

# Janet Fyle

## 29 June 2019



Promoting • Supporting • Influencing

## 1. Perinatal mental health problems in the UK

- Context
- The impact on mother/father/child(ren)
- Cost of doing nothing/piecemeal approach *versus* action
- Collaboration and Lobbying

## 2. FGM What/Why/Who

- Impact on girls & women
- Getting it on to govt. agenda
- What happened next
- Animations
- Q&A

Behind closed doors are millions of women struggling silently, suffering from mental health turmoil relating to the birth of a child.

The deficiency in identifying, providing care and support cost us dear as a society and shames us all.

# Its not all about cute babies

4

Pregnancy and the post birth period – a trying time

Being pregnant and giving birth ranges from wonderful and joyous, to traumatic and difficult

Coping with the practicalities of caring for a new baby

Adjusting as a woman

Relationship with partner, friends and/or family

Overwhelmed by expectations

WHO 2008: “Despite the recent upsurge of interest in this area, many questions remain unanswered resulting in a myriad of research implications.”

## **Maternal mortality across the UK**

The conditions that women died from in the UK as a result of pregnancy/childbirth have mainly been eradicated – Yet

- 2011-13: Almost a quarter of women who died between six weeks and one year after pregnancy died from mental-health related causes (MBBRACE-UK 2016)
- (2012- 14: 15 %, (MBBRACE-UK 2016)
- 2013-15: - 14%, (MBBRACE-UK 2016)
- 2016-18 – 18% (MBBRACE-UK 2018)

Intergenerational risk factors – childhood abuse linked to antenatal depression; anxiety in pregnancy linked to child behaviour problems  
Emerging evidence on infant and maternal mental health links  
PTSD and birth trauma

Perinatal mental illnesses are a major public health issue and exerts a toll on the lives of women & families

Up to 20% of women develop a mental health problem during pregnancy or within 2 years of giving birth

Major cause of death in women during pregnancy and up to 2 years after post birth

Suicide is the leading cause of direct death for women during pregnancy and in the 2 years after giving birth

Long term health and psychological impact and consequences on the child/children

Anxiety can be crippling, yet sometimes overlooked or minimised:  
11.8% to 15.3% during pregnancy & 8% post birth

Depression in pregnancy – 7.4%, 13.1%, to nearly 15% in late pregnancy

Depression post birth – 7.4 to 11.0% in the first 3 months after birth  
Between 7.8 to 12.8% 3<sup>rd</sup> to 6<sup>th</sup> months

8.5 to 12.0% in the 6<sup>th</sup> to 9<sup>th</sup> months  
Half of these who develop depression progress to severe depression

Depression and anxiety mostly occur together in pregnancy and up to 2 years post birth

2/1000 develop psychosis directly after childbirth and remain at higher risk of relapse

Between 2014-16 – **9.8 women per 100,000** died during pregnancy or up to six weeks after childbirth or the end of pregnancy.

Most women who died had multiple health problems or other vulnerabilities.

**114 women** died from mental health-related causes during or up to one year after pregnancy in the UK and Ireland

**18% of women** who died between six weeks and one year after the end of pregnancy, died by suicide



The women who died by suicide were average age 30 years, **86%** were of white ethnicity and **91%** were UK or Irish citizens

Over two thirds (**71%**) had previous children, **39%** were known to social services.

Almost a quarter (**24%**) had a known history of domestic abuse, but for **59%** complete information was missing.

**86%** percent of women who died by suicide received some antenatal care but only **31%** of those who received antenatal care received the recommended level of care.

One in five (**21%**) booked for care after 12 weeks' gestation.

# Women's experience of perinatal mental health - RCOG, 2016

10

- 27% thought it was normal in pregnancy to experience mental health problems
- 32 % did not realise healthcare professionals could help
- 28 % felt embarrassed worried about stigma
- 40% thought it would be noted in records
- 23 % were not sure what was wrong
- 13% were worried about how they were feeling.
- 23% felt the clinical team were unapproachable
- 20% were not asked about mental health problems

Almost 23% did not want to take up the clinician's time

Many women do not report – Fear of losing children

Culture – Religion - Stigma

*“They were more concerned about the baby and not me as the mother” “Everyone asked how I was coping, but no one had any help they could offer, so it was pointless”*

- *3rd year student midwife - “Mental health is briefly mentioned, but physical health is given far more priority” Postnatal depression was not something covered in my training”*
- *Midwives – Time pressure, Lack of knowledge – Referral and services*

Physical symptoms; feeling unwell, loss of appetite

Tired

Outward emotional signs, crying, erratic behaviour

Unable to cope with basic tasks/caring for baby

Blames the baby or partner

Poor bonding/none

Confusion - Not understanding what is happening

Fear

Denial

Premature Births

Cognitive impairment

Mother & child interaction/early emotional development

Infant Deaths

Emotional problems

Depression and anxiety (Adolescent girls)

Special educational needs

Conduct problems/classified as a disorder

Partners of women with postnatal depression are more likely to experience distress and depression

Wide range of feelings – worry and concern for partner

Anger and frustration – poor understanding of mental health issues

Lack of help and support, poor access to services

Marriage breakdown – **18%** of marriages end following perinatal depression or postpartum psychosis

Negative impact of paternal depression on children

We are part of the 1:4

£12.5 billion for care provided by the NHS, local authorities, private & charity funded services, family and friends;

£23.1 billion in lost output in the economy

£41.8 billion in the Human costs of reduced quality of life/loss of life, amongst those experiencing a mental health problem.

Impact on families – tragedy- male suicide

# When we don't Act.....we all pay

16

Pregnancy related depression, anxiety and psychosis cost society about £8.1 billion for each one-year cohort of births - an extra £10,000 for every baby born in the UK –

NHS and Social Care bear the burden of around £1.2 billion (20%) each year –

Nearly three-quarters (72%) of this cost relates to adverse impacts on the child rather than the mother

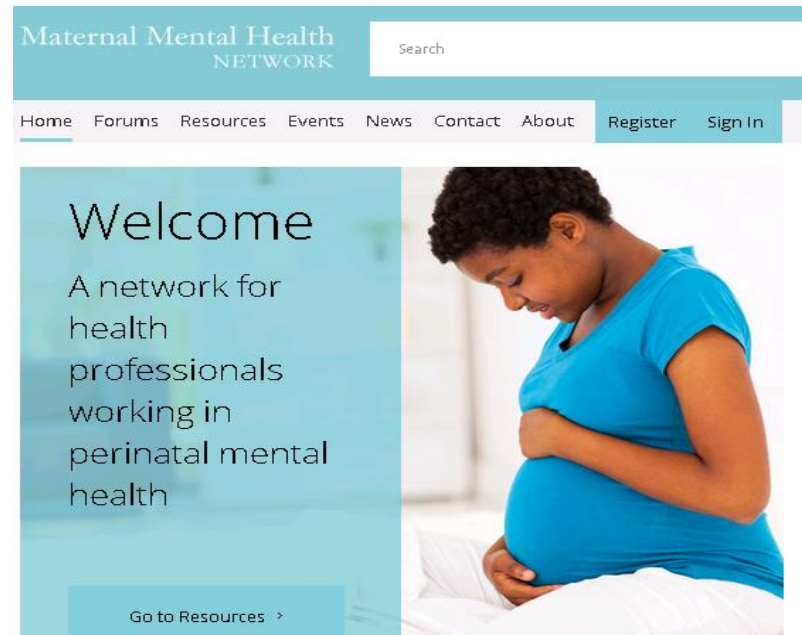
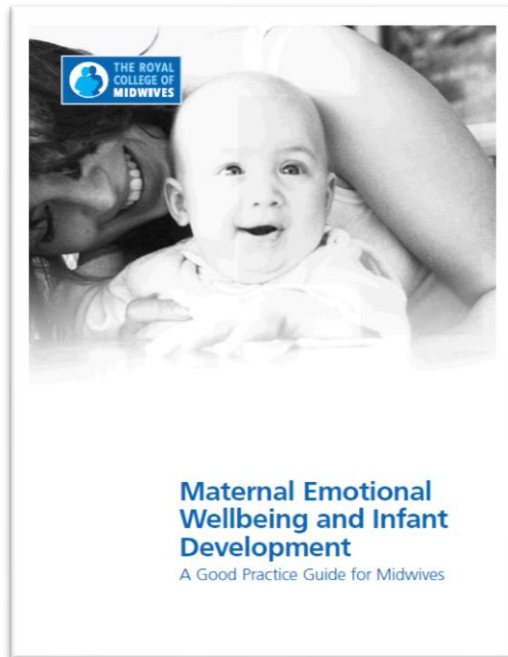
The greatest costs – human cost & impact on children

Compared to spending £280 million a year to bring the care to recommended national standards

The cost to the public sector of perinatal mental health problems is **5 times** the cost of improving services.



- Almost half of depression and anxiety undetected
- Many women downplay their mental illnesses
- Even when detected, we fail to offer consistent effective care & support
- Lack of service provision & specialist services
- Evidence based care & pathways
- Education and awareness



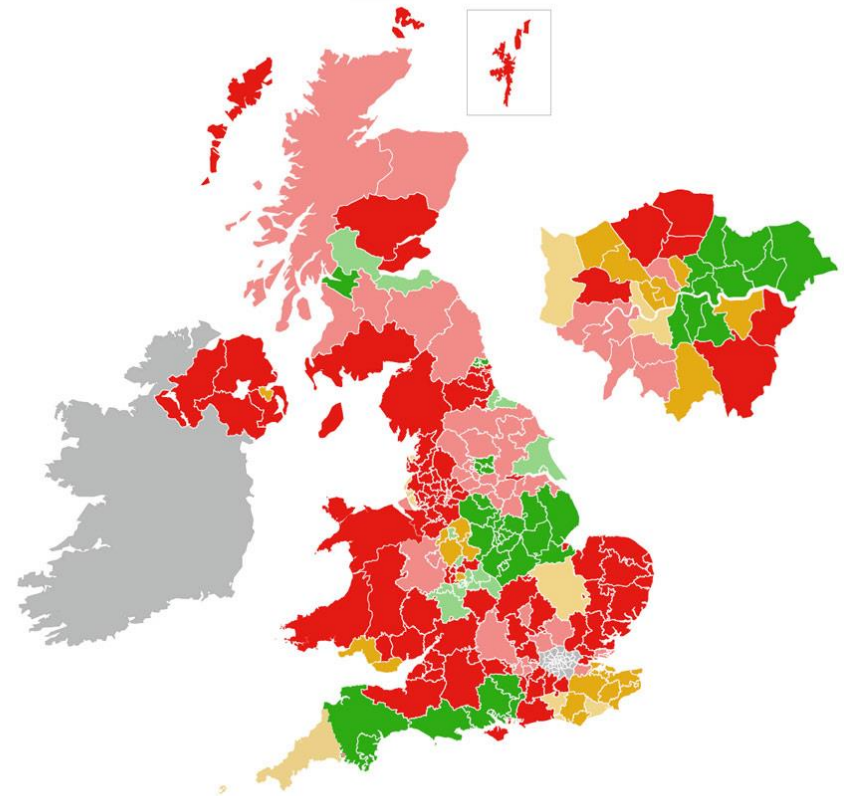
- Evidence of the importance of mother and baby interaction.
- Impact of the mother's emotional wellbeing during pregnancy and the transition to parenthood.
- Support healthy parent-infant relationships.



# Collaboration/Lobbying – Maternal Mental Health Alliance

20

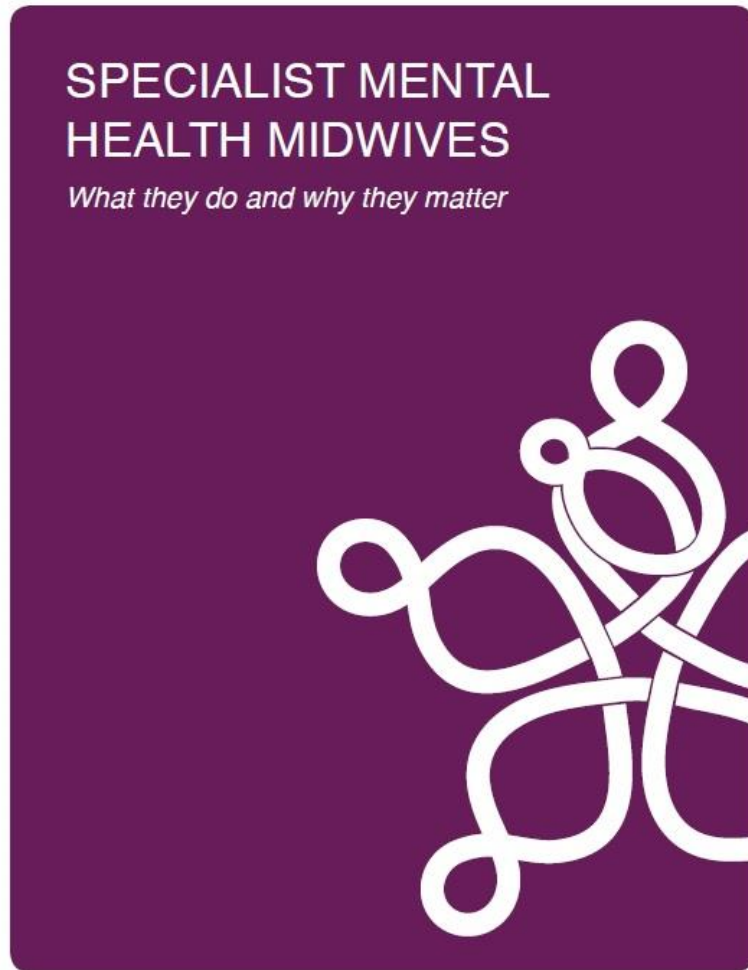
- Building the MMHA
- Drafting the Manifesto
- *Everybody's Business*
- *The Call to Act*
- *MABIM*



Gaps in mental health care for new mothers cost UK £8bn a year – study







## Ministerial Mandate

Work with partner organisations to reduce the incidence and impact of Perinatal Mental Health through earlier diagnosis and better intervention and support

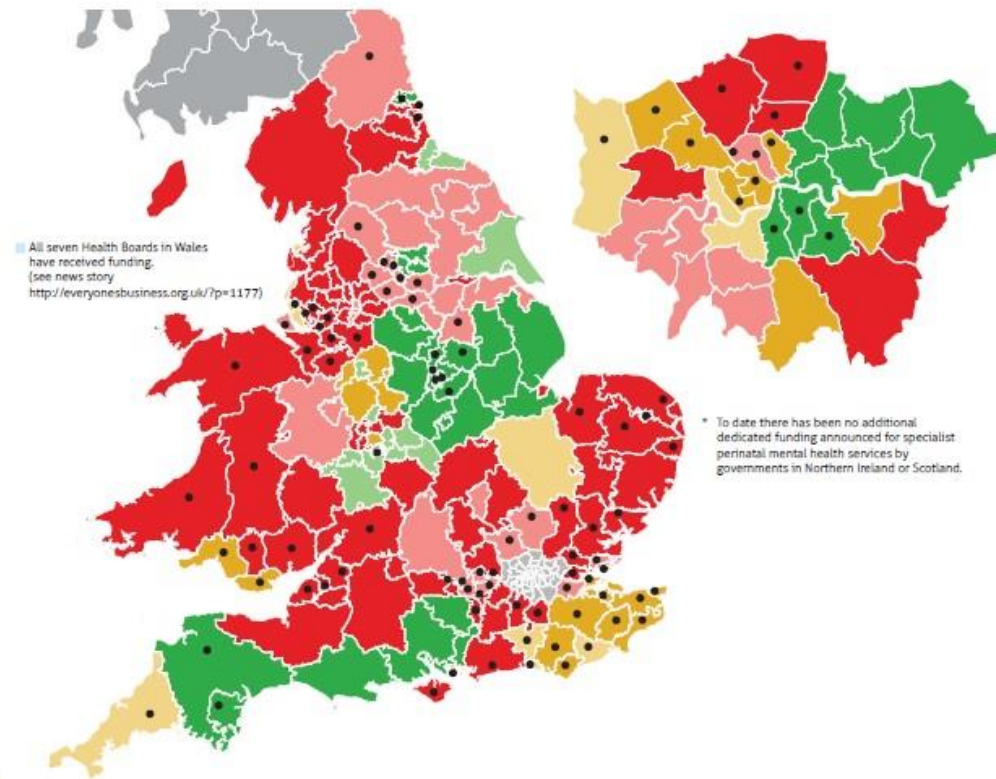
Ensure Pre and post registration training in perinatal mental health to enable there to be specialist mental health midwife available in every maternity unit by 2017.

2015 mapping data: 2016 / 17 funding update

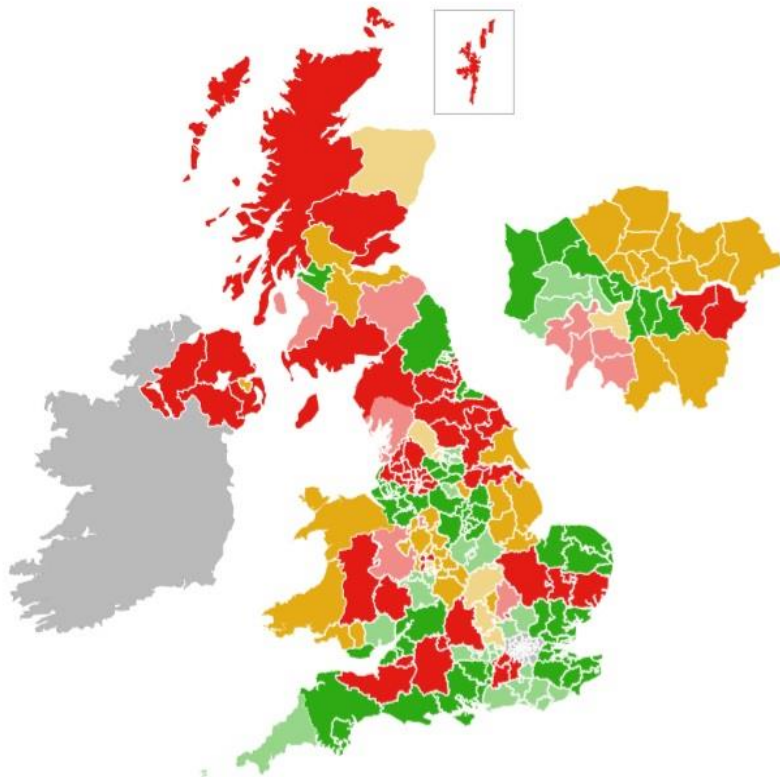


**Specialist Perinatal Mental Health Community Teams**  
(dots show areas in England and Wales in receipt of dedicated funding in 2016)

**Community Services Development Fund Wave 1 (NHS England) & Government Funding Announced (Wales)\***



# UK Specialist Perinatal Mental Health Community (April 2018)



**Green areas** - Women and families can access treatment that meets nationally agreed standard

## **Amber areas**

Some basic level of provision exists but currently falls short of national standards and needs expanding

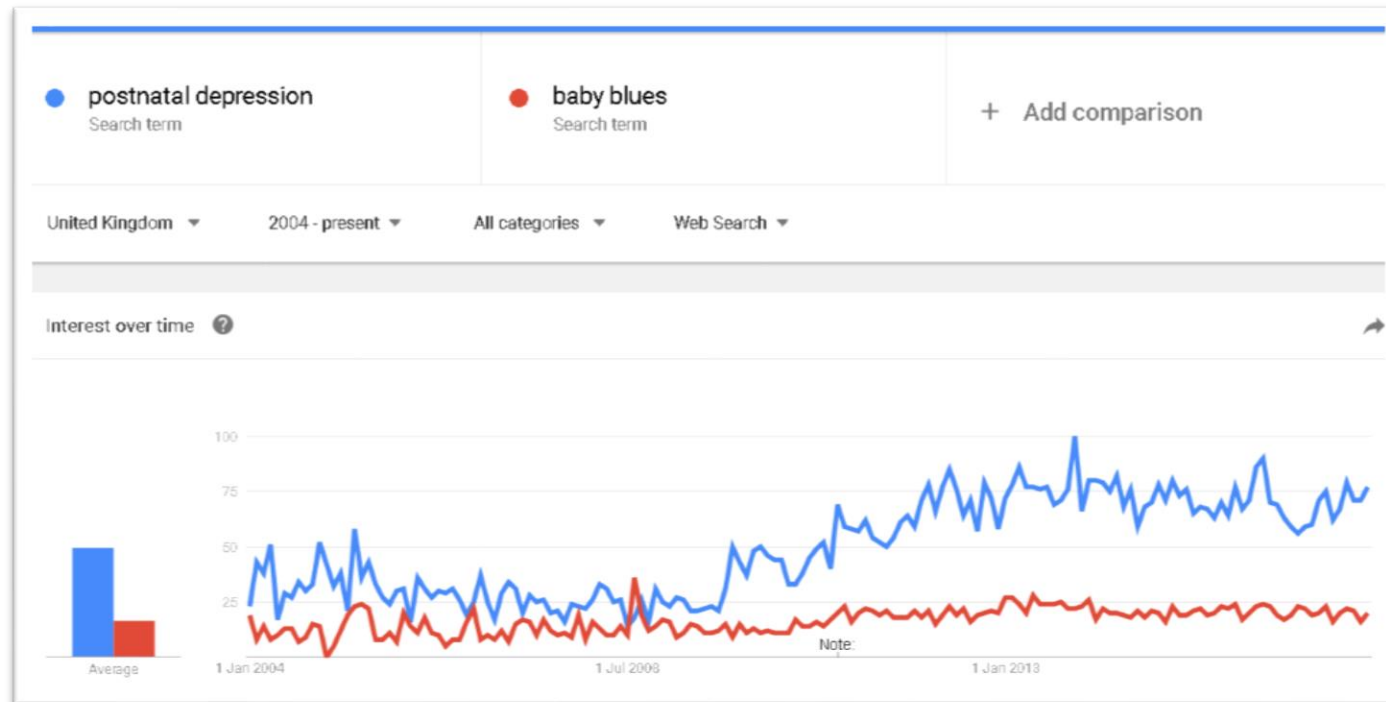
## **Pink areas**

Some extremely basic level of provision exists but currently falls short of national standards and needs expanding

## **Red areas**

no specialist team exists





- 'No health without mental health'
- 'Life chances' and social determinants of health
- Champions in government
- Lived experiences and impact of social media and web 2.0

We know the statistics – the who, when and what to do

In UK almost 100% of pregnant women interact with midwives/GPs etc

What makes it difficult for us to act

Women reported experiencing low rates of referral, long waits, regional variation of care, a lack of continuity of care, misunderstanding and stigma

The mental health of women's partners is also often neglected by healthcare professionals and services

Conduct disorder - antisocial behaviour – crime – high suicide rate among men.

Another interpretation of “from Cradle to grave”



Female Genital Mutilation (FGM) remains a global problem. An estimated 200 million women and girls in approximately 30 countries (mainly in Africa) are living with its consequences of FGM.

FGM is a deep-rooted social norm in some pressuring girls and women to conform to peer expectations.

FGM is without question a form of gender-based violence, and should be treated as such, without any excuses

FGM is a cruel act perpetrated by parents and family members upon young girls who are entrusted to their care.

FGM is not simply an exotic or cultural ritual that girls need to undergo, but a practice that has intolerable long term physical and emotional consequences for the victims and is a violation of a girl's rights as a child and her entitlement to bodily integrity.

It is related the social control of women's sexuality, as well as to a wide range of issues affecting women and girls – Early & Forced Marriage, domestic abuse and the general status of women with these countries

Where there is one abuse, there are other multiple abuses

Annually, 3 million girls are at risk of FGM. Migration has increased the number of girls and women living with, or at risk of FGM in Europe, Australia and North America.

Consequently, healthcare providers and midwives in these areas have to address the health and psychological care needs of this emerging diverse population.

In UK, it is estimated that over 80,000 girls are at risk

200, 000 women living with FGM

Year end data 2018 showed girls under the age of 5 & 8 have undergone FGM in UK

Bleeding

Infection (recurrent)

Death

Disruption to menstrual cycle

Incontinence

Sexual Dysfunction; Infertility

Scarring

Fibromyalgia

Anxiety Disorders

Severe Depression

Sleep disturbance

Flash backs

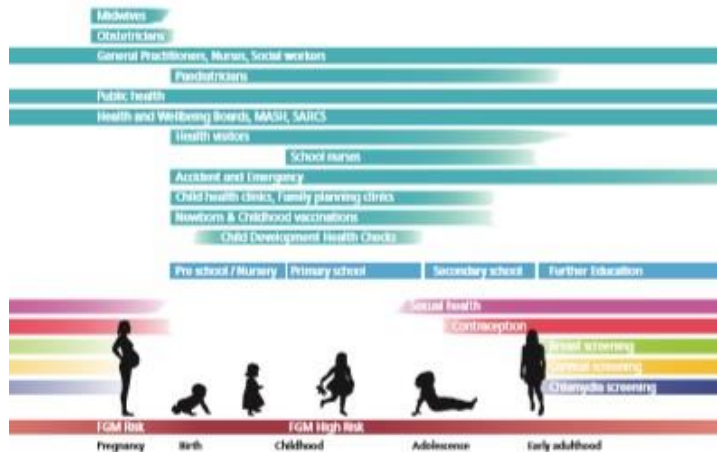
Post traumatic stress

Control Issues



## Tackling FGM in the UK

Intercollegiate recommendations for identifying, recording and reporting



#tacklingFGM

### Top Intercollegiate recommendations for Tackling FGM in the UK

- 1. Treat it as Child Abuse:** FGM is a severe form of violence against women and girls. It is child abuse and must be integrated into all UK child safeguarding procedures in a systematic way.
- 2. Document and collect information:** The NHS should document and collect information on FGM and its associated complications in a consistent and rigorous way.
- 3. Share that information systematically:** The NHS should develop protocols for sharing information about girls at risk of – or girls who have already undergone – FGM with other health and social care agencies, the Department for Education and the police.
- 4. Empower frontline professionals:** Develop the competence, knowledge and awareness of frontline health professionals to ensure prevention and protection of girls at risk of FGM. Also ensure that health professionals know how to provide quality care for girls and women who suffer complications of FGM.
- 5. Identify girls at risk and refer them as part of child safeguarding obligation:** Health professionals should identify girls at risk of FGM as early as possible. All suspected cases should be referred as part of existing child safeguarding obligations. Sustained information and support should be given to families to protect girls at risk.
- 6. Report cases of FGM:** All girls and women presenting with FGM within the NHS must be considered as potential victims of crime, and should be referred to the police and support services.
- 7. Hold frontline professionals accountable:** The NHS and local authorities should systematically measure the performance of frontline health professionals against agreed standards for addressing FGM and publish outcomes to monitor the progress of implementing these recommendations.
- 8. Empower and support affected girls and young women (both those at risk and survivors):** This should be a priority public health consideration; health and education professionals should work together to integrate FGM into prevention messages (especially those focused on avoiding harm, e.g. NSPCC 'Pants' Campaign, Personal, Social and Health Education, extracurricular activities for young people).
- 9. Implement awareness campaign:** The government should implement a national public health and legal awareness publicity campaign on FGM, similar to previous domestic abuse and HIV campaigns.

The full recommendations, including recommendations for government, lead health, social care and education agencies, are presented in Section 3.



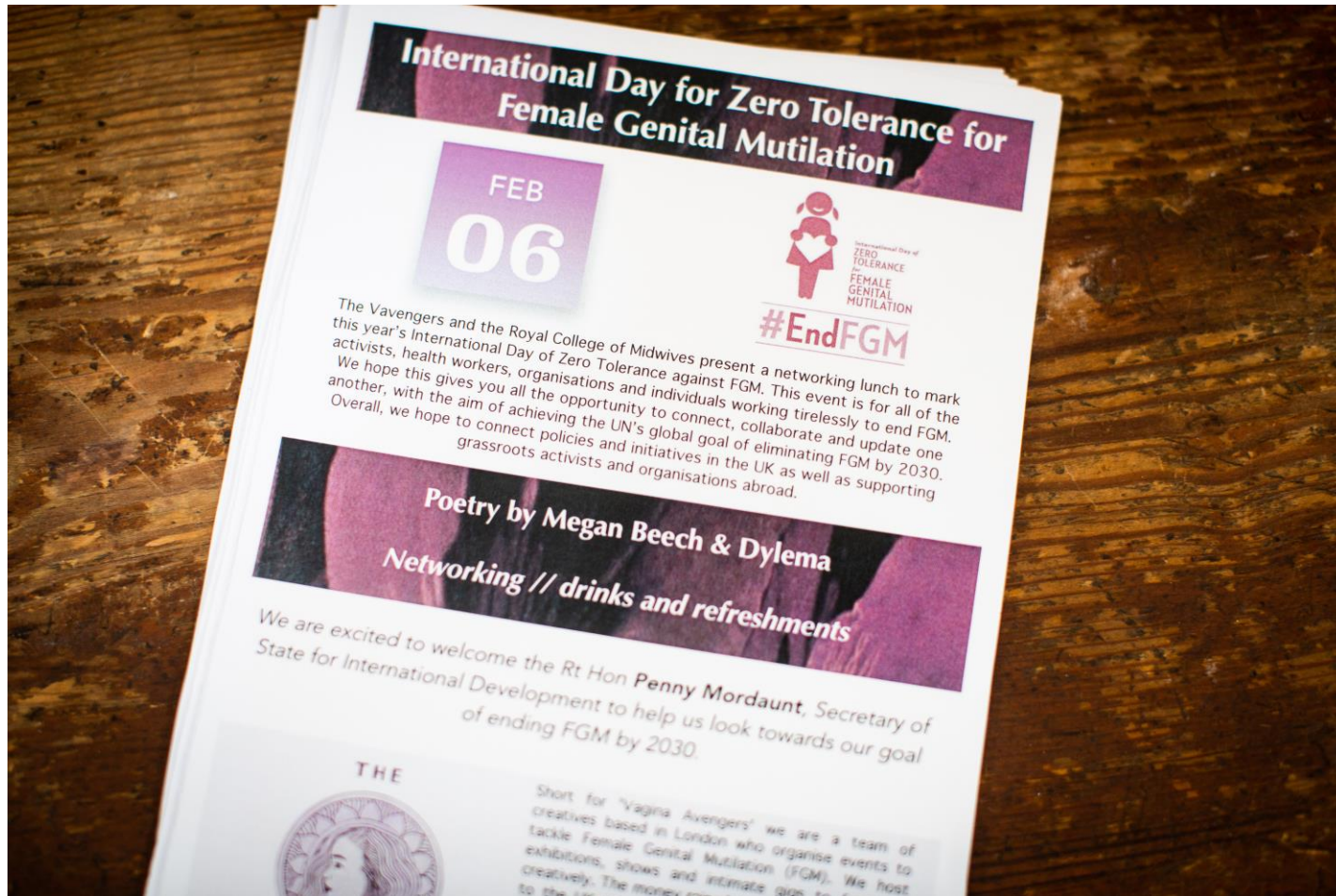
## A Call to Act to End FGM

**We call on each of the UK governments to develop, implement, monitor and evaluate a National FGM Action Plan, with the goal of ending FGM in the UK by 2030.**

**This plan will include:**

- providing accessible specialist health and psychological care and support services in community settings for FGM survivors of all age groups
- a commitment by all government agencies to end FGM, support survivors and share information to keep women and girls safe
- a commitment by all governments to run evidence-based public awareness campaigns, in partnership with survivors to change hearts and minds, through education for young people and dialogue with families and influential leaders in practising communities
- education and training for the children's workforce in their role and responsibilities for safeguarding girls and young women







# Friends in high places

36

