

North West Regional Early Onset FGR Integrated Care Pathway

This integrated care pathway is for use in the management of FGR pregnancies diagnosed before 32 weeks' gestation.

Version 1.0
March 2019

Booklet to be kept with handheld notes



North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	1 of 27

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Version control

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Ed Johnstone

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North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	2 of 27

Contents

1	Patient Identifier and Demographics	4
2	Communication, Principles and Management	5
3	Information on Fetal Growth Restriction	6
3.1	Baby's movements	6
3.2	Other sources of information & support	7
3.3	Organisations that you may find helpful:	7
3.4	Words you may hear used;	7
4	Diagnosis checklist for this NW eFGR Integrated Care Pathway	9
5	Managing an eFGR pregnancy and when to refer	10
6	Counselling at Diagnosis	10
6.1	Survival Statistics (General Information)	10
7	Investigations	12
7.1	Chromosomal abnormalities:	12
7.2	Infection:	12
7.3	Maternal Conditions:	12
8	Neonatology Counselling	13
9	Delivery Discussion	14
10	Surveillance of the FGR Fetus & Maternal Monitoring	15
10.1	Active Management	15
10.2	Maternal Surveillance	15
10.3	Conservative management	16
10.4	Computerised CTG (cCTG)	17
11	Gestational Age Indication for Delivery	19
11.1	Delivery Indication by Gestation at the Time of Assessment	21
12	Visit Record	22
13	Scan Reports	24
14	Maternal Postnatal Discharge Check list	25
15	Follow up Visit Prompt List	26
16	FGR Research	27

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	3 of 27

1 Patient Identifier and Demographics

Surname	
First Name	
Hospital No.	
Date of Birth	
Address	
Contact Tel No	
Consultant	
GP Name	
GP Address	
Interpreter required	Y/N Language
Partners Name	
Local Unit	
Local Contact Name	
Local Contact No.	

2 Communication, Principles and Management

Communication	Principles	Management	Page
With parents;	Ensure privacy	Diagnosis of eFGR	9
- answer questions openly and honestly	Involve both parents where appropriate	NW eFGR referral	9
- if you do not know the answer say so and find someone who can answer the question	Use empathic and unambiguous language	Counselling at Diagnosis	11
	Respect culture and religious beliefs	Investigations after diagnosis	12
With colleagues;	Provide written information	Neonatal Counselling	13
- provide relevant and consistent advice	Allow time for decision making	Delivery Discussion: Conservative vs. Active	14
		Pregnancy Surveillance:	15
	Repeat information	Active management	15
		Conservative management	16
		cCTG	17
	Promote continuity of care and carer	Gestational Age based Indications for Delivery	19
		Delivery Indication Algorithm	21
	Involve experienced staff	Visits	22
	Inform relevant care providers	Scan reports	24
	Co-ordinate referrals	Information for Parents	6
		Postnatal Care and Investigations	26
		Plan for future pregnancies	26

Accountability Sheet

Signature	Print	Designation

3 Information on Fetal Growth Restriction

We understand that being told that your baby has Fetal Growth Restriction (FGR) and will be born prematurely is devastating. Living with the uncertainty of a positive birth outcome is a highly anxious time. You may feel alone and that you don't know anyone else who this has happened to. We care for many women who have pregnancies complicated by FGR, we will support you and your family and answer your questions.

FGR is sometimes also IUGR (Intrauterine Growth Restriction), both terms refer to a condition where the baby is much smaller than expected. This is because the baby's growth has slowed down and can eventually stop. Please be reassured that in most cases nothing you have done, or could have done differently, has caused this to happen.

There is a lot of information to take in at your first appointment and everything can feel very uncertain. It is normal to feel confused, scared and anxious after being told that your baby has growth restriction. We will give you more information at each appointment and together we will take your pregnancy scan by scan.

You may be faced with making a very difficult decision about how to proceed with your pregnancy, only you can decide what is best for you and your family. This can be very challenging but the team caring for you will support you, you can ask as many questions as needed.

Living with FGR will have an emotional impact on you and your family, there is no right way to feel, use the support around you including the team caring for you.

These things can help:

- Write down any questions as they come into your head – there are no silly questions and we understand that this is all new to you. You can call your named midwife if you have any questions or bring them to your next appointment.
- Some of the things we need to explain are quite complicated and we apologise if we don't always explain properly the first time we try. Please feel free to ask us to explain anything again, as many times as you need.
- We can provide a letter for your employer and your partner's employer to explain that you will need to attend the hospital frequently for additional appointments and that your baby will be born prematurely.
- If you are coming to the hospital 3 or more times a week we can help with parking or travel expenses.

3.1 Baby's movements

It is important to be aware of your baby's pattern of movements and to inform the maternity unit caring for you immediately if you notice any change in the pattern.

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	6 of 27

3.2 Other sources of information & support

It is natural that you will want to find out as much as possible about FGR and how it will affect you and your baby; however, some of the information available on the internet can be very frightening and isn't always accurate. Please ask the team caring for you if you have any questions.

3.3 Organisations that you may find helpful:

Tommy's – The Baby Charity	www.Tommys.org.uk	Helpline: 0800 0147800
Provide evidence based, expert and user-led, accessible pregnancy information to support expectant parents in understanding what they can do to support a safe and healthy pregnancy.		
ARC Antenatal Choices and Results	www.arc-uk.org	Helpline: 0845 0772290
Support for parents whose baby is diagnosed with a fetal abnormality in pregnancy		
Bliss for babies born sick or premature	www.bliss.org.uk	Helpline: 0808 010322
Family support helpline offering guidance and support for expectant parents of premature and sick babies		

3.4 Words you may hear used;

Fetal Growth Restriction (FGR): where baby is much smaller than expected due to slow growth in the womb, the baby may eventually stop growing all together.

Intrauterine Growth Restriction (IUGR): where baby is much smaller than expected due to slow growth in the womb, the baby can eventually stop growing all together.

Doppler: Doppler ultrasound measures the movement of blood in vessels. The blood flow is often measured in several places to monitor baby's wellbeing in the womb, changes in these measurements can indicate when it may be time for baby to be born, this is usually earlier than expected.

Umbilical Artery Doppler (UAD): measurement of blood flow through baby's umbilical cord

Middle Cerebral Artery Doppler (MCA): measurement of blood flow through an artery in baby's brain.

Ductus Venous (DV): blood vessel connecting the umbilical vein to the baby's heart. Can be used as an assessment of baby's wellbeing in certain circumstances.

Uterine Artery Doppler: the measurement of blood flow through your uterine arteries which are the main blood vessels that supply blood to your womb (or uterus). The presence of a 'notch' in one or both uterine arteries represents an abnormal waveform and suggests that there may be a problem with the blood supply to the placenta.

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	7 of 27

Liquor Volume or Amniotic Fluid Index: the measurement of the water also known as liquor or amniotic fluid surrounding your baby.

Computerised CTG: An assessment of baby's heart rate over a period of time to check baby's wellbeing.

Neonatal Intensive Care Unit (NICU): a specialist unit providing intensive care for sick or premature newborn babies

A diagnosis of an eFGR infant is an emotionally and physically demanding time for families. Being cared for and having access to a known /dedicated team can be helpful for families. It is helpful for families to have the ability to contact their dedicated team directly:

Named Midwife

- Contact No

Named Consultant

- Contact No.

Regional Centre information

- Directions/Map

Car parking exemption or assistance with travel expenses

- Information / permit given ____/____/____ (date)

Offer a letter of support for employers explaining the increased frequency of appointments and early delivery.

Letter provided____/____/____(date)

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	8 of 27

4 Diagnosis checklist for this NW eFGR Integrated Care Pathway

Needs to meet criteria 1 **AND** either criteria 2 or 3

1. Gestation at diagnosis: before 31+6 weeks

AND

2. Estimated Fetal Weight <3rd centile or Abdominal Circumference <3rd centile

OR

3. Estimated Fetal Weight (EFW) < 10th centile with Umbilical Artery Doppler
PI > 95th centile or Absent or Reversed End Diastolic Flow

Initial Ultrasound report

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	9 of 27

5 Managing an eFGR pregnancy and when to refer

Once diagnosed, eFGR pregnancies require regular maternal and fetal assessment and appropriate postnatal care including:

- ultrasound measurement of fetal growth
- ultrasound Doppler measures of the Ductus Venosus (DV)
- computerised CTG (cCTG)
- tertiary (level 3) NICU facilities

6 Counselling at Diagnosis

Discussion of possible cause/pathology;

- Placental
- Chromosomal
- Infection
- Constitutional

6.1 Survival Statistics (General Information)

Based on eFGR cases managed through St Mary's Hospital since June 2009, 71% of eFGR pregnancies end in a live birth, and 29% unfortunately end in a stillbirth. Of those born alive, 23% die in the days or months following delivery.

Survival rates for infants alive at the start of labour, less than the 10th centile

The figures below are based on work that was performed in the late 1990s¹, and updated figures are awaited. Neonatal care has advanced greatly over the past 20 years and more premature babies are surviving now than previously², therefore we would expect the updated figures to be better than those quoted here.

Gestation at delivery	Predicted survival (alive at the start of labour)
<26 weeks	43%
28 weeks	63%
30 weeks	86%
32 weeks	93%

¹ Draper E., Manktelow B., Field D., James D. Prediction of survival for preterm births by weight and gestational age: retrospective population based study. BMJ 1999; 319:1093-1097

² Moore T., Hennessy E.M., Myles J., Johnson S.J., Draper E.S., Costeloe K.L., Marlow N. Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. BMJ 2012; 345:e7961

Discussion regarding viability thresholds

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	11 of 27

7 Investigations

7.1 Chromosomal abnormalities:

FGR secondary to chromosomal abnormalities is more common if; structural abnormalities are identified, 1st/2nd trimester screening for aneuploidy is high risk, or if Doppler abnormalities are absent in severe FGR. This will obviously have consequences for the likely postnatal prognosis of the child. Chromosomal abnormalities can be tested for by amniocentesis, the principle risk of this test is miscarriage (which is nationally 1% above the background rate for that gestation).

7.2 Infection:

FGR secondary to infection is more common in cases with; associated fetal abnormalities (especially of the fetal brain), where FGR occurs before 23 weeks or where there has been a history compatible with maternal infection. Test for Toxoplasma, Rubella, Cytomegalovirus (CMV). In the case of equivocal results, it can be helpful to check the IgM and IgG status on the stored booking serum sample.

7.3 Maternal Conditions:

FGR is frequently associated with preeclampsia and therefore a BP and urine dipstick should be performed at every visit. Where proteinuria is present, quantify using urinary protein creatinine ratio (confirm absence of infection and repeat if between 30 – 50mg/mmol). Consider the possibility of underlying renal disease or chronic hypertension.

Test	Date Offered	Date Accepted	Result (Date)
Amniocentesis			
TORCH/CMV			
uPCR			
sFlt/PIGF test (if available)			

Discussion of appropriate investigation with parents

Date _____

Name _____

Designation _____

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	12 of 27

8 Neonatology Counselling

A detailed discussion regarding anticipated care on NICU, potential complications and prognosis would usually be provided by a neonatology consultant or member of the NICU team.

Offered ☐

Accepted / Declined (delete as appropriate)

Documentation of neonatal discussion:

Date _____

Name _____

Designation _____

Neonatal Tour offered YES/NO

Date & Time arranged: _____

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	13 of 27

9 Delivery Discussion

Discussion regarding viability thresholds (when weight EFW<500g and gestation<26 weeks)

Pregnancy Management options;

- **Conservative Management**
 - Monitoring at a frequency requested by parents
 - Induced vaginal delivery when intrauterine death occurs
- **Active Management**
 - Regular surveillance (maternal and fetal)
 - Pre-delivery management – steroids & magnesium sulphate
 - Delivery by Caesarean section
 - A duration of stay on NICU
 - Risk of Stillbirth or Neonatal Death
- **Termination of Pregnancy**

Further delivery details discussed

Date _____

Name _____

Designation _____

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	14 of 27

10 Surveillance of the FGR Fetus & Maternal Monitoring

10.1 Active Management

The suggested frequency of monitoring (see figure 1, page 16) represents the recommended surveillance for women with eFGR affected pregnancies following active management and EFW>450g at 28⁺⁰ weeks or >500g at 26⁺⁰ weeks.

This surveillance pathway is based on optimizing the timing of delivery for the fetus. However, many of these eFGR pregnancies will be due to preterm preeclampsia and as such may warrant more frequent monitoring of BP and blood tests for maternal disease surveillance.

10.2 Maternal Surveillance

Maternal wellbeing should be assessed at every visit (symptoms, BP and urine). Once proteinuria is confirmed (PCR >50mg/mmol with a negative MSSU) protein quantification does not need to be repeated, and should not be used as a measure of deterioration. If pre-eclampsia is diagnosed/suspected, then blood tests should be performed twice weekly and BP should be maintained within a target of 130-150/80-100mmHg. If the fetal condition is stable prior to 32 weeks, antihypertensive medication should be increased to control BP rather than triggering delivery. A diagnosis of pre-eclampsia does not mandate delivery before 34 weeks unless;

- thrombocytopenia (platelets <100 x10⁹/L)
- abnormal renal function (new onset Creatinine >100mmol/L)
- abnormal liver function (ALT/AST > double normal unit range)
- severe hypoalbuminaemia (albumin <15g/L) severe or increasing proteinuria is not an indication to deliver in isolation

A diagnosis of pre-eclampsia should not prompt steroid administration unless there is a maternal or fetal indication for delivery (see flow chart, page 21).

In women with pre-existing hypertensive or renal disease, thresholds for BP and blood test abnormalities may need to be adjusted, and LMWH considered if proteinuria >300mg/mmol, in these cases tertiary centre input may be helpful.

Where possible AN appointments and scanning should be combined to minimise attendances and pregnancies should be supervised/co-ordinated by a named provider in your Local eFGR Network Centre. It may be necessary to offer inpatient stay if attending the appointments is logistically difficult or at maternal request.

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	15 of 27

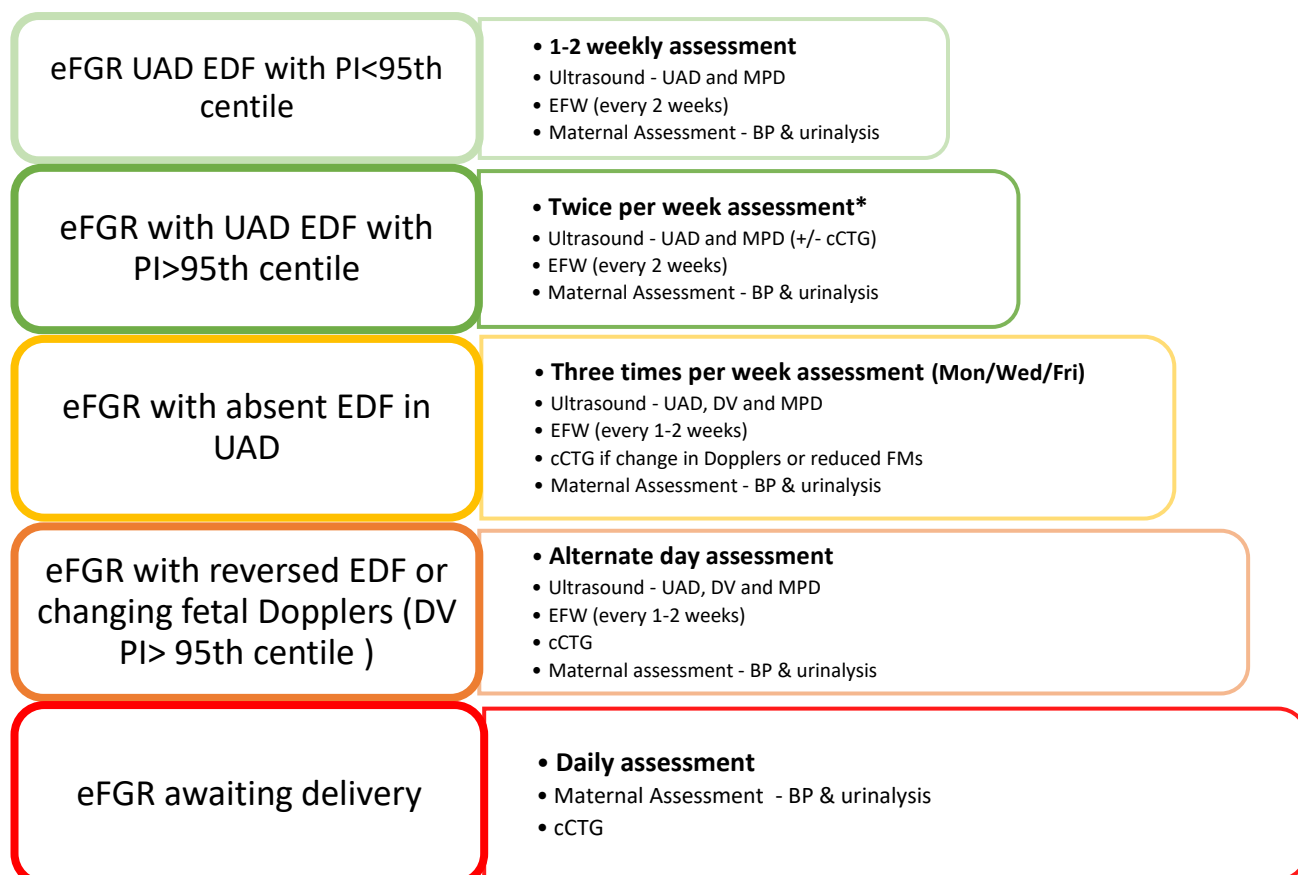


Fig 1: Frequency of monitoring

* if UAD PI returns to <95th centile then surveillance can be stepped down to 1-2 weekly assessment.

10.3 Conservative management

If the estimated fetal weight is <500g before 26⁺⁰ weeks' gestation, or <450g at 28⁺⁰ weeks' gestation or above, the chances of healthy survival of the infant is remote. Conservative management (as below) is advocated, except where after detailed counselling of the parents (including neonatal counselling) the parents wish for active management. In these situations, please follow the care plan.

Conservative management includes;

- Maternal assessment for the early diagnosis of conditions related to eFGR such as pre-eclampsia (blood pressure and urine)
- Weekly scan for viability
- Estimate fetal weight weekly to assess whether viable weight has been achieved (not to assess growth trajectory)
- Dopplers may be recorded for counselling purposes, but not to instigate delivery
- Not for cCTG
- Not for delivery for fetal reasons

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	16 of 27

10.4 Computerised CTG (cCTG)

cCTG calculated STV is based on the Dawes–Redman algorithm, and is the only objective measure of fetal heart rate that has been validated against invasive testing in fetal hypoxemia and acidemia. Simple visual interpretation of a regular CTG may not be sufficiently informative or sufficiently objective to provide reassurance about the fetal condition. cCTG will also detect repetitive fetal heart-rate decelerations.

cCTG assessment should be performed until Dawes-Redman criteria met, or for a maximum of 60 minutes. The machine first evaluates for criteria at 10 minutes and repeats this analysis every 2 minutes. The cCTG can be stopped once the Dawes-Redman criteria have been met. If the cCTG continues to the full 60 minutes, it will report 'CRITERIA NOT MET' and give a justification. In these eFGR pregnancies, if the calculated STV value is above the specified safety net criteria for that gestation (>2.6ms if <29 weeks, or >3.0 at 29 weeks and beyond) CTG monitoring can be discontinued. A cCTG STV below the gestation safety net is a trigger to prepare for delivery.

All cCTGs should be considered in relation to the gestation and clinical situation.

cCTG may fail to meet criteria for a number of reasons beyond STV (see table below). In these situations, consider a repeat cCTG or obstetric consultant review.

Dawes Redman CRITERIA NOT MET codes:

1. Basal Heart Rate outside normal range (110 – 160)
2. Large decelerations
3. No episodes of high variation
4. No movements and fewer than 3 accelerations
5. Baseline fitting is uncertain
6. Short-term variation is less than 3ms
7. Possible error at end of the record
8. Deceleration at the end of the record
9. High-frequency sinusoidal rhythm
10. Suspected sinusoidal rhythm
11. Long-term variation in high episodes below acceptable level
12. No accelerations

Should there be spontaneous repeated unprovoked decelerations which may warrant a plan for delivery the cCTG should be repeated after a 1-hour break. If the spontaneous repeated unprovoked decelerations persist, discuss with the named care provider or the Obstetric Consultant on-call for Delivery suite. In the presence of accelerations, smaller decelerations are of uncertain significance and should not trigger delivery, particularly without fetal lung maturation. Observation of continuous

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	17 of 27

CTG tracing over a 24-hour period has shown that before 32 weeks, both normal and FGR babies show decelerations, but these do not seem to have any immediate bearing on the pregnancy outcome.

The use of cCTG in eFGR is based on the TRUFFLE randomised controlled trial³⁻⁴. In TRUFFLE the frequency of cCTG assessment was not specified. cCTG should be performed if there is a further deterioration in fetal wellbeing or maternal concern, such as;

- **Reduced fetal movements**
- **New oligohydramnios**
- **Increase in Ductus Venosus (DV) PI**

³ Ganzevoort W, Mensing Van Charante N, Thilaganathan B, Prefumo F, Arabin B, Bilardo CM et al. How to monitor pregnancies complicated by fetal growth restriction and delivery before 32 weeks: *post hoc* analysis of TRUFFLE study. *Ultrasound Obstet Gynecol* 2017;49:769-777

⁴ Wolf H, Arabin B, Lees C, Oepkes D, Prefumo F, Thilaganathan B et al. Longitudinal study of computerized cardiotocography in early fetal growth restriction. *Ultrasound Obstet Gynaecol* 2017;50:71-78

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	18 of 27

11 Gestational Age Indication for Delivery

If decision is made for ACTIVE MANAGEMENT a **plan for delivery** should be made on maternal condition or if delivering on fetal grounds based gestational specific criteria, please see algorithm (page 21).

If there are concerns regarding maternal condition which indicate a consistent deterioration justifying preterm delivery this should ALWAYS override the fetal wellbeing assessment. Approximately 1 in 3 eFGR pregnancies will be delivered on maternal grounds, most commonly preeclampsia.

On meeting a criterion for delivery in the algorithm;

1. Admit
2. IM Dexamethasone or Betamethasone 12mg (two doses 12 hours apart) for fetal lung maturity
3. Aim for delivery 12 - 24 hours after 2nd dose of corticosteroids
4. Delivery is usually by Caesarean section (<34 weeks with abnormal UAD PI or absent/reversed EDF)
5. Inform Delivery Unit to arrange Magnesium Sulphate (below 34 weeks' gestation) to be given for at least 4 hours prior to delivery
6. Inform NICU co-ordinator
7. Inform Consultant on-call
8. Consider transfer out if delivery is delayed by more than 24 hours

The closer to birth the corticosteroids are given, the greater the benefit to the infant; in particular steroid-delivery intervals >7 days are associated with reduced benefit from steroid administration⁵. Review of data from 100 cases of early onset FGR from the Manchester Placenta Clinic since 2009 has shown a median interval from UAD absent EDF to delivery of 17 days (only 9 delivered within 24hours, and 71 infants delivered after more than 7 days). Thus, antenatal steroids should not be administered without a plan to deliver in the next 48 hours. There is also evidence that there is benefit in giving antenatal steroids for fetal lung maturation even if delivery cannot be delayed to receive a full course of treatment⁶.

If the umbilical artery EDF remains present, pregnancies with EFW <5th centile should be delivered by 37 weeks (see SGA guidelines). In these pregnancies induction of labour may be appropriate.

⁵ Wilms FF, Vis JY, Pattinaja DA, Kuin RA, Stam MC, Reuvers JM et al. Relationship between the time interval from antenatal corticosteroid administration until preterm birth and the occurrence of respiratory morbidity. Am J Obstet Gynecol 2011;205(1):49.e1-7

⁶ Norman M, Piedvache A, Borch K, Drasbek Huusom L, Edstedt Bonamy A, Howell EA et al. Association of short antenatal corticosteroid administration-to-birth intervals with survival and morbidity among very preterm infants. Results from the EPICE cohort. JAMA Pediatr 2017;17(7):678-698

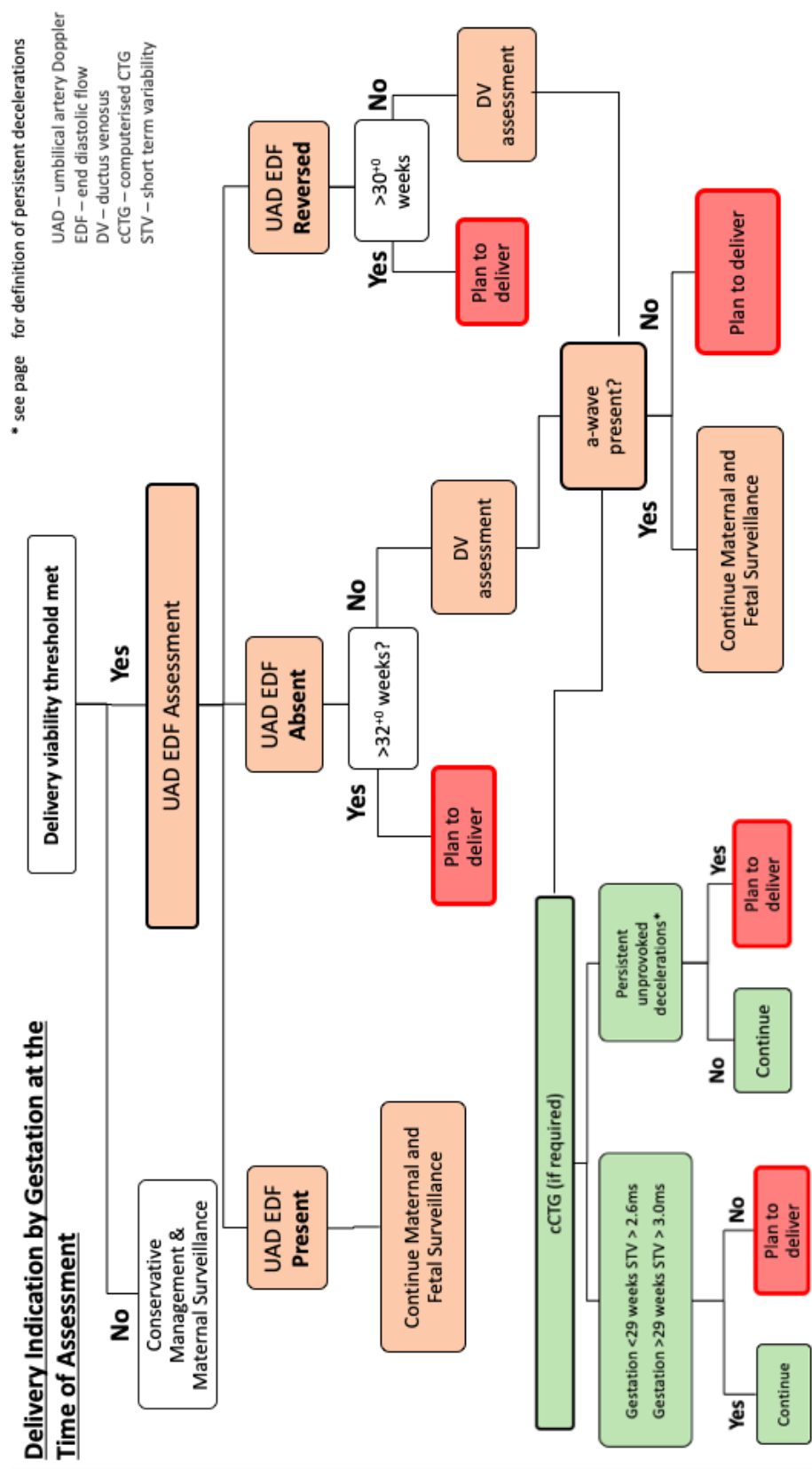
North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	19 of 27

Using the indication for delivery algorithm (page 21)

- orange boxes represent scans
- green boxes represent cCTG assessment, the safety net STV value changes at 29 weeks' gestation
- if in any arm you end at a red 'Plan to deliver' box, then corticosteroids should be given and delivery occur within 24-48 hours.

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	20 of 27

11.1 Delivery Indication by Gestation at the Time of Assessment Algorithm



North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	21 of 27

12 Visit Record

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

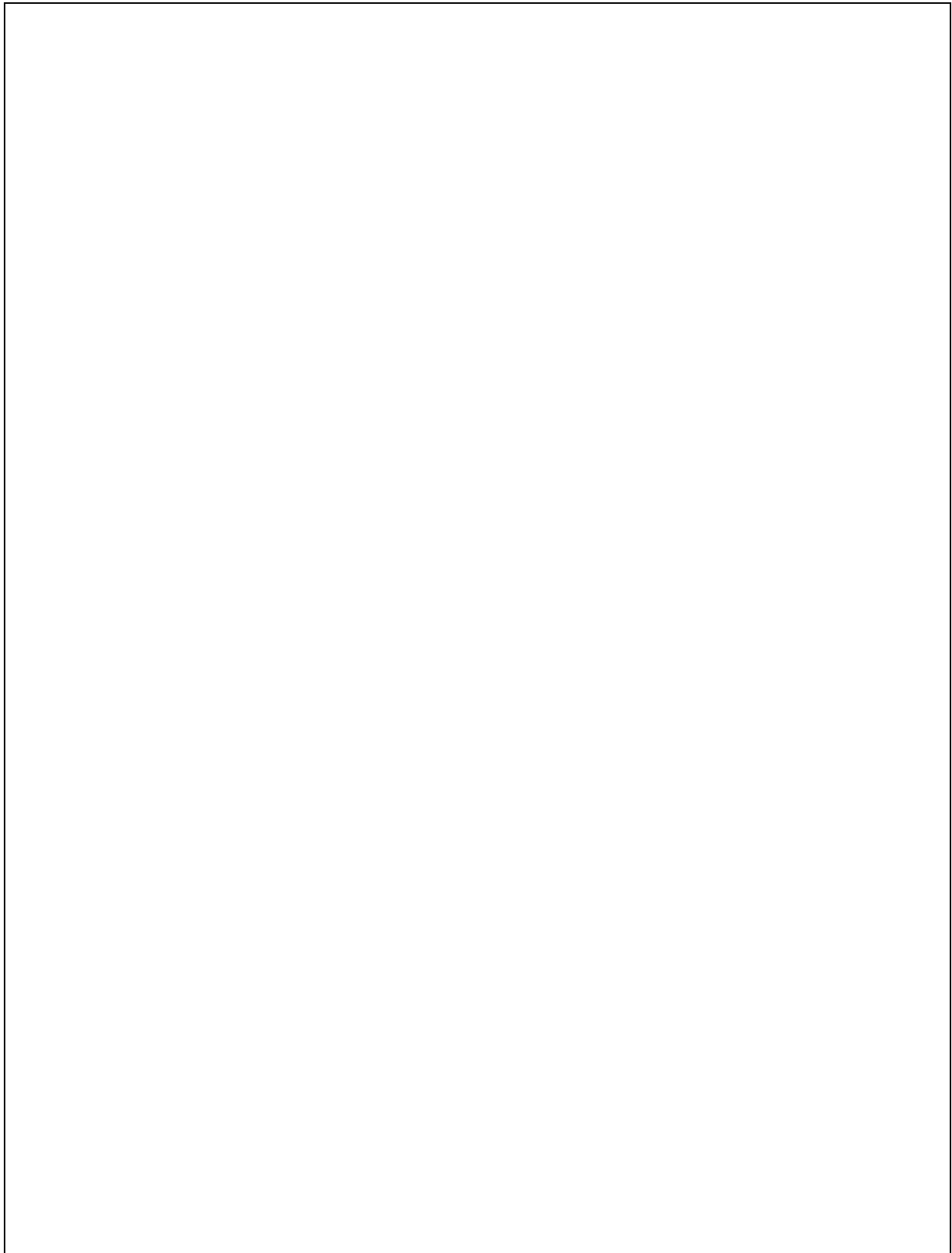
Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

Date		Gestation		BP	
Urine		FMs		FM Discussed	

13 Scan Reports



North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	24 of 27

14 Maternal Postnatal Discharge Check list

Please ensure that the placenta is sent for histopathology

Maternal Discharge Date _____

Placental Histology sent ☐

Discharge letter to GP sent ☐

Postnatal fasting glucose performed ☐

Blood pressure on discharge _____

PN antihypertensive treatment required ☐

Medication/Dose _____

Discussion regarding weight optimisation (if applicable) ☐

Discussion regarding contraception ☐

Additional notes

15 Follow up Visit Prompt List

This visit is usually with the named consultant 6-8 weeks following delivery.

Visit Date _____

Baby's Name _____ Gestation Delivered _____ LB/SB/NND

Observations: BP _____ Urine _____

Investigation Results

Karyotype _____

Placental Pathology _____.

Thrombophilia screen (if indicated by placental histology) _____

Final Diagnosis

Plan for Future Pregnancy

Pre-conception (via GP)

- Folic Acid ☐
- Optimising Hypertension ☐
- Optimising Weight ☐
- Optimising HbA1c ☐

Who to contact when pregnant: _____

At Consultation

- Folic Acid ☐
- Aspirin 150mg (from 8 weeks) ☐
- Optimising Hypertension ☐
- Serial Ultrasound Scan from _____ weeks' gestation
- Uterine artery Doppler at 20-24 weeks' gestation

Other _____

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	26 of 27

16 FGR Research

We are always trying to find out more about the cause of FGR and develop tests and treatments to improve outcomes for women and their babies. This is done through carefully designed research. You may be asked to take part in research at some point during your pregnancy or afterwards. You do not have to take part in any of the research studies offered to you, your care will not be affected if you choose not to or decide that you want to withdraw from a study.

North West eFGR Pathway Final v1.0 22.03.2019		Issue Date	22/03/2019	Version	1.0
Status	Final	Review Date	22/03/2021	Page	27 of 27