Making the Case for Better Miscarriage Care in Wales

SEPTEMBER 18

In partnership with FTWW Wales
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Foreword

This report has been written in partnership with the voluntary organisation, 'Fair Treatment for the Women of Wales' (FTWW)

FTWW is a patient led organisation, set up for women and girls living in Wales who need practical advice, help and support navigating their local health services and accessing optimum care. Earlier this year, Jessica Evans, a 35-year-old woman living in Llangollen, North Wales, approached us for help in lobbying Welsh Government for improvements to care available to those suffering recurrent miscarriage in the region. Having discussed the issue in depth with her and, subsequently, many hundreds of other women in Wales, we were more than happy to assist and fully support the recommendations made within this report.

Jessica herself has gone through a total of four miscarriages. Her experiences of services in both England and Wales have evidenced the significant shortcomings in the quality of care women receive in Wales compared to that of England. Furthermore, it has become apparent that accessing quality, specialised care for recurrent miscarriage is extremely difficult for women living in Wales.

In Wales there are no dedicated recurrent miscarriage clinics and pathways to achieving a referral to a dedicated clinic in England are, at best lengthy and complicated, and at worst, impossible.

We believe that it is incredibly unfair that women all over Wales are having to endure the devastation of multiple miscarriages and are being given very little chance of understanding why this is happening to them. Whilst in England, women can quickly and easily access specialised care, women in Wales have to accept non-specialised care, which varies significantly in quality.

This current situation in Wales seems very much at odds with the core principles of NHS Wales, in particular the aim of providing quality, innovative care that reduces inappropriate variation and harm.

The aim of this report therefore, is to provide NHS Wales with the service-user perspective of miscarriage care in Wales and how it could be improved to reduce the harm being caused by poor-quality, inconsistent care.

FTWW is in a unique position, able to immediately seek its members' views and

represent their voices. As a result we have successfully compiled and contributed to similar service-user led reports for Welsh Government with the aim of improving the quality of care experienced by service users and developing appropriate policy. As always, the members of FTWW have provided a highly valuable evidence base, ensuring that this report gives an accurate and broad range of service-user perspectives of miscarriage care in Wales. We now look forward to working with you in making its recommendations a reality.

Deborah Shaffer
CEO FTWW

1. What is Pregnancy loss and Recurrent Pregnancy loss?

***1.1 Definitions**:* A pregnancy loss (miscarriage) is defined as the spontaneous demise of a pregnancy before the baby reaches viability. The term therefore includes all pregnancy losses from the time of conception until 24 weeks of gestation (1).

Up to 1 in 4 women will experience a miscarriage in their lifetime. Amongst those women who know that they are pregnant, it is estimated that 1 in 5 pregnancies end in miscarriage.

Miscarriages are often referred to as 'early' or 'late'. An Early miscarriage is a pregnancy loss that takes place within 13 completed weeks of pregnancy. A pregnancy loss between weeks 14 and 24 is referred to as a late loss. Late losses are much less common than early losses. Early losses account for over 50,000 admissions in the UK annually, which will equate to approximately 2500 admissions in Wales (2)

Miscarriage can cause both significant physical symptoms and pain, as well as considerable psychological distress. A recent study, 'Post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy: a prospective cohort study' published in the journal BJM Open, found that 4 in 10 women reported symptoms of Post-Traumatic Stress Disorder (PTSD) three months after pregnancy loss (3). In the UK, recurrent pregnancy loss (RPL) is defined as the loss of three or more consecutive pregnancies. It is important to note that recent guidance from The European Society of Human Reproduction and Embryology (ESHRE) has recommended that a diagnosis of RPL could be considered after the loss of two or more pregnancies.

Under the current UK definition, recurrent pregnancy loss will affect 1% of couples trying to conceive. It has been estimated that 1–2% of second-trimester pregnancies miscarry before 24 weeks of gestation (4). Late pregnancy loss and recurrent miscarriage are particularly distressing, with studies showing that a third of women attending specialist clinics because of miscarriage are clinically depressed (5).

2. Treatment of Early Pregnancy Loss

2.1 The Guidelines: The National Institute for Health and Care Excellence (NICE) has produced clear guidance outlining the appropriate treatment for women suffering from miscarriage and ectopic pregnancy. Welsh Government has an agreement in place with NICE, ensuring that all such clinical guidelines continue to apply in Wales beyond the devolution of health services.

The NICE guidelines state that care for women who are experiencing a miscarriage should be woman-centred, meaning that women should be treated with dignity and respect and all information and support should be provided in a sensitive manner. This very much reflects strategy in Wales, which aims to allow the public voice and control over their healthcare, empowering them through information, supporting shared decision making, choice, and peer support (6).

NICE guidelines state that healthcare professionals providing care for these women should be given training on how to communicate sensitively and in breaking bad news. Non-clinical staff working in settings where early pregnancy care is provided should also be given training on how to communicate sensitively with women experiencing early pregnancy complications.

Women should have the opportunity to make informed decisions about their care and treatment, in partnership with a healthcare professional. NICE guidelines identify key information that early pregnancy assessment services should provide, ranging from when and how to seek help if symptoms worsen to where to access support and counselling services.

Regional services should also be organised so that an early pregnancy assessment service is available 7 days a week for women with early pregnancy complications, where scanning can be performed and decisions about management made. Early pregnancy assessment services should accept self-referrals from women who have experienced recurrent miscarriage (7).

2.2 The Current Situation in Wales: Whilst the Welsh NHS is devolved from that of England, it still has obligations to follow European and NICE guidelines. At present, care for women experiencing miscarriage, recurrent miscarriage, and late miscarriage is inconsistent and does not reflect latest evidence of best practice.

Women who experience a miscarriage will receive their care in an Early Pregnancy Unit (EPU). Many EPUs in Wales are not open 7 days a week for women with early pregnancy complications. As a result, many women have to present to Emergency Departments in order to access care, or are left to miscarry at home with little or no help and support.

"My fiancé and I have suffered through four miscarriages and on our first we were told to go to A&E. The whole experience was awful and I swore I would never go through that again. On our last three losses we stayed at home and prayed for the best" (Anon)

Staff in Emergency Departments are unlikely to be trained in communicating sensitively with women experiencing early pregnancy complications. With an average of 2750 a day attending A&E departments in Wales in 2015/16 (8) this is adding an extra and unnecessary strain to already overstretched departments. Further evidence of this was present in recent reports of a Welsh woman experiencing a miscarriage waiting for seven hours in A&E, only to be sent home, untreated, at the end of this time (9)

For the women presenting to these departments it also means that they are likely to face a lack of appropriate facilities, private beds and time for personnel to spend with them when they are, in essence, experiencing pain, bleeding, and the distress of a bereavement.

These patients are also likely to categorise as non-emergency cases, meaning that they will face long waiting times, with nearly 34,000 patients spending over 12 hours in A&E Departments in Wales in 2015/16.

2.3 The Evidence: Through our petition and the FTWW community, we invited Welsh patients to share their experiences of the healthcare they received after experiencing a miscarriage.

"I hated having to be scanned with other people in the same waiting room smiling at their scan pictures. I was also put in a waiting area next to a couple with a tiny new-born baby sitting next to me" (AO, 28)

The responses we received demonstrate a worrying lack of sensitivity and respect shown by staff towards women having a miscarriage; many are not given the opportunity to make informed decisions about their care. One of the most common complaints centred on the fact that many women receive a scan alongside pregnant women who are attending their 12 and 20 week scans.

"'I turned up to the 10 week scan (for twins conceived by IVF) to be told that their hearts had stopped....I opted for medical management. I was informed that I would have normally been placed in a private room, but they had none available and I was placed on a gynaecology ward. When the meds started to work, the nurses were busy on the labour ward and my partners' mum had to assist me. I passed our twins in to a bedpan! The whole experience was the worst in my life, made even worse because I had no dignity or privacy during my miscarriage." (KLB, 37)

Women were also unhappy with the way that they were treated by some staff, how bad news had been communicated to them, and the lack of privacy that they experienced during their consultations. Information was provided by issuing printouts and leaflets, with couples being given little time to process this information or ask questions.

"'After a silent miscarriage I was given some information sheets on what I could do next – on a ward for the world to hear and then was pretty much sent on my way.' (Anon)

'When I had my miscarriage, I was called into a room to see the doctor as I had no idea what was happening. I was literally told you have suffered a miscarriage and that was that, I was ushered back into the corridor. No explanation, nothing! I have never felt so afraid in all my life." (DL)

By far the most common grievance raised was the lack of psychological support that women receive during and after experiencing a miscarriage. Women felt that treatment is based solely around the physical impact of miscarriage, not the emotional one.

"I received no further counselling (after two miscarriages)...and am now dealing with extreme anxiety." (Anon)

In the Parliamentary Review of Health and Social Care in Wales, it is recommended that care and support should be seamless, without artificial barriers between physical and mental health (10). Clearly, this is not currently happening when it comes to miscarriage care.

At best, women are handed leaflets with contact numbers for charitable organisations that may be able to help; at worst, women are made to feel as though they are an inconvenience and 'making a fuss about nothing'.

This lack of support has led to a number of women experiencing depression, anxiety, PTSD and the breakdown of their relationships. This has a potentially significant economic impact when considering the silent and unspoken associated costs of miscarriage, such as mental health referrals, psychiatric medication, lost days at work,

and benefit claims.

In terms of any existing children, these issues would undoubtedly constitute adverse childhood experiences, with all of their long-term implications already established by Public Health Wales amongst others (11).

"'Our first pregnancy in 2005/6 was a natural conception. I had zero support from my GP and was told that my body would fix itself and return to normal. Our second (pregnancy) was through IVF. I was offered counselling a very long time after...too late in fact... this resulted in the breakdown of our relationship." (EL, 38)

The evidence we have collected from Welsh patients suggests that NICE guidelines are not being followed in a worrying number of cases in Wales and this is building inequality into the system. Women experiencing a miscarriage often face a lack of sensitivity, dignity and respect. Information giving is poor and psychological care following a miscarriage is practically non-existent.

"'I have never been offered counselling or any support on the NHS. I have PTSD, but have had to pay privately to access appropriate support for this." (BSS, 33)

3. Treatment of Recurrent Miscarriage and Second Trimester Pregnancy Loss

3.1 The Guidelines on the Tests and Treatments for Recurrent Miscarriage: The most up to date and comprehensive guidance on recommended tests and treatments in incidences of recurrent pregnancy loss was published by The European Society of Human Reproduction and Embryology (ESHRE) in November 2017.

The Royal College of Obstetricians and Gynaecologists has also produced guidance on the tests and treatment in incidences of recurrent miscarriage and late miscarriage in the document 'The Investigation and Treatment of Couples with Recurrent First-trimester and Second-trimester Miscarriage' (RCOG). This document is accredited by NICE.

The care, investigations, and treatments available in the UK vary considerably, particularly when women suffering from recurrent or late pregnancy loss do not receive their care in dedicated specialist clinics. It is important to note that this lack of consistency leads to many couples moving from hospital to hospital in search of answers. Couples are also vulnerable to offers of tests and treatments that are not evidence-based (12).

3.2 Recurrent Pregnancy Loss (RPL) Clinics: Both RCOG and ESHRE guidelines agree that women who suffer from recurrent first-trimester pregnancy loss should be offered referral to a specialist recurrent pregnancy loss clinic (13). ESHRE guidelines suggest that this should include women with two or more pregnancy losses. (14).

A recurrent pregnancy loss (RPL) clinic is an outpatient clinic offering specialist investigations, support, and, if possible, treatment of couples experiencing RPL. Women who have suffered from one or more second trimester loss should also be referred to these clinics. Experienced personnel, comprising gynaecologists, fertility doctors and specialised nurses trained in performing ultrasound and with appropriate listening skills, should staff RPL clinics. There should also be trained and qualified staff to offer support tailored to the psychological needs of the couple.

Time should be given for clinicians to review patient history, answer questions, and propose a plan for investigations and, perhaps, treatment. A RPL clinic should have

excellent ultrasound provision and have close contact with the appropriate laboratories for further testing. Whilst treatment plans will vary from patient to patient, they should be appropriate to the individual based on age, fertility/sub-fertility, pregnancy history, family history, previous investigations and/or treatments. This should include discussion of wishes or views that the patient already has regarding the investigations she does or does not want (15).

Appropriate support and care in subsequent pregnancy/ies is also recommended by ESHRE, whilst RCOG guidance points out that data from several non-randomised studies has suggested that attendance at a dedicated early pregnancy clinic has a beneficial effect on pregnancy outcomes (16). This support may include access to the team either in person, by phone or online and additional / early scans if wanted.

RPL clinics should also give couples the opportunity to take part in clinical trials as this can feel like a positive step forward. Many areas that require further research are outlined in both the ESHRE and RCOG guidance documents.

3.3 The Current Situation in Wales: All guidelines relating to care for recurrent miscarriage agree that women who suffer from recurrent, first-trimester pregnancy loss, should be offered referral to a specialist recurrent pregnancy loss clinic. Unfortunately, in Wales, there are no specialist recurrent pregnancy loss clinics.

There are many specialist recurrent pregnancy loss clinics in England, including the world-leading Tommy's Centres for miscarriage research. Due to the policy of Patient Choice in England, any woman who receives her health care in England can request a referral to these clinics. In stark contrast, women who receive their health care in Wales have to accept whatever local care is available to them. Often, the general gynaecologists to whom women in Wales are referred have neither the interest nor expertise to provide these women with the care that they both need and deserve.

Cross-border health arrangements between England and Wales were a focus of the House of Commons Welsh Affairs Committee in 2015. A key recommendation of this committee was that England and Wales need to maintain close links to ensure that patients receive the treatment they need, regardless of their country of residence (17).

The then Minister for Health in Wales, Mark Drakeford, stated that patient needs must come first and made a commitment not to allow the border to become a barrier. In North, Mid and South Wales, this commitment is not being met and the border is a

serious barrier to women being able to access quality, specialised care.

3.4 North Wales: Betsi Cadwaladr University Health Board (BCUHB) in North Wales does have an agreement in place with Liverpool Women's Hospital for local women to access their RPL clinic. However, these women can only gain the necessary referral with the agreement of their local consultant, making this process unreasonably lengthy and inefficient.

3.4.1 Long Waiting Times: The process is lengthy due to the long waiting times for gynaecology appointments in Wales. This is often exacerbated by the fact that referrals for recurrent miscarriage are deemed non-urgent, meaning that some appointments are repeatedly cancelled for cases that are more urgent.

> ***"My appointment was cancelled three times in total, twice due to emergency cancer clinics needing to take place and on the third occasion due to an admin error. I completely understood and accepted that the emergency clinics should take priority, but this only served to further diminish my own experiences – it made me feel very isolated and as though my situation didn't really matter to anyone." (Anon)***

Assuming the local consultant knows of the referral pathway to Liverpool Women's Hospital and is willing to make the referral, once a patient finally attends their appointment with a local consultant, she will have to join a second waiting list. Hospitals in England are only obliged to meet Welsh targets for waiting times - which means Welsh women waiting longer than their English peers. This entire process builds both variation and harm into the system.

Variation in patient care and excessive waiting times could be easily avoided if GP's in North Wales were able to refer patients directly to Liverpool Women's Hospital, if that is where they would prefer to be treated.

3.4.2 Inefficient Referral Processes: The system of referral to Liverpool Women's Hospital is also very inefficient. Referral directly to Liverpool Women's hospital from a GP would go some way towards relieving the strain on over-stretched local gynaecology departments. Given that a good many consultants in North Wales will only be able to

offer their patients a referral to Liverpool, a valuable consultation has been unnecessarily taken up.

However, by way of providing some interim measures, local consultants may run basic blood tests on recurrent miscarriage patients. Many of these patients are then referred on to Liverpool and the tests repeated. This seems an extremely wasteful use of NHS resources.

Further evidence from patients reveal that some consultants are unaware of the referral pathway to Liverpool Women's Hospital, meaning that women have to fight to access the care to which they are entitled at a very difficult and upsetting time.

"I live in North Wales and was told time and time again that I couldn't be referred outside of Wales. I finally got my GP to refer me to a different hospital in my Health Board, and it was there that I was finally able to get a referral on to Liverpool." (Anon)

Whilst women in North Wales do have access to Liverpool Women's Hospital, we also collected evidence suggesting that the distances involved in attending clinics in Liverpool can make accessing this care very difficult for some, particularly those in the West of the region.

"I have now had 8 losses and the travel to the clinic in Liverpool costs a small fortune. I'm just grateful to be being tested, and am happy where I'm being seen, but it could have saved me a lot of years and heartbreak if there had been help for us locally." (AO, 28)

Long journeys in order to access high quality care is very much at odds with the recommendations made in the Parliamentary Review of Health and Social Care in Wales. The recommendations state that 'Care should be organised around the individual and their family as close to home as possible, be preventative with easy access and of high quality' (18). Clearly, at present, women in North Wales suffering from recurrent

miscarriage are unable to access high quality care close to home.

3.5 Mid and South Wales: As far as we can establish, none of the Health Boards in Mid and South Wales have referral pathways in place that will allow women living in these areas to access specialist RPL clinics across the border. For these women, their only chance of accessing specialised care is through the completion of an Individual Patient Funding Request (IPFR). This is a time consuming and complex process that is reliant on a consultant being willing to support the IPFR.

Whilst FTWW is aware that the IPFR process was reviewed between 2016 and 17, as the only women's patient-led health and equality organisation in Wales, we were concerned that a) we were never informed of the review taking place , b) that there was only one patient representative on the review panel, c) that there were no women on the review panel, and, d) that the focus of the review seemed to be on access to medicines as opposed to specialist service provision.

3.6 Second Trimester Pregnancy Loss: Women in Wales who experience a second trimester loss face the same barriers in accessing specialised care as those who suffer from recurrent miscarriage. Late miscarriage has more in common with preterm birth and therefore it is important that women who experience a late loss have access to a high-risk care centre. The evidence we have collected suggests that women who have experienced a late loss also face a number of additional issues in accessing appropriate care, including long delays for follow-on appointments, and further appointments being held in inappropriate locations, such as Antenatal Units.

"Following the birth of our daughter, Rose, we were asked to attend a follow up appointment. We found it unfathomable that this appointment was held in the Antenatal Unit. The waiting room was filled with pregnant women. The receptionist made the assumption that we were there for a scan and asked us about this several times, despite us having handed her a letter stating the reason for our visit – for a couple who had just lost their baby at 22 weeks this was totally devastating" (SD, 31)

Further to this, feedback from service users also identified issues with the procedures in place for conducting 20 week scans.

A 20 week scan is an anomaly scan and therefore it is possible that a problem is identified with the way the baby is developing at this appointment. In these circumstances, a clinician should be available to provide a second opinion. However, this is not always happening in Welsh hospitals, leaving parents to go through an agonising wait to find out if there are serious problems, which can have devastating consequences.

A 20-week anomaly scan should not be completed if the provisions are not in place to manage an identified anomaly. In addition to this, a dedicated pathway is also needed to deal with problems identified at twenty-week scans.

In his response to our petition, Vaughan Gething, the Cabinet Secretary for Health, Wellbeing and Sport recognises that 'Stillbirth and miscarriage can be devastating for the baby's parents and for the wider family members.' (19)

In Wales, the current system is that each Health Board has its own bereavement service, which supports not only the parents but also wider family members. However, this is not happening consistently and some parents, who have gone through the devastating experience of a second trimester loss, are not receiving appropriate bereavement support in a timely manner.

3.7 Research: A further benefit of care being delivered in a dedicated recurrent miscarriage clinic, is that patients can be given the opportunity to take part in research trials.

Many of the current research trials relating to miscarriage are led by the Tommy's Clinics for Miscarriage Research. Hospitals around the country will then support this research by recruiting patients to take part in the trials and sharing their findings with the lead clinician.

There is only one hospital in Wales which has taken part in any research trials relating to miscarriage, that hospital being Singleton Hospital in Swansea (20). Singleton Hospital has taken part in two research trials, Alife2 and the MifeMiso trial.

It is an encouraging start to see a hospital in Wales taking part in research trials relating to miscarriage; however, it is important to note that there are many trials in which Singleton Hospital has not participated. Furthermore, with Singleton Hospital being the

only hospital in Wales contributing to any research relating to miscarriage, the outcome is that the vast majority of Women in Wales will be unable to take part in any research trials. Welsh patients are clearly being disadvantaged by this.

ESHRE guidelines point out that taking part in research trials can make patients feel as though they are taking a positive step forward, for both themselves and others (21). Furthermore, through The Well-being of Future Generations Act, Welsh Government has committed to creating a society in which people's physical and mental well-being is maximised and in which choices and behaviours that benefit future health are understood (22). The limited participation in innovative research into miscarriage means that NHS Wales is negatively affecting the well-being of future generations. This inevitably results in Wales always being one-step behind in terms of latest treatments and strategy.

4. Recommendations

1: In accordance with NICE guidelines, measures should be taken to ensure that Early Pregnancy Assessment Services are available regionally 7 days a week for women with early pregnancy complications.

Welsh Government has an agreement in place with NICE, ensuring that all clinical guidelines continue to apply in Wales beyond the devolution of health services. In order to meet this agreement it is important that immediate steps are taken to make Early Pregnancy Assessment Services available 7 days a week. This will also reduce the number of women presenting to A&E departments where they are not receiving appropriate care and support. GPs, Midwives, A&E departments and Emergency Doctors/111 Services should be able to make a referral to Early Pregnancy Assessment Services quickly and easily.

2: A review of Early Pregnancy Assessment Services should be conducted to ensure that women who attend these units are being cared for in a way that is consistent with NICE guidelines and is appropriate for the distressing life event that they are experiencing.

The evidence that we have gathered strongly suggests that many Early Pregnancy Assessment Services in Wales are not consistently providing care that is in line with NICE guidelines, and that this is causing too many women to experience substandard care. Particular attention should be paid to the issues surrounding privacy, staff training and scanning facilities, which have been raised in this report.

3: A system should be put in place to ensure that women are receiving a greater level of psychological and emotional support during and after a miscarriage.

The evidence that we have collected has clearly demonstrated that the vast majority of women do not feel that the current level of psychological support is sufficient after suffering a miscarriage. At the very least, women should be receiving follow up calls from either a trained nurse or their GP. These calls should focus on how women are coping with their loss and advise them of the support available should their experience be having a detrimental impact on their mental health. At least two follow up calls at set intervals would be necessary to properly support patients.

4: Two dedicated Recurrent Pregnancy Loss Clinics should be opened in Wales.

In order for Welsh Government to best meet its aim of providing quality health care close to home, serious consideration should be put into opening two dedicated recurrent pregnancy loss clinics, one in North Wales and one in South Wales. Tommy's would be prepared to support this development of services by offering advice and support from the Tommy's Miscarriage Centres.

If funding dictates there be only one, South Wales could be prioritised only if existing agreements with Liverpool Women's Hospital be maintained and strengthened in North Wales. For women in Mid-Wales, a pathway to one or the other, depending on their location, must be consistently implemented.

The opening of one or more dedicated RPL clinics should also give women in Wales the opportunity to be involved in research, particularly as Tommy's would offer any new dedicated recurrent miscarriage clinics in Wales their support in joining the Tommy's trial network. This would bring NHS Wales up to date with latest treatment strategies which will in turn have a positive impact on future generations.

5: Primary care providers should be able to refer patients directly to a dedicated RPL clinic. An easily accessible resource delineating referral pathways should be made widely known to GPs and patients.

This is vital to ensure that all women in Wales have equal and fair access to specialised services. GPs should be able to make this referral, regardless of whether or not it is out of area. Referral pathways should be made clear and known to both GPs and patients. An online resource listing all specialist services designated for the various health conditions / needs would be an excellent may of making this information easily accessible to all, ensuring equity of access and reducing variation and harm.

6: A diagnosis of Recurrent Pregnancy Loss should be considered after the loss of two or more pregnancies.

The most up to date, evidence-based research on recurrent pregnancy loss has been produced by ESHRE who clearly recommend that a diagnosis of RPL should be considered after two or more pregnancy loses.

This is particularly important as it will facilitate 'research, shared decision making and psychological support to couples' (23). Changing the diagnostic guidelines will also allow for testing to take place for some of the more common, treatable causes of RPL at an earlier stage. This should prevent many women from experiencing a third miscarriage unnecessarily whilst also reducing both the personal and economic costs associated with that incidence.

Further support for this approach is provided in the ESHRE guidelines, which give clear recommendations on investigations that should be carried out after 2 pregnancy losses, allowing for a clinical decision to be made on tests that should be postponed. This means that couples can be offered referral without the risk of inappropriate or premature tests being carried out wastefully.

7: To ensure consistency of care, all consultants treating women for recurrent miscarriage in Wales should use the ESHRE guidelines to determine the appropriate investigations and treatments for an individual patient.

NHS Wales has committed to the principles of prudent healthcare. Central to this is the aim of reducing inappropriate variation, using evidence-based practices consistently and transparently.

As an overarching body, NHS Wales is therefore supposed to create equality, however giving the seven health boards the autonomy to do different things is inevitably causing variation, which in turn is causing harm to patients.

By using the most up to date, evidence-based guidelines produced by ESHRE, a much greater degree of consistency of care can be achieved for women experiencing recurrent or late miscarriage. This is particularly important as costs associated with traveling to a dedicated RPL clinic may make this service inaccessible for some women. However, consistency and high quality care that is delivered close to home is still achievable if all clinicians treating women for recurrent miscarriage are using the ESHRE guidelines to determine the appropriate investigations.

8: All women diagnosed with recurrent pregnancy loss should be offered support, including a reassurance scan, in subsequent pregnancies.

Pregnancy following multiple losses is an extremely anxious time for parents. The stress associated with this may be detrimental to the pregnancy, and also have a negative impact on existing children.

A system is needed to ensure women are offered appropriate support in pregnancy after loss. This approach is clearly supported by the RCOG guidance, which states ‘Women with unexplained recurrent miscarriage have an excellent prognosis for future pregnancy outcome without pharmacological intervention if offered supportive care alone in the setting of a dedicated early pregnancy assessment unit.’(24)

The economic arguments for avoiding pharmacological intervention are obvious. There are also indirect economic benefits in providing dedicated psychological support, most

notably that it will contribute to a reduction in the silent and unspoken associated costs of miscarriage, such as depression, anxiety, lost days at work and relationship-breakdown.

ESHRE guidelines also strongly urge support in pregnancy after loss, stating that 'With or without specific treatment, couples value a plan for the pregnancy after RPL, with the care of a dedicated and supportive individual physician or team'. (25)

9: Recommend that recurrent miscarriage is taken out of the hands of individual health boards and is instead commissioned by WHSSC so that we have consistency and GPs and Secondary Care providers can know referral pathways.

This would go some way to ensuring equity, consistency and high quality care for women across Wales. The current system, where individual health boards are able to choose whether or not to prioritise - and fund - pathways of their own devising is proving ineffective and harmful for patients.

10: Twenty-week anomaly scans should not be conducted if provisions are not in place to manage an identified anomaly. A dedicated pathway is also needed to deal with problems identified at twenty-week scans.

It is important that provisions be in place to manage an identified anomaly at a 20 week scan in order to prevent further distress being caused for parents who are already facing a devastating diagnosis. Sensitive and supportive treatment is of the utmost importance in these circumstances. The only way this can be guaranteed is through the establishment of a dedicated pathway to deal with identified problems.

11: Anyone who has experienced a late miscarriage should be referred to a high-risk care centre in their next pregnancy

It is essential that parents who experience a late miscarriage are able to access a high-risk care centre. Clear referral pathways should be in place to ensure that all women who experience a late loss have access to one of these centres, regardless of their location. Where this care is not easily accessible in Wales, clear pathways should exist to allow referral across the border.

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25) https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Recurrent-pregnancy-loss.aspx, page 18.