- % of people in PAHT screened for alcohol consumption using Audit C
- % of people in PAHT screened for alcohol consumption using Audit C who score +3 at 1st antenatal appointment
- % of people in PAHT who scored Audit C+3 at 1st antenatal appointment with a reduced Audit C score at 2nd contact
- % fitted with LARC by a midwife prior to discharge at PAHT
- % of people at risk of AEP (AUDIT C +3 at booking) who are fitted with LARC by a midwife prior to discharge at PAHT

### TGICFT metrics:

- % of people in TGICFT asked about consumption prior to pregnancy
- % triggering TWEAK questions
- % of people in TGICFT screened for alcohol consumption using TWEAK who score +2 at 1st antenatal appointment
- % of people in TGICFT who scored TWEAK +2 at 1st antenatal appointment with a reduced TWEAK score at 2nd contact
- % fitted with LARC by a midwife prior to discharge at TGICFT
- % of people fitted with LARC by a midwife who scored +2 (TWEAK) at first antenatal appointment

## Qualitative Methodology

Morrello (2021) conducted semi-structured interviews with six practising midwives, three working at each of the participating Trusts. The interviews took place between November 2020 and December 2021 via telephone or video conferencing. The ability to recruit to this research was impacted by COVID-19 as midwifery services were under significant staffing pressures. The Theory of Planned Behaviour was used to inform the interview and analysis, since this has been found to be an appropriate tool for investigating and predicting the behaviour of clinicians. A framework analysis was carried out using themes identified in a review of the literature and additional themes discerned during data analysis. Four key themes were identified, with associated sub-themes, these were:

- The effects of the Reducing AEP programme
- Communication
- Factors influencing behaviour change
- COVID-19

# FINDINGS

## Quantitative Findings

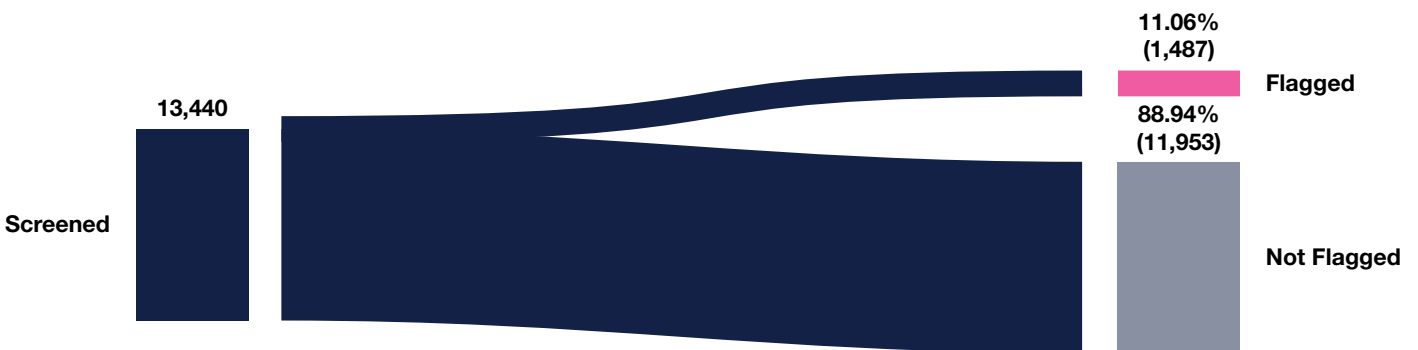
From July 2019 to February 2021, 15,436 people entered services in PAHT and TGICFT services. Of these, 15,170 (98.3%) were asked about alcohol consumption. Figure 3 below shows the proportions being screened.



**Figure 3:** PAHT & TGICFT – Total Numbers Screened

A small number, 266 (1.7%), were not screened. This metric was regularly reviewed, and feedback was given to providers to improve the performance around this metric. This was particularly important in the period immediately following the first national lockdown in response to the COVID-19 pandemic, as the percentage of people being screened dropped to 92% for PAHT. This was driven largely by a decrease in the number of people being screened in Rochdale, which went from 98% in March 2020 to 87% in June 2020. Other areas saw larger decreases in the run up to the second national lockdown, with Oldham decreasing from 99% in August 2020 to 94% in November 2020. The reason for the decreases in screening in the different areas is attributed to the impact of COVID-19 on the maternity workforce. High levels of sickness and periods of isolation for the midwives resulted in alternative hospital staff conducting some of the maternity booking process. These staff were not always trained in alcohol screening in pregnancy, although this was addressed once identified.

Of the 13,440 people screened using Audit C and TWEAK, 1,487 (11.06%) went on to score +3 Audit C or +2 TWEAK at first appointments (referenced as flagged or not flagged below).



**Figure 4:** Total number being flagged by Audit C or TWEAK

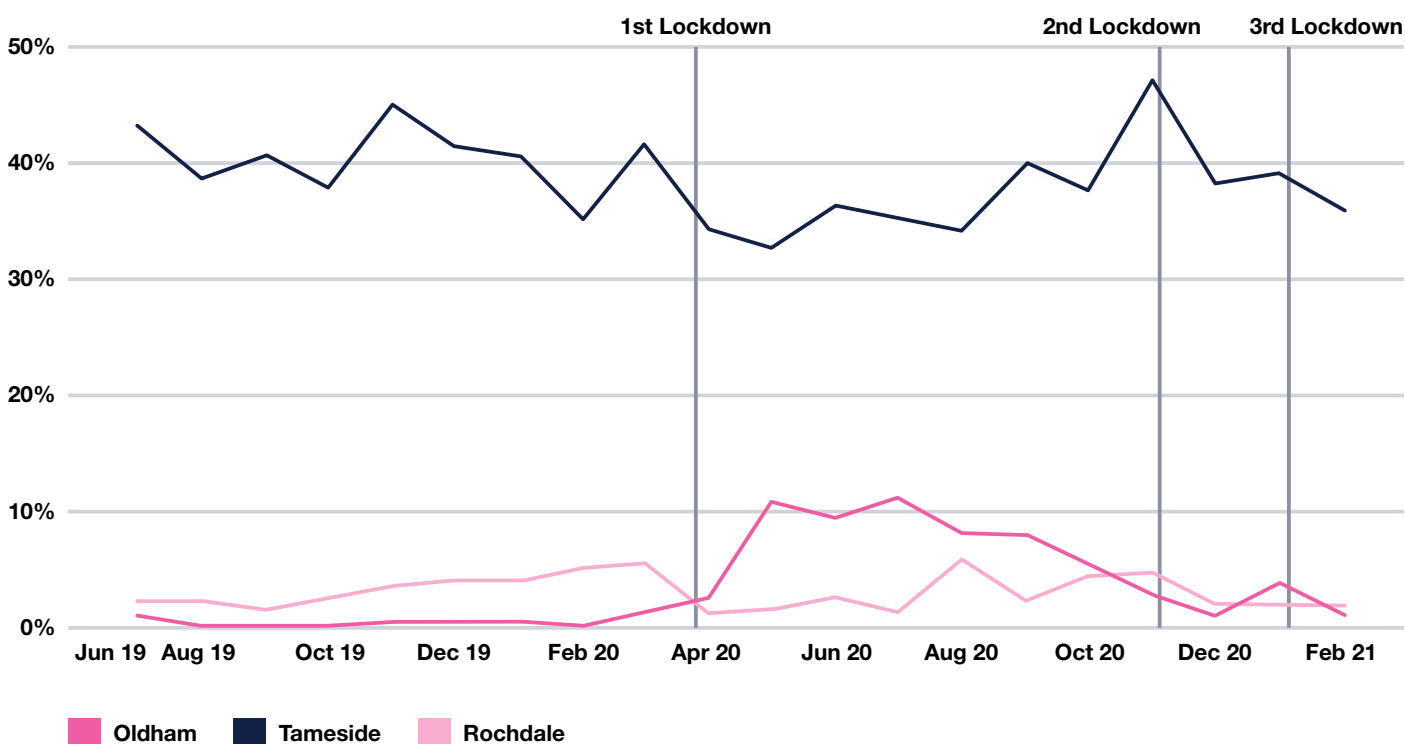
However, PAHT and TGICFT have different processes for how people were asked about alcohol consumptions and at which point they implement their respective questionnaire.



# FINDINGS

## Audit C and TWEAK

It was found that over the course of the programme TWEAK was considerably more sensitive to answers people provided around alcohol consumption. Of those triggering TWEAK Questions, 38.5% of people asked scored +2 whereas only 6.9% of those screened in PAHT services scored +3. Figure 5 shows this trend from July 2019 to February 2021. Note that we can also see that a higher percentage +3 Audit C scores in Oldham after the first national lockdown but a decrease for Rochdale and +2 TWEAK scores in Tameside. As the AEP programme was paused for a short period during the first months of the pandemic this was not queried but warrants further investigation.



**Figure 5:** Scoring +3 Audit C or +2 TWEAK – July 2019 to February 2021

This higher sensitivity is due to the difference in screening processes between TGICFT and PAHT. At PAHT the aim is to screen all people with Audit C when entering the service, however at TGICFT the process is to ask people about any alcohol consumption which may then trigger further questions via TWEAK. This process leads to significantly reduced denominators which produces higher percentages. In TGICFT, since July 2019, 4,719 (98.7%) of people entering the service were screened about alcohol consumption. Of those screened, 2,989 (63.3%) triggered TWEAK questions. Finally, of those asked TWEAK questions, 1,148 (38.4%) scored +2.

# FINDINGS

## TGICFT – Screening & Reduction Summary

The way that data has been captured around the TGICFT process has been designed to follow the journey of people through the service. The key metrics explored here, in sequential order:

Metric	Numerator	Denominator	%	Monthly Avg.
<b>Total number entering service</b>	4,782	NA	NA	239.1
<b>People in TGICFT asked about consumption prior to pregnancy</b>	4,719	4,782	98.7%	236.0
<b>Of those asked about consumption, number triggering tweak questions</b>	2,989	4,719	63.3%	149.5
<b>% Of people triggering tweak questions who score +2 at 1st antenatal appointment</b>	1,148	2,989	38.4%	57.4
<b>% Of total people in service who score tweak +2 at first antenatal appointment</b>	1,148	4,782	24%	57.4
<b>% Of people in TGICFT who scored tweak +2 at 1st antenatal appointment with a reduced tweak score at 2nd contact</b>	347	1,148	30.2%	17.3

**Figure 6:** Total numbers of people entering TGICFT – July 2019 to February 2021

Of the total baseline population in Figure 6, nearly a quarter (24%) scored positive for risk of AEP. While the initial screening process has been successful, with over 98.7% of people being asked about alcohol consumption prior to pregnancy, there are issues which require further investigation in terms of score reduction. Over the course of the programme from July 2019 to February 2021, 30.2% (347) of people who were flagged via TWEAK went on to reduce their consumption by the time of their second contact with the service. This means that 69.8% (801) did not reduce their alcohol consumption, increasing their risk of an AEP.

It should also be noted that due to problems with the TGICFT reporting system, Euroking, there is currently no available data on the levels of consumption at third contact however this is expected to be available for analysis in the future.

# FINDINGS

## PAHT – Screening and Reduction Summary

Of the total baseline population in Figure 7, only 3.3% scored positive for risk of AEP. There have been clear successes in the screening process, with 98.1% (10,451) of all people entering the service being asked about alcohol consumption using Audit C. Of those screened, 3.2% (339) scored +3 Audit C at their first contact. 88.2% (299) of this cohort have so far reduced their score at second contact, with 40 either not reducing or not yet had their second contact.

However, only 29.3% (88) of those scoring +3 Audit C at their first contact have a reduced score at their third contact, meaning that, up to 221 people have not maintained their reduction since the second contact. As these are overall figures, we must also factor in the time lag with this data. To explore this further, Figure 7 below uses an example free from any possible lag in data reporting by showing the key metrics measured between December 2019 and May 2020. Like the metrics used in TGICFT, the metrics below follow a sequential order:

Metric	Numerator	Denominator	%	Monthly Avg.
<b>Total number entering service</b>	3,160	NA	NA	526.7
<b>People in PAHT screened for alcohol consumption using audit C</b>	3,079	3,160	97.4%	513.2
<b>People in PAHT who scored +3 on audit C at 1st antenatal appointment (% of those screened)</b>	103	3,079	3.3%	17.2
<b>People in PAHT screening audit C +3 (% of total persons in service)</b>	103	3,160	3.3%	17.2
<b>People in PAHT who scored audit C +3 at 1st antenatal appointment with a reduced audit C score at 2nd contact</b>	99	103	96.1%	16.5

*Figure 7: PAHT, December 2019 to May 2020*

It should be noted that data regarding PAHT 36 week screening has not been included as a recent audit has identified issues relating to data recording and processing thus impacting on data quality. The programme leads and data analysts are working with the PAHT AEP lead and BI team to resolve.

# FINDINGS

## LARC access and take up

Providing women with the option of being fitted with LARC prior to discharge from the antenatal ward increased the uptake of postpartum contraception within the more vulnerable groups, who may have previously struggled to attend a community appointment due to various complexities. This offer was particularly significant when, in the context of COVID-19, community sexual health services paused the offer of LARC. Throughout the duration of the programme a total of 291 have been fitted, with 252 (86.6%) women being fitted with LARC across the two maternity providers, with the majority being fitted at PAHT, as they successfully trained midwifery staff.

## Qualitative findings

Morrello<sup>10</sup> found from the sample of midwives interviewed that routine alcohol screening had been embedded at both Trusts: *“Participants demonstrated a commitment to universal screening and information giving, setting aside any preconceptions.”*<sup>11</sup>

All the midwives interviewed were aware of the Chief Medical Officers’ guidance to abstain from alcohol in pregnancy and confirmed it was their usual practice to communicate this to people. Clear referral pathways and dedicated specialised teams gave the midwives the confidence to screen as they felt equipped to respond to disclosures.

All participants had received training within their Trusts on AEP/FASD and the delivery of Brief Interventions (BI). They confirmed knowledge of the harmful effects of AEP and the ability to deliver BI. However, *“The midwives who worked in routine care, reported rarely, or never having cause to deliver brief interventions and showed some hesitancy about doing so due to inexperience.”*<sup>12</sup>

On communication, Morrello’s analysis identified:

*“Under-reporting of alcohol consumption as a barrier to giving appropriate advice. Despite midwives demonstrating awareness that women commonly conceal their true alcohol intake from clinicians, they tended to accept maternal self-reports of abstinence and consequently opportunities for information giving were missed. Midwives observed that women frequently disclosed having drunk alcohol in the period prior to pregnancy recognition, but they tended to focus on reported drinking following pregnancy awareness. Participants appeared to under-appreciate the significance of early pregnancy drinking as a risk factor for further alcohol exposure.”*<sup>13</sup>

10. Morrello, R., Midwives’ perspectives on their role in the Greater Manchester Health and Social Care Partnership’s programme to Reduce Alcohol Exposed Pregnancies, Unpublished dissertation, University of Salford, 2021

11. Ibid, p3

12. Ibid, p25

13. Ibid, p4

# FINDINGS

Of the factors known to influence behaviour change (from the Theory of Planned Behaviour), findings suggested that:

*“The norms and attitudes within the two Trusts were supportive of compliance with the newly implemented protocols. Participants felt that discussing alcohol was an important part of the role of the midwife and they believed that these discussions could be effective in influencing maternal drinking behaviour.”<sup>14</sup>*

When asked about the use of #DRYMESTER and associated resources, several midwives mentioned ‘#DRYMESTER,’ but use of resources was low. Two of the specialist midwives had #DRYMESTER leaflets to hand out during the interview, but only one participant referred people to the #DRYMESTER website. The midwives who worked in routine care did not signpost people to any resources.

Finally, COVID-19 had complicated service delivery; participants confirmed there had been a reduction in face-to-face contacts in early pregnancy which impacted on effective alcohol screening. Further, infection prevention control measures prevented partners attending appointments which limited opportunities to provide information.

## Summary:

Morrello’s findings support further roll out of the programme across Greater Manchester: *“Maintenance of the good screening practice identified would cement the programme’s legacy”*.<sup>15</sup>

Although AEP/FASD training is embedded in both Trusts, the findings from the interviews suggest training could be developed to emphasise the *“Ubiquity of under-reporting of alcohol consumption and prepare midwives for managing this... and... consolidation of the existing brief intervention training could optimise midwives’ sense of capability”*.<sup>16</sup>

The number of people at PAHT who appear to have resumed alcohol use at 36 weeks requires further investigation and an audit comparing paper and electronic records is underway. The number of people who do not have a reduced TWEAK score at second contact at TGICFT also warrant’s further investigation. Further research is also needed to explore strategies for obtaining more accurate assessment of prenatal drinking when screening.

## Recommendations:

3. Programme leads use data available to further investigate the sensitivity and suitability of the two screening tools.
4. Establish a GM AEP Maternity working group to share learning and good practice.
5. All GM maternity providers implement AEP pathways and fulfil the requirements of the NICE FASD Quality Standards 1 & 2.
6. Early data quality audits to be completed when implementing AEP pathways across the remaining GM maternity providers.
7. Digital innovation and transformation of maternity records in Greater Manchester must support AEP maternity pathways and the need to record and share information regarding prenatal alcohol use.

14. Morrello, R., Midwives’ perspectives on their role in the Greater Manchester Health and Social Care Partnership’s programme to Reduce Alcohol Exposed Pregnancies, Unpublished dissertation, University of Salford, 2021

15. Ibid, p5

16. Ibid, p5

# FINDINGS

## IMPACT 3: CLEAR AND CONSISTENT MESSAGING FROM PROFESSIONALS REGARDING ALCOHOL AND PREGNANCY IN PILOT AREAS

### Introduction

Prior to the AEP programme AEP/FASD training was not readily available to professionals in GM. To equip health and social care staff with the correct knowledge and skills to raise awareness of the harms of alcohol use in pregnancy and FASD, a comprehensive training package was required.

### Overview of activities

#### Red Balloon Training

Following a procurement process, a training contract was awarded to Red Balloon Training. A bespoke, CPD accredited, training session was developed that could be delivered to all staff involved in the delivery of the programme

The training was to include:

- The Chief Medical Officer's guidance regarding alcohol and pregnancy
- Details on the harm alcohol can cause during the different stages of pregnancy
- Raising awareness of the harm associated with alcohol exposed pregnancies
- FASD and the different conditions that sit under this umbrella term
- How FASD affects a child and adult
- Having difficult conversations
- Motivational Interviewing and Brief Interventions techniques
- Preventing an AEP including information on Long-Acting Reversible Contraception (LARC) and pathway to local services
- Support available for those who are at risk of an AEP or had an AEP

Initially, 14 training sessions were procured and these were delivered face to face, across the four localities, over a three-month period. A total of 212 staff involved in the programme delivery were trained. To ensure consistent messaging across the programme, this included C21 (digital marketing company) and Oldham Theatre Workshop.

Following a successful evaluation of the initial wave of face-to-face training, eight further sessions were procured and delivered across the pilot areas. Additional sessions have since been procured by the different pilot locality commissioners to expand the reach of the programme. Further, Greater Manchester Mental Health NHS Trust have procured the training to enable them to roll out the AEP programme across their Substance Misuse Services in non-pilot areas; Bolton, Salford and Trafford and Stockport NHS Trust have procured the training to support them in embedding an AEP maternity pathway.

This training delivery moved to virtual due to COVID-19 and feedback from participants remained positive.

# FINDINGS

## **Brief AEP and FASD awareness Training**

The programme also delivered FASD/AEP awareness training to professionals within their locality areas; for TGICFT this was Tameside and Glossop and for PAHT this was Bury, Rochdale and Oldham. This training was delivered flexibly to a broad range of health and social care professionals. The delivery of this training paused due to COVID-19.

## **FASD eLearning**

To sustain the availability of FASD workforce training, the programme commissioned NOFAS UK and Red Balloon training to develop an interactive, CPD accredited and expertly reviewed eLearning course. The course includes information relevant to the upcoming NICE Quality Standards and adheres to the UK FASD Preferred Language Guide and Best Practice in FASD Training Guide and features the latest research and lived experience.

Following a successful pilot in March 2021, the eLearning launched in May 2021 and the programme has access to 300 training licences to support continued AEP and FASD workforce development across GM.

## **Methodology – Red Balloon Training**

The Red Balloon training was evaluated by the trainer via questionnaires used on the day, pre and post training to establish improved knowledge against key aims.

## **Methodology – Brief AEP and FASD awareness Training**

The midwifery leads were required to report on the brief awareness training they were delivering alongside their maternity data using the following metric.

Number of systemwide workforce (health and care staff) trained in AEP and FASD awareness

This training was not formally evaluated but informal qualitative feedback was provided.

## **Methodology – FASD eLearning**

The eLearning was piloted prior to release via subject matter experts and professionals from a range of disciplines.

## **Findings – Red Balloon**

The Red Balloon training became the foundation to the programme with all programme partners attending, ensuring consistent knowledge and messaging.

Of the 212 professionals who attended the initial training, 71% described the training as good with a further 25% describing it as excellent. Nobody described it as poor. The participants were asked to rate their knowledge pre and post training via questionnaires completed on the day.



# FINDINGS

## Survey based on 212 participants

Pre-course	Poor	%	Average	%	Good	%	Excellent	%
FASD	135	64	65	30	10	5	2	1
FAS	134	64	66	30	9	5	2	1
ARND	201	95	8	4	2	1	1	0
BI	67	32	44	21	70	33	31	15
MI	52	25	52	24	76	36	32	15
Post-course	Poor	%	Average	%	Good	%	Excellent	%
FASD	0	0	9	4	150	71	53	25
FAS	0	0	8	4	149	71	55	26
ARND	0	0	14	7	153	72	45	21
BI	0	0	13	6	112	55	87	44
MI	0	0	7	3	118	56	87	41

Figure 8: Pre and post knowledge evaluation

### Feedback received included:

*“Information provided (facts/figures) will enhance my confidence in raising awareness with our service users. Could be easily incorporated into some of group work sessions”*

*“Really enjoyed the course, engaging very knowledgeable trainer who you can see is passionate. Will apply what I have learnt today in my day-to-day role. Thank you!”*



# FINDINGS

## Findings – Brief AEP and FASD awareness Training

Over 900 of systemwide workforce (health and care staff) have been trained in AEP and FASD awareness across the pilot localities. These consist of health visitors, education, school nurses, speech and language therapists, social care, family support, sexual health, and GPs.

## Findings – FASD eLearning

The response from the pilot was positive:

*'I think education plays a really important role to prevent FASD instead of victim blaming. In pregnant patients it's so important to reiterate the impact alcohol during pregnancy as people may not be aware of the consequence'. (Junior Dr)*

*'It has definitely improved my understanding of FASD and will enable me to be more aware of it when working with children in my class and on the SEN register'. (Special educational needs co-ordinator)*

## Summary:

Training was consistently well received by professionals. Most who attended the training had received no or little previous training relating to AEP and FASD. Practitioners who attended the training frequently commented that with their new knowledge of FASD, they believed they may have been supporting people with undiagnosed FASD throughout their careers. Practitioners left the training feeling confident and motivated to take action to prevent alcohol harm in pregnancy. It was noted that in areas where senior leaders and commissioners attended the training, the programme mobilised quickly, and they remained engaged throughout.

Maternity services in the pilot areas and Stockport have included AEP/FASD training on their mandatory annual maternity public health development day.

The method for collecting data on the number of professionals trained during the time of the programme was not followed consistently which resulted in uncertainty regarding final figures.

Training has been the catalyst for change in the pilot areas and in other areas of GM.

## Recommendations:

8. Access to FASD and AEP training should be increased across GM to a broad range of professionals. This training should be delivered in line with the 'Best Practice in FASD Training Guide' and the 'FASD: UK Preferred Language Guide' produced by National FASD and the Seashell Trust.
9. As a minimum professionals should complete the 'Introduction to FASD' eLearning available at <https://eschool.nationalfasd.org.uk/>
10. Midwifery staff should complete the free 'Alcohol, Pregnancy and FASD' eLearning currently in development by National FASD and utilise the supplementary resource pack in development.
11. All GM maternity services should include AEP/FASD training as part of their annual mandatory training requirements.

# FINDINGS

## IMPACT 4: INCREASED PUBLIC UNDERSTANDING AND AWARENESS OF THE RISK OF ALCOHOL USE IN PREGNANCY AND FASD AS A HIDDEN DISABILITY

### Introduction

Increasing public understanding and awareness of the risk of alcohol use in pregnancy and FASD was a key programme objective. Conflicting professional advice over the years had led to mixed messages, with many believing it is safe to drink one or two units of alcohol a week, with no harmful effects to a developing baby.

### Overview of activities

#### #DRYMESTER

The programme leads identified there was limited accurate, non-judgmental, accessible information for the public and parents-to-be. A decision was made to commission a targeted digital public marketing campaign. Following a procurement process, creative marketing agency C21 was appointed. Through research with would-be families, adoptive parents of children living with FASD and a range of local, regional, and national partners, C21 developed #DRYMESTER a digital-led awareness campaign. A full account of the campaign and its evaluation is given in the journal *Perspectives in Public Health* (Reynolds et al., 2021b).<sup>17</sup>

From May to July 2019, the programme tested how a public marketing campaign could contribute towards reducing AEP and preventing new cases of FASD in the city-region. This was the first digital campaign addressing the issues associated with alcohol use in pregnancy.

The aims of the campaign were to raise awareness of:

- Risks of drinking alcohol during pregnancy
- Chief Medical Officers guidance
- Impacts of FASD

The approach had a clear, consistent message of 'No safe time, no safe amount'. A broad audience including potential new parents (age 18 to 35) and partners, families, friends (aged 18 to 50) was targeted, and the campaign included a website that hosted supporting materials for midwives, GPs, health and community partners.

The campaign was delivered in two phases via a range of social media platforms; in phase 1, awareness was established in the four areas (May to June 2019). After an evaluation, phase 2 focused on building community ownership and participation across GM (October to December 2019).

17. Reynolds, R., Cook, P. A. & McCarthy, R. A digital campaign to increase awareness of alcohol-exposed pregnancy. *Perspectives in Public Health*. 2021;141(3):124-126. doi:10.1177/1757913920955218

# FINDINGS

## Birthday

In April 2019, the programme's locality leads commissioned Oldham Theatre Workshop (OTW) to create an interactive performance and educational workshop raising awareness among young people of the impact of drinking alcohol in pregnancy. This production was developed in partnership with a range of stakeholders including parents.

The production aims were:

- To identify the key issues around Alcohol Exposed Pregnancies and investigate how are they most effectively communicated/discussed with young people?
- To raise awareness and levels of responsibility about alcohol and the potential negative effects during pregnancy
- To achieve this through exploring Youth Culture and alcohol in relation to sex and relationships with reference to AEP



*Figure 9: Pre and post knowledge evaluation*

The production was delivered across schools in Bury, Oldham, Rochdale and Tameside and in total 5,052 young people saw the production.

### Methodology – #DRYMESTER

C21 evaluated the success of the campaign in real time. Weekly progress reports were provided to the programme leads which enabled changes to be made to achieve biggest impact.

An independent evaluation was also commissioned from social research agency Bluegrass Research. They conducted face-to-face interviews shortly before the start of phase 1 of the campaign and afterwards, involving 1,304 people from across the four localities where phase 1 campaign activities were focused.

### Methodology – Birthday

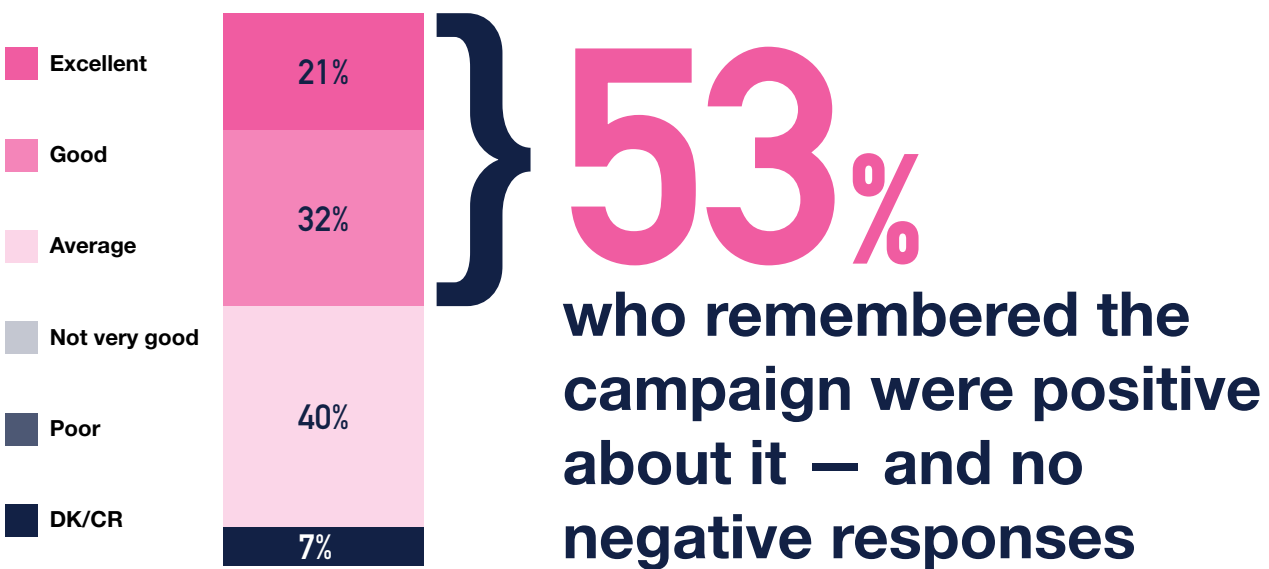
Each audience member was invited to complete a short questionnaire before and after watching the performance, to gauge the extent to which the play had improved their knowledge of the risks of AEP and their awareness of FASD. 4,032 forms were completed.

# FINDINGS

## Findings – #DRYMESTER

### Phase 1

Analysis of phase 1 showed a strong reach, 4.5 million views, among the primary audience of would-be-mums, but also found promising engagement from male partners (80% women, 20% men). Over half of people (53%) who saw the campaign responded positively, and more than one in five thought it 'excellent'. Nobody thought it was 'not very good' or 'poor'.



**Figure 10:** #DRYMESTER Phase 1 Analysis

The campaign was believed to be important, clear, believable, and non-judgmental, in dealing with a potentially sensitive subject matter. It was remembered most frequently by the core target audience of would-be-mums, including those who are already pregnant. But, when prompted with campaign material, recall was only slightly lower among the secondary audience, of potential partners, family and friends. Of those who recalled the campaign, around a quarter (26%) took away the main message of 'go alcohol free during pregnancy' and one in five (18%) that no alcohol means no risk. Awareness of almost all health harms of drinking alcohol in pregnancy was higher among people who recalled the campaign. And almost four out of five associated FASD as one of the risks. However, two in five people (41%) couldn't clearly remember the message, showing that more needed to be done to overcome confused and mixed messaging in this area in phase 2.

# FINDINGS

## Phase 2

Phase 2 of the campaign was not independently evaluated but intelligence provided by C21 showed increased reach and engagement.

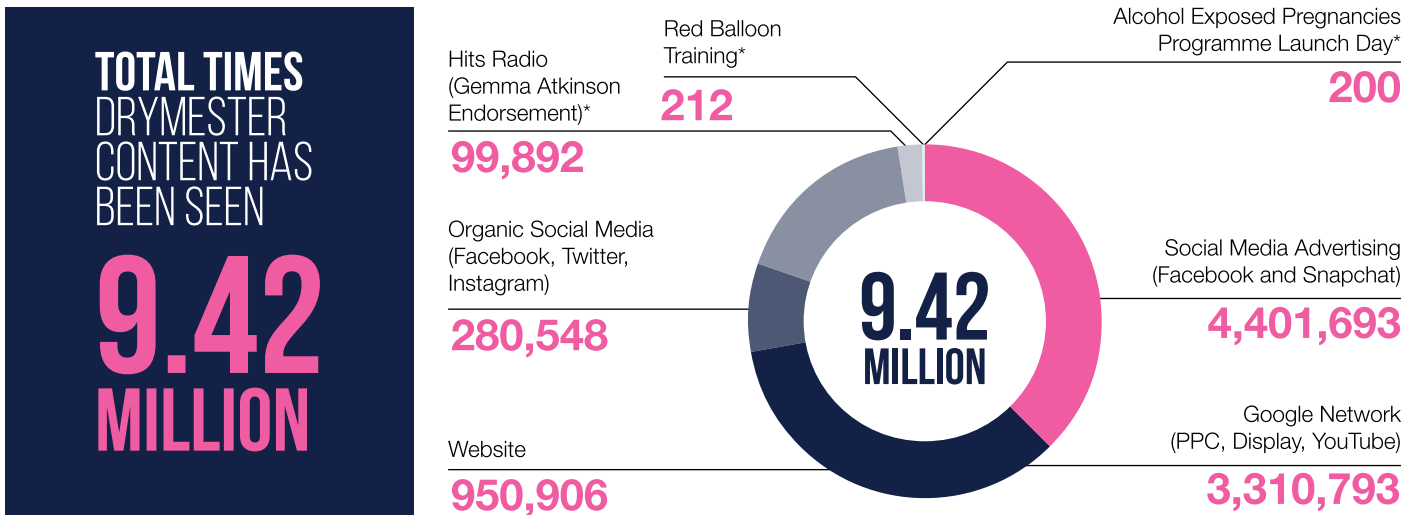


Figure 11: #DRYMESTER Summary

## Findings – Birthday

5,052 young people saw the production, with 4,032 (79.8%) providing completed or partially completed feedback forms. 3,758 (93.2% of respondents) felt what they had learned during the performance/workshop would inform their future choices. The number who understood the terms FASD and AEP increased from 122 to 3,788 (93.9% of respondents) as did the number who knew that you should consume no alcohol during pregnancy, which increased from 1,963 (48.7%) to 3,902 (96.7% of respondents).

Following the successful evaluation of Birthday, it has been adapted into a short film to increase access and reach to young people. The film is available with supporting lesson plans and will be hosted on [Oldham Theatre Workshop's webpage](#) for professionals and the public to access free of charge. The film launched on June 24th 2021 and was well received by both families and professionals.

# FINDINGS

## Summary:

These findings indicate the programme has been successful in achieving this impact. The reach of the #DRYMESTER campaign has far exceeded expectation and has been adopted both nationally, by maternity providers, and internationally by FASD campaigners. The campaign has been shortlisted for several marketing awards, one of which was won, another received a highly commended award. The messaging from the campaign has been referenced as good practice in a research paper published by the University of Bristol in January 2020 and it features in Public Health England's Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy as a best practice case study. The campaign resources have also been adopted by both Pharmacy and Oral health teams across GM and utilised in health promotion activities. There is some evidence that the word '#DRYMESTER', invented by C21 for this campaign, has entered the lexicon.

## Recommendations:

- 12. The film Birthday and supporting lesson plans are utilised in education and youth settings across GM and nationally.
- 13. Maternity services in GM and beyond continue to use the #DRYMESTER resources to support conversations regarding alcohol free pregnancies with parents-to-be.
- 14. Further funding is identified to ensure the continuation of the #DRYMESTER website and resources.

## HITTING THE HEADLINES NATIONALLY AND GLOBALLY



Figure 12: Hitting the headlines nationally and globally



# FINDINGS

## IMPACT 5: FAMILIES AFFECTED BY FASD IN GM HAVING MORE SUPPORT

### Introduction

Providing support to families in Greater Manchester that have children with FASD or suspected FASD was not in the original scope of the programme specification, as the focus of the programme was prevention. However, the absence of support for families was highlighted by the 'parents as partners' group and the programme leads agreed this needed to be a key aim of the programme.

The programme sought to meet this aim via providing small grants to voluntary organisations, to fund FASD-related activities. Further, the programme sought to involve parents affected by FASD in its design and delivery (via a 'parents as partners' group) with the aim of ensuring the programme was meeting the needs of parents, families, and carers affected by FASD.

### Overview of activities

Grants of up to £1,000 were made available and applications were asked to deliver a peer support activity or event that will take place at least once a month. Groups that were successful and received a grant included [Our Kids Eyes](#), [Crescent Radio](#), [RammyMen](#), [Rochdale Connections Trust](#), [Manchester Settlement](#) and [FASD Greater Manchester](#).

This section of the report also draws on findings from the Assessing the Prevalence of Developmental Disorders in Greater Manchester Children Study (ADD-GM) which was commissioned by the Greater Manchester Health and Social Care Partnership as part of the AEP programme. The study aimed to provide more accurate data on the number of children in Greater Manchester with FASD via the completion of an active case ascertainment study. To complement the quantitative data, parents that had participated in the study were interviewed by the University of Salford about their experience; key findings from which are reported below.

### Methodology

Four interviews were carried out with representatives from the following organisations: Crescent Radio; Our Kids Eyes; RammyMen; and FASD Greater Manchester. The interviews were carried out by a Senior Principal Researcher from the Greater Manchester Combined Authority's Research Team who has knowledge of the AEP programme but has not been involved in its design or delivery.

With the exception of one interview, which was changed to a telephone interview due to poor internet connection, the interviews were recorded in Microsoft Teams; notes were taken during the interview which were supplemented by listening back to the recordings. The interview notes were subsequently analysed. This section of the report explores the findings from the interviews. All interviewees gave their consent to having quotes from their interviews included within this report and to be potentially identifiable from the quotes' inclusion.

# FINDINGS

The intention was to undertake a focus group with people that had been involved in the 'parents as partners' group, to understand the experiences of parents involved in the programme. Unfortunately, none of the parents took up the invitation to participate in a focus group so instead an email was sent with questions for them to respond to; the questions sought parents' feedback on their involvement in the programme. Only two parents responded and, as such, the findings below are only a partial perspective.

## Findings – How the grants were used

Grants were broadly used for activities that were designed to support parents and carers of children affected by FASD or were suspected to have FASD (recognising the very real challenge of obtaining a diagnosis even for children with clear evidence of need and a known history of alcohol exposure), including providing peer-to-peer support, and to raise people's awareness of FASD.

FASD Greater Manchester used the grant funding to make a change in their support group: changing the location for meeting from high street coffee shops to a more private and quiet coffee shop within a church. The privacy of the new location meant that those attending could speak more openly and finding space was no longer an issue. The grant was also used to pay for refreshments which, it was felt, helped encourage people to attend that might otherwise not be able to afford to regularly buy refreshments for themselves in a high street coffee shop.

Similarly, Our Kids Eyes used the grant to establish a support group for parents and carers affected by FASD. The aim of the group was to provide a space for parents and carers to share their experiences amongst peers:

In brief, the research with parents that had participated in the ADD-GM study involved semi-structured interviews with six parents that had received a neurodevelopmental report for their child following participation in the research, at least 29 days prior to being contacted by the University of Salford. Full details of the methodology, and the complete findings, can be found in the report: 'Reporting the parent experience Assessing the Prevalence of Developmental Disorders in Greater Manchester Children Study' (2020), authored by Robyn McCarthy and colleagues.<sup>18</sup>

*"The stories they shared were as if they were talking about same child. All very similar stories. It was quite mind-blowing to listen to the stories and children... Many parents hadn't met another parent with a child with FASD"* (Interview with representative from Our Kids Eyes)

RammyMen also intends to establish a peer support group using some of their grant funding; whilst they hope to attract birth parents to join, they expect that foster carers and adoptive parents will be easier to identify and more likely to attend.

Crescent Radio used some of their grant to establish a coffee morning for members of the South Asian community. In contrast to FASD Greater Manchester and Our Kids Eyes, which targeted parents and carers of children with FASD specifically, Crescent Radio's groups were intended to raise awareness of FASD and challenge assumptions, some of which it was felt were a result of shame:

*"There is a lot of denial and a myth that South Asian women don't drink... People don't think it's an issue and women don't want to admit it, there's a lot of shame."* (Interview with representative from Crescent Radio)

18. McCarthy, R., Kirby, L. and Cook, P. A. "Without what you guys have done, it would never have been done": Reporting the parent experience of taking part in the ADD-GM study. 2020. Unpublished report, University of Salford



# FINDINGS

In addition to groups, some of the organisations also used the grant to fund specific awareness raising activities such as workshops. FASD Greater Manchester had organised a number of workshops on topics such as: sleep, sensory activities, and non-violent resistance.

For RammyMen, the grant also gave them the opportunity to create a booklet, based on people's lived experiences, with the aim of raising awareness about FASD. They identified that "Nobody outside foster care knew FASD existed" (Interview with representative from RammyMen) and the booklet aimed to address this.

## Findings – The impact of the grant funded activities

All the organisations interviewed were very positive about the grant and felt that the funded activities had made a difference. Most of the groups hadn't done any formal monitoring or evaluation but had picked up anecdotal feedback. For FASD Greater Manchester, the grant had enabled them to pay for the costs associated with the peer support groups (refreshments); it was felt that not having to pay out for drinks in high street cafes had helped to encourage people to come along. The grant also enabled FASD Greater Manchester to book rooms for hosting workshops: something that would not have been possible without a grant.

For Our Kids Eyes, getting involved in the AEP Programme and receiving a grant had raised the organisation's own awareness of FASD. The interviewee described having thought FASD was "very rare" and that, without the impetus of the AEP Programme, Our Kids Eyes would not have considered establishing a support group of this nature. The support group established by Our Kids Eyes was described as having become self-sustaining and it had grown into a place for peer-to-peer and social support, and place for advocacy on FASD issues. It was also described by the interviewee as being "full of laughter" and the following feedback from a member of the group was shared by the interviewee:

Unsurprisingly, the COVID-19 pandemic interrupted some of the grant-funded activities that had been established or planned. Crescent Radio and FASD Greater Manchester moved their groups to meeting on Zoom; this was considered a reasonable alternative in the circumstances, but attendance wasn't always as consistent as with the face-to-face meetings. FASD Greater Manchester also described that the natural rapport and flow of conversations that used to arise during face-to-face meetings was difficult to recreate on Zoom.

*"I really enjoyed the group, it felt like therapy... a good laugh, we need more groups"* (Feedback provided by representative from Our Kids Eyes)

Whilst meetings have stopped, it was reported that friendship groups had been established and sustained and that people have kept in touch privately, including going on outings together when COVID-19 restrictions have allowed.

At the time of the interview, RammyMen were making plans for a series of awareness raising workshops on FASD; whilst it is too soon to know the impact of the booklet and the workshops, the grant and involvement in the AEP Programme had enabled RammyMen to explore a new area of focus in FASD.

*"It's not a huge amount of money but it's a huge help and allows us to do a huge amount we otherwise couldn't do."* (Interview with representative from RammyMen)

# FINDINGS

For Crescent Radio, it was felt that the main impact was raising awareness of FASD and challenging misconceptions about FASD in the South Asian population specifically. The interviewee felt that the grant had enabled them to broach:

*“A controversial topic [and to] tackle something that people aren’t talking about”* (Interview with representative from Crescent Radio)

This included wider activities that, whilst not explicitly grant-funded, had been instigated by their involvement in the AEP Programme such as interviews about FASD on the radio station. The same interviewee gave anecdotal feedback that, having attended the groups, people had left with greater insight about FASD and a knowledge of where to seek support. It was felt that this was going some way in tackling:

## Findings – Learning

For FASD Greater Manchester, one of their key learning points was that the process of accessing a grant could be easier than they had previously thought. They had welcomed the encouragement they had received from the AEP Programme and they felt that accessing a grant had got them out of their ‘comfort zone’.

RammyMen reflected that they regretted not having realised earlier, the exceptions of support groups from some of the COVID-19 restrictions which could have helped establish/sustain activities that were disrupted by the pandemic.

Looking to the future, Our Kids Eyes recognised that there is a need to develop support specifically for young people to help them understand their diagnosis and to meet other children and adults with FASD to try and alleviate the stigma. For Crescent Radio, they felt that more awareness raising is needed amongst younger generations and they reported that they would be keen to produce content for social media, targeting people in their 20s and 30s.

*“An underground and unrecognised issue amongst the South Asian community”* (Interview with representative from Crescent Radio)

Some of the groups interviewed recognised that there was more to do to raise awareness amongst the wider population further; indeed, most of the groups reported that they had mainly engaged with adoptive parents, foster carers, and grandparents of children with FASD as opposed to birth parents. It was recognised that there is likely to remain unmet needs amongst birth parents and that shame may be what is holding birth parents back from joining groups and attending workshops and events.

## Findings from the ‘parents as partners’ feedback

The two parents that provided feedback via email were positive about their involvement in the AEP programme. Both felt that their knowledge and experience of FASD had been drawn upon:

*“I was asked questions by professionals at the launch day on our circumstances and how it was to live with children who have FASD.”* (Feedback from parent)

*“We were asked to talk about our experiences of living with someone with FASD and what services we have received. The difficulties we have had getting diagnosis and services to help with our families.”* (Feedback from parent)

One of the parents commented that being involved in the AEP programme had been a good opportunity to ‘network’:

*“It was great to be involved with the launch of the campaign and the conference in May 2018. Networking and meeting many professionals in the field of FASD.”* (Feedback from parent)

# FINDINGS

They went on to comment:

*“It has been a privilege to be involved with the project and the many people we have met via the programme.”* (Feedback from parent)

Both parents also suggested that the AEP programme had contributed towards raising people’s awareness of FASD:

*“It is also brilliant Manchester had the insight and courage to invest and raise awareness in a condition which has been ignored for far too many years and is now leading the way for the rest of the country.”* (Feedback from parent)

*“When I contacted my GP recently for my eldest daughter’s prescription, she commented about how much she’s now hearing about FASD.”* (Feedback from parent)

## Findings from parents that had participated in ADD-GM

Research by the University of Salford found that parents that had participated in the ADD-GM Study had found it to be a positive experience and that the subject matter had been handled with sensitivity. Whilst some of the parents had found the results of their child’s assessment shocking, the report had provided important insight into their child and participating in the study had armed them with more information:

*“Parents talked about using the information in their child’s report to put in place changes at home or taking a different approach to parenting their child. Several parents felt taking part had*

*made a big difference to their understanding of their child’s needs and that they felt more hopeful for their future.”* (McCarthy, R., 2020)

This is illustrated by the following feedback from a parent whose child had received a neurodevelopment report as part of the study:

*“I found the [neurodevelopmental] report very helpful... now I can go forward and help (my child) even more now I know what I’m dealing with.”* (Parent participant in the ADD-GM Study)

## Summary:

Semi-structured interviews with organisations that have received grant funding found that the grants received as part of the AEP Programme have helped to establish new activities and, in the case of FASD Greater Manchester, improved a support group that already existed. Feedback, from the organisations, suggests that these activities have helped to provide support to parents and carers affected by FASD and have increased awareness of FASD. Most of the groups interviewed described how the grant had instigated new work related to FASD and, in some cases, increased the organisation’s own awareness of FASD as an issue affecting individuals and families they work with.

# FINDINGS

Whilst COVID-19 disrupted some of the group activities, adaptations were sought. For example, Action Together facilitated a virtual space for the groups to come together, collectively as a network. This network recently developed an FASD parent and carers experience eBook to support people caring for children with FASD, raise awareness and shared lived experiences to drive positive change.

Parent and carers who are supported by the groups have shared their stories of caring for children with FASD. The peer support eBook<sup>19</sup> includes journeys to diagnosis, navigating health and social care support systems, schools, and education. It has been created to support parents and carers of children diagnosed, or in the process of seeking diagnosis, with FASD.

Facilitating peer support in the pilot areas was one of the programme objectives, but what has been achieved via the small group of FASD grants far exceeds the original ambition. The network of groups is a successful legacy of the programme.

Parents involved in the development and delivery of the AEP programme that responded with feedback were positive about their involvement, believing their knowledge and experience had been drawn upon and they suggested that the programme had helped raise awareness of FASD. Involving parents in procurement processes and programme design has been fundamental to the success of the AEP programme and it is recommended that a co-production approach continues in any future developments.

Parents that had participated in the ADD-GM Study (commissioned by the AEP Programme and conducted by the University of Salford) were positive about their experience; whilst the results from the assessments sometimes took time to come to terms with, parents reported being appreciative of the insight and knowledge that their child's report offered them.

It is acknowledged that birth parents of children with FASD are under-represented as both parents involved in the co-production of the programme and those accessing support from the VCSE groups. Overcoming the stigma associated with prenatal alcohol use has been at the heart of the programme, as the Acorn peer mentor initiative demonstrates. However, more needs to be done to support birth families to access support and opportunities to influence future policies and service development.

## Recommendations:

15. Voluntary Community Faith and Social Enterprise (VCFSE) partners continue to provide support and structure to GM FASD groups, including applying for future funding, to enable them to grow and sustain their vital role.
16. The positive experiences reported by the parents who participated in the ADD-GM Study to be used to support discussions advocating for increased access to FASD assessment and diagnosis.
17. The needs and experiences of birth parents to be central to the development of future FASD support provision.

# FINDINGS

## IMPACT 6: UNDERSTANDING OF FASD PREVALENCE

### Introduction

When the programme began there was limited knowledge regarding FASD prevalence in GM, as there had been no UK FASD prevalence studies. However, it was known that the UK has the fourth highest drinking rate in pregnancy in the world, and whilst an international modelling study suggested 3.24% of young people in the UK have FASD it was recognised that FASD is difficult to diagnose and is under-diagnosed.<sup>20</sup> A decision was therefore made to commission the first UK FASD prevalence study. The following section reports findings of the study which, whilst not evaluation findings, illustrate how the programme has increased understanding of FASD Prevalence in GM.

### Overview of activities

Following a procurement process, the University of Salford were awarded a contract to complete an FASD prevalence study in GM. The aim of the study<sup>21</sup> was to identify children with FASD from a complete year group, using the best method for estimating the prevalence of FASD, namely an 'active case ascertainment' method. The study took place between May 2019 and March 2020. The research was led by Professor Penny Cook from the University of Salford. The project was a collaboration with the National FASD Clinic, led by leading UK FASD expert Dr Raja Mukherjee, and the University of Manchester and the University of Liverpool. Professor Clayton-Smith (University of Manchester) and Dr Mukherjee led the case conferences and used their clinical expertise to identify FASD. There was an independent steering group to oversee the study, including reviewing the study design, ethical considerations, and data interpretation. The independent group included parents and foster parents of children with FASD and was chaired by Professor Jonathan Green (Neuroscience & Experimental Psychology University of Manchester and Royal Manchester Children's Hospital).

### Methodology

The researchers carried out a two-phase study to actively identify FASD in three mainstream primary schools in Greater Manchester. The schools were situated in areas that ranged in socioeconomic circumstance, from relatively deprived to relatively affluent. An entire year group of children, all those who were aged 8–9 years, were invited to take part. In the first phase, children were selected on criteria for factors known to be related to FASD risk: if they were small for age; on the schools' special educational needs register; if they were currently/previously in care; and if they had significant social/emotional/mental health symptoms. Children who screened positive at this stage were invited for further assessment. Additionally, if parents had concerns, they were able to put their child forward for assessment. The further assessment included a range of questionnaires with the parent and some tests, including an IQ test, on the child.

20. Shannon Lange et al., Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis, *JAMA Pediatr.* 2017

21. McCarthy, R., Mukherjee, R. A. S., Fleming, K. M., Green, J., Clayton-Smith, J., Price, A. D., Allely, C. S., & Cook, P. A. (2021). Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study. *Alcoholism: Clinical and Experimental Research*, 00, 1– 11. <https://doi.org/10.1111/acer.14705>

# FINDINGS

## Findings

The prevalence of FASD in the three schools was 1.8% (with a confidence interval of 1.0-3.4%). When possible cases of FASD were included, the prevalence was 3.6% (confidence interval: 2.1-6.3%). None of these children had previously identified with a neurodevelopmental diagnosis.

Although it is difficult to apply the findings to the whole of Greater Manchester, since only three schools were used, if the prevalence was representative there would be between 619 and 1,238 affected live births each year and a similar number of affected children will be starting school in Greater Manchester each year. It is also worth bearing in mind that these results may be an underestimate as many children, considered most at risk, were not available to be assessed. Often the children who the teachers were most concerned about were withdrawn by their parents or parents were uncontactable. Also, only mainstream schools were included. Because of their significant difficulties, children with FASD may be more likely to be found in specialist schools that support children with social, emotional, and mental health issues.

## Recommendations:

The study's finding that this preventable condition is relatively common should be promoted widely with the hope that this will be used to drive further investment into:

18. Increased access to diagnosis for FASD.
19. Interventions to support families and individuals affected by FASD (to reduce the burden of the condition on individuals but also other services).
20. A national prevalence study for more precise estimates and a greater geographical range.



# FINDINGS

## UNINTENDED IMPACTS

The programmes approach and early impacts have made an important contribution to the recently published DHSC FASD Health Needs Assessment. This government document is the first health needs assessment for people living with FASD, their carers and families, and those at risk of alcohol exposed pregnancies in England. Both the AEP programme senior advisor and project manager are acknowledged for their contribution and the programme is cited as one of the only examples of good practice.

Improving FASD diagnostic pathways in GM, although required, was not in the scope of this programme. However, as a result of the programme's FASD prevalence study a number of GM paediatricians have gone on to make an FASD diagnosis. Further, following an AEP/FASD awareness session delivered by the programme leads, Children's and Adolescent Mental Health services staff have approached the team for support in improving FASD assessment pathways. There is ongoing work supporting them with this.

The FASD Prevalence research findings published by The University of Salford stimulated significant media interest and created an opportunity for the UK's leading FASD experts, including those with lived experience, to speak publicly on the issue. This coverage included BBC TV and a feature on Radio 4 Women's hour. The publication of the findings, alongside the DHSC needs assessment, the impending Nice Quality Standards and the tireless work of FASD advocates has created a compelling case for change.

The reach and impact of the programme has travelled not only outside of the boundaries of the pilot areas, but also beyond GM and England with international teams adopting the programme's resources, such as #DRYMESTER and Birthday. #DRYMESTER may have entered the lexicon as a term for being abstinent in pregnancy. The programme leads also took part in research conducted in Australia by The Foundation for Alcohol Research & Education (FARE). The aim of the research was to explore different examples of good practice in addressing alcohol harm in pregnancy via public health campaigns. The research took place through the format of semi-structured telephone interviews and focused specifically on the #DRYMESTER campaign and the approach taken

The senior advisor for the programme, Róisín Reynolds, was also invited to be a professional advisor to the Irish based support group, ÉNDpae. This is an all-island parents' and carers' support group dedicated to supporting people affected by neurodevelopment from prenatal alcohol exposure (ÉNDpae) and their families. It also promotes education for professionals and public awareness of the condition and promotes the #DRYMESTER website and resources.

# CONCLUSIONS

**The Alcohol Exposed Pregnancies Programme has achieved good success. The pilot programme learnings and recommendations provide a clear pathway to prevent alcohol exposed pregnancies so that fewer babies are born with lifelong health problems.**

The reach and impact of the programme has travelled not only outside of the boundaries of the pilot areas, but also beyond GM and England with international teams adopting the programme's resources such as #DRYMESTER and Birthday.

The prevention interventions identifying women 'at risk' of an AEP in the specialist commissioned services saw high numbers of women identified and good engagement. Uptake of LARC was relatively low which was impacted by COVID-19. This reflects the national picture at the time which saw the number of LARC primary care prescriptions issued fall by over 80% between April and May 2020 compared to the volume issued 2018 to 2019 (PHE 2021, p5). The commissioned prevention services have embedded these screening and behaviour change interventions as business as usual and progress against Impact 1 continues as delivery of these interventions expands to universal services.

The programme has achieved the ambition outlined in Impact 2, with routine alcohol screening in pregnancy being fully embedded across the pilot areas. Further, the programme has started to support the Greater Manchester maternity services outside of the pilot area to implement maternity alcohol screening pathways. The programme has provided insights into the differences in the sensitivity of both AUDIT C and TWEAK as alcohol screening tools in pregnancy. This provides an opportunity for the newly established GM AEP maternity working group to refine GM maternity alcohol screening processes.

Providing clear and consistent messaging on alcohol harm in pregnancy and FASD is the responsibility of professionals spanning a breadth of health, social care, and education settings. The programme has made significant progress against Impact 3 through workforce training and the award winning #DRYMESTER campaign. The adoption of the #DRYMESTER materials by services outside of GM exceeds the programme's original ambition for this impact. The programme has successfully provided the foundations for professionals to develop the skills and knowledge to provide clear and consistent messaging to parents-to-be. Further workforce development in this area continues through mandatory training and the commissioned National FASD eLearning.

The programme has achieved its intended impact to increase public understanding and awareness of the risk of alcohol use in pregnancy, through a number of the programme's activities. Independent evaluation of the #DRYMESTER campaign reported an increase in public understanding, and data provided by C21 evidenced public engagement with the campaign assets and social media platforms. The progress against Impact 3 has, in turn, contributed to the success of Impact 4 with professionals across GM equipped to have informed discussions with the public. The #DRYMESTER website and resources continue to provide the public with accurate and accessible information on AEP and FASD including a range of tips and guidance for parents-to-be on alcohol free pregnancies. Unfortunately, a lack of awareness or misunderstandings of AEP and FASD persist in our communities and therefore activities to increase public understanding must continue.



# CONCLUSIONS

The programme leads engaged with families affected by FASD early and through a process of co-production the families' experience and expertise influenced the design and delivery of the programme. This partnership work provided valuable insights to the support needs of families and the programme successfully worked with VCFSE partners to create opportunities for families affected by FASD in GM to access peer support. In the programme's short time a GM FASD support network has been established and continues to evolve with guidance from Action Together. The recent development of the FASD Parent and Carer Experience eBook extends the reach of this support far beyond GM.

It is important to note that families affected by FASD have needs that cannot be met via peer support. Access to local and timely assessments for FASD assessments and support is still limited in GM and until this is improved families and individuals with FASD will not be fully supported.

One of the biggest challenges faced by the programme was the absence of a UK FASD Prevalence rate. This was a priority impact area that was addressed through commissioning the first UK FASD active case ascertainment study led by The University of Salford. Through this research, we now know that at least 1.8% of children in Greater Manchester may have FASD (the equivalent of 619 lives births each year) and that potentially 3.6% of children are affected, when including children who possibly had FASD (the equivalent of 1,238 children a year). This is ground-breaking research and provides an evidence base of need that must inform future service development and commissioning decisions.

This report concludes that the Alcohol Exposed Pregnancy Programme has made important progress and, in some cases, exceeded the ambitions set out in the impact areas. However, there is much more to be done to prevent alcohol harm in pregnancy and FASD in Greater Manchester and across the UK, as reflected in the following observation:

*"FASD is something that has been around for a long time and is unlikely to disappear. Finding ways to prevent and manage this has therefore become essential. The project in Greater Manchester was one of the first in England to really embrace this and find solutions to some of these questions. Such a lot of good work came out of this, that will change the longer-term approach going forward. Having said that, we cannot see this as a 'job done'. There is much more to do and whilst it is, from a cup half full approach, a job well done, it has to be the start of the process and not the end."*

Raja Mukherjee, Consultant Psychiatrist, National Clinical Lead for FASD."

# RECOMMENDATIONS

## **Fewer alcohol exposed pregnancies within pilot areas:**

1. Interventions to prevent AEP should be embedded in universal services across Greater Manchester as AEP risk is not exclusive to those with alcohol dependency issues
2. AEP prevention interventions should include enhanced support to access all forms of contraception

## **Alcohol screening in pregnancy as standard across maternity services:**

3. Establish a GM AEP Maternity working group to share learning and good practice
4. Programme leads use data available to further investigate the sensitivity and suitability of the two screening tools
5. All GM maternity providers implement AEP pathways and fulfil the requirements of the NICE FASD Quality Standards 1 & 2
6. Early data quality audits to be completed when implementing AEP pathways across the remaining GM maternity providers
7. Digital innovation and transformation of maternity records in Greater Manchester must support AEP maternity pathways and the need to record and share information regarding prenatal alcohol use

## **Clear and consistent messaging from professionals regarding alcohol and pregnancy in pilot areas**

8. Access to FASD and AEP training should be increased across GM to a broad range of professionals. This training should be delivered in line with the 'Best Practice in FASD Training Guide' and the 'FASD: UK Preferred Language Guide' produced by National FASD and the Seashell Trust
9. As a minimum professionals should complete the 'Introduction to FASD' eLearning available at <https://eschool.nationalfasd.org.uk/>
10. Midwifery staff should complete the free 'Alcohol, Pregnancy and FASD' eLearning currently in development by National FASD and utilise the supplementary resource pack in development
11. All GM maternity services should include AEP/FASD training as part of their annual mandatory training requirements

## **Increased public understanding and awareness of the risk of alcohol use in pregnancy and FASD as a hidden disability:**

12. The film Birthday and supporting lesson plans are utilised in education and youth settings across GM and nationally
13. Maternity services in GM and beyond continue to use the #DRYMESTER resources to support conversations regarding alcohol free pregnancies with parents-to-be
14. Further funding is identified to ensure the continuation of a the #DRYMESTER website and resources

# RECOMMENDATIONS

## **Families affected by FASD having more support:**

15. VCSFE partners continue to provide support and structure to GM FASD groups, including applying for future funding, to enable them to grow and sustain their vital role
16. The positive experiences reported by the parents who participated in the ADD-GM Study to be used to support discussions advocating for increased access to FASD assessment and diagnosis
17. The needs and experiences of birth parents to be central to the development of future FASD support provision

## **Understanding of FASD Prevalence:**

The study's finding that this preventable condition is relatively common should be promoted widely with the hope that they will be used to drive further investment into:

18. Increased access to diagnosis for FASD
19. Interventions to support families and individuals affected by FASD (to reduce the burden of the condition on individuals but also other services)
20. A national prevalence study for more precise estimates and a greater geographical range

# REFERENCES

- Department of Health and Social Care (2021), Fetal alcohol spectrum disorder: health needs assessment. Available at <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment> (Accessed September 2021)
- Lange, S. Probst C, Gmel G, Rehm J, Burd L & Popova S. (2017) Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis, *JAMA Pediatrics*; 171(10): 948–956
- McCarthy, R., Kirby, L. & Cook, P. A. (2020) “Without what you guys have done, it would never have been done”: Reporting the parent experience of taking part in the ADD-GM study. Unpublished report, University of Salford
- McCarthy, R., Mukherjee, R. A. S., Fleming, K. M., Green, J., Clayton-Smith, J., Price, A. D., Allely, C. S., & Cook, P. A. (2021). Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study. *Alcoholism: Clinical and Experimental Research*, 00, 1–11. <https://doi.org/10.1111/acer.14705>
- Morrello, M. (2021). Midwives’ perspectives on their role in the Greater Manchester Health and Social Care Partnership’s programme to Reduce Alcohol Exposed Pregnancies, Unpublished dissertation, University of Salford,
- Public Health England. (2021) Extending Public Health England’s contraception return on investment tool. Maternity and primary care settings. Available at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1001464/ROI\\_LARC\\_maternity.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1001464/ROI_LARC_maternity.pdf) (Accessed September 2021)
- Reynolds, R., McCarthy, R. & Cook, P.A. (2021a) We do things differently here: the Greater Manchester approach to preventing alcohol-exposed pregnancy. *Perspectives in Public Health*;141(5):252-254. doi:10.1177/1757913920985553
- Reynolds, R., Cook, P. A. & McCarthy, R. (2021b) A digital campaign to increase awareness of alcohol-exposed pregnancy. *Perspectives in Public Health*. 2021;141(3):124-126. doi:10.1177/1757913920955218
- Seashell Trust/National FASD, FASD: Preferred UK Language Guide, 2020, <https://nationalfasd.org.uk/languageguide/> (Accessed August 2021)
- Velasquez, M. M., Ingersoll, K. S., Sobell, M.B., Floyd, R.L., Sobell, L.C. & von Sternberg, K. A (2010). Dual-Focus Motivational Intervention to Reduce the Risk of Alcohol-Exposed Pregnancy, *Cogn Behav Pract*; 17(2): 203–212
- Warwick Medical School & Public Health England, Toolkit for applying behavioural science to barriers in reproductive health, [https://warwick.ac.uk/fac/cross\\_fac/phew/resources/toolkit\\_for\\_applying\\_behavioural\\_science\\_to\\_barriers\\_in\\_reproductive\\_health\\_19\\_march\\_2021\\_research\\_retold.pdf](https://warwick.ac.uk/fac/cross_fac/phew/resources/toolkit_for_applying_behavioural_science_to_barriers_in_reproductive_health_19_march_2021_research_retold.pdf) (Accessed August 2021)