



# Lessons learnt from piloting the fetal anomaly ultrasound coverage key performance indicator

Public Health England leads the NHS Screening Programmes

# About Public Health England

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Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG Tel: 020 7654 8000 www.gov.uk/phe

Twitter: @PHE\_uk Facebook: www.facebook.com/PublicHealthEngland

# About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

#### www.gov.uk/phe/screening

Twitter: @PHE\_ScreeningBlog: phescreening.blog.gov.ukPrepared by: Fetal Anomaly Screening Programme teamFor queries relating to this document, please contact: phe.screeninghelpdesk@nhs.net

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# Introduction

The fetal anomaly screening programme (FASP) introduced a new key performance indicator (KPI) in April 2016. This indicator (FA2) measures the coverage of the fetal anomaly ultrasound scan. This KPI provides assurance that screening is offered to all eligible women and where the offer is accepted; women complete the screening pathway.

This KPI was introduced following a successful pilot involving 10 providers in 2014/15 (appendix 1). This guidance aims to:

- acknowledge some of the challenges associated with collecting these data
- share the lessons learnt from the pilot (it is neither exhaustive nor prescriptive) and
- to highlight the risks associated with not collecting these data

Our approach to collecting data on this indicator is not purely as a data collection exercise but it is more about the integrity of the screening pathway. Coverage is defined as the proportion of women eligible for screening who are tested and is a measure of timely screening to the eligible population.

Low coverage may indicate:

- not all eligible women are offered screening
- those offered screening are not accepting the test
- those accepting the test are not tested within the specified timeframe

We acknowledge that there are many challenges associated with collecting this data:

- it requires each woman to be tracked through the system
- tracking women who book and subsequently miscarry or terminate the pregnancy is difficult
- the IT systems in use are multiple and are often not linked
- women move from one provider to another during pregnancy, sometimes multiple times
- the follow up of women who do not attend appointments is challenging
- there are capacity issues in many ultrasound departments that make it difficult to accommodate women at short notice for example women who book later in the gestational window
- the lag time between booking and completing the fetal anomaly scan makes reporting more challenging
- the fetal anomaly ultrasound scan may not be uniquely identified from other pregnancy scans on IT systems

Lessons learnt from piloting the fetal anomaly ultrasound coverage KPI

This guidance document should be read together with the KPI definitions document and submission template. Please access these documents from GOV.UK as they are updated regularly.

# Getting started

The pilot sites told us that early engagement with key stakeholders is crucial. As no single department has all of the information it is important to include all those who can contribute. For example the local screening coordinator may already have experience with submitting the other antenatal coverage KPIs and they share common exclusion criteria. They also reported that engaging with other departments that may not be initially obvious like the audit department and the performance monitoring lead may be helpful.

They suggested the following people are included:

- local screening co-ordinator
- sonographer
- maternity IT systems lead
- radiology data analyst
- IT department
- audit team
- fail safe officer (if one exists)

It may be necessary to involve maternity and/or radiology IT systems suppliers to assist, for example they may be able to help with setting up audit queries, reports and codes for scans.

'Our hospital IT department is often asked for reports from other parts of the Trust but is not always utilised by maternity services. It essential to contact your IT department from the start of this work to see how they able to assist'

The pilot sites reported that it is beneficial to think carefully about the following questions:

- what is the question you need to answer?
- what data do you currently have to answer the question?
- where will you find the data?
- who can help you? internally? externally?
- who is going to lead and drive the process?
- how often do you need the data, frequency of reports- remember that you will need reports to identify any missed screens early not only for reporting the KPI

'We ran comparison lists (bookings and scans) at different intervals some weekly, the rest monthly in order to capture any missed women within the time frame to enable us to offer them an anomaly scan by 23 weeks and this allowed us to track the women in real time and also to report on the KPI'

It may be beneficial to set up access to local IT systems for example the local screening coordinator may need access to ultrasound/ radiology IT system and the sonographer to the maternity IT system. You should consider any training needs that may be required to use new IT systems.

Once you have a process in place you should document this in a standard operating procedure which should outline the steps and specify roles, responsibilities and time frames. See appendix 2 for an example of a standard operating procedure.

# Collecting the data – the denominator

## Identifying the eligible population

Start with the eligible population - the booking population, this is available for other antenatal coverage KPIs, exclusions can be applied afterwards to work out the denominator. To identify the booking population it may be helpful to define the main demographic identifiers, this may be an NHS number or hospital number dependent on local policy/issues, name and date of birth.

The denominator is the total number of pregnant women booked for antenatal care during the reporting period excluding women who:

- present to service ≥ 23 weeks + 1 day (as they are not part of the eligible population for the screening programme)
- miscarry between booking and testing
- opt for termination between booking and testing
- transfer out between booking and testing (do not have a result)
- transfer in at ≤ 23 weeks + 0 days of pregnancy who have a result from a screening test performed elsewhere in the NHS in this pregnancy
- have had private screening and do not wish to have NHS screening
- are offered an appointment within the gestational screening timeframe but choose to attend at a different time for personal reasons

#### In addition:

We recognise that ultrasound departments may not always have the capacity to accommodate women presenting later in pregnancy and have allowed leeway of one week. Therefore if you are not able to offer and complete the fetal anomaly scan to women presenting to service between  $\geq 22$  weeks + 0 days and  $\leq 23$  weeks + 0 days they can be **excluded**. If you were able to offer these women the fetal anomaly scan they should be **included** in the denominator and numerator.

#### **Exclusions**

Women who are ineligible for screening should be excluded from the total number of women booked to work out the denominator. This will include women who book too late for the screening test, that is,  $\geq 23^{+1}$  weeks of pregnancy. Women who choose to access private screening and therefore do not wish to participate in the NHS screening pathway, or, for individual reasons, choose not to attend within the screening timeframe of  $18^{+0}$  to  $23^{+0}$  weeks of pregnancy.

#### Miscarriages and terminations

The volume of women who book for maternity care and subsequently miscarry during the pilot accounted for just over half of all the exclusions. Therefore capturing the number of miscarriages can be challenging but it is essential to make sure the denominator is accurate.

Close collaboration with early pregnancy assessment units and primary care helps with notification and identifying these women. The local screening coordinator may already have this information as it is also required for other antenatal KPIs.

Some providers were not able to separate the miscarriages and terminations – this should be made clear when submitting the KPI data in the commentary. Data should be entered into one of the categories only in this case.

'Our clerical staff are informed by both community midwives and the early pregnancy unit of any miscarriages and the pregnancy episode is closed on the maternity IT system.'

'We have a hospital wide database on a shared drive that all staff can access; anyone with information about a miscarriage can enter the information unto this database'

'We have a unique code for miscarriages discovered on scan, so we devised a monthly list and give this to the person responsible for entering the information on to the maternity IT system'

#### Transfers in and out

The provider that has responsibility for the woman at the time of screening must include the woman in their coverage KPI data, including women who have transferred out after they were tested and received a result. Other providers should still make sure women transferring into their service have completed screening with documented screening results as part of their duty of care, but these women should not be included in their coverage KPI data

Women transferring in  $\ge 23^{+1}$  are not part of the eligible population.

'We are a large provider with multiple sites. It is possible for a woman to be booked for maternity care in one site but have her fetal anomaly ultrasound scan in another. We are able to manage and track women as the CRIS (ultrasound IT system) is accessible across all sites.

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#### 'A data sharing agreement is in place amongst all providers in the locality, this enables us to see if a woman has had a scan at another neighbouring provider within the area.'

'We have 2 hospitals, KM (the main unit where there are full maternity services) and NH (a limited scanning and antenatal clinic service). All women booking for birth at KM are scanned at one of the two sites. Women booking at one of our neighbouring hospitals NUH are offered the option of having their fetal anomaly scans at NH. In preparation for being involved in the pilot for this KPI we started to record on the scan report if the woman was booked for NUH. A code was written on the report which enabled the IT analysts to separate scans for women booking at KM or NUH. In this way the women could be included in the appropriate KPI report for their Trust of choice.'

## Women presenting for care between 22<sup>+0</sup> and 23<sup>+0</sup>

We recognise that capacity in ultrasound departments is often limited and it is a challenge to accommodate women for a scan at short notice. Whilst every effort should be made to facilitate screening before 23<sup>+0</sup> we have allowed a leeway of one week. Where departments are able to scan women presenting between 22<sup>+0</sup> and 23<sup>+0</sup> these women should be counted in the denominator and numerator but equally where capacity does not allow this to happen these women can be excluded from the denominator and numerator without adversely affecting the KPI performance threshold.

#### Patient choice

Where departments have offered a fetal anomaly ultrasound scan within the screening window (18<sup>+0</sup> to 23<sup>+0</sup>) but the woman requests a change of date taking her outside the screening window, these women can be excluded from the denominator provided that this was fully explained to the woman. Ultrasound departments should work towards documenting this on the IT systems. Administrative staff including receptionists should be fully aware of the screening gestational age window and flag up to more senior staff any problems with allocating appointments to women within these parameters.

Similarly, where women have accessed private screening, are offered but do not wish to enter the NHS screening pathway they may be excluded from the denominator.

# Collecting the data – the numerator

The numerator is the total number of *'eligible women'* for whom a completed screening result was available from the  $18^{+0}$  weeks to  $23^{+0}$  weeks fetal anomaly scan at the day of report

Ultrasound scans are undertaken for various reasons in pregnancy. In order to accurately report and track women through the screening pathway the fetal anomaly ultrasound scan should be assigned a unique code that differentiates it from other pregnancy scans. It will also be important to identify those women requiring a further scan to complete the fetal anomaly ultrasound. See appendix 3 for an example of one provider's approach to coding.

It is important to note that the optimal gestational window for completing the fetal anomaly ultrasound scan is  $18^{+0}$  to  $20^{+6}$  weeks of pregnancy. The scan can be completed up to  $23^{+0}$  weeks for women:

- who commence screening between 18<sup>+0</sup> weeks to 20<sup>+6</sup> weeks of pregnancy and require a single further scan to complete screening where the image quality of the first scan is compromised by one of the following:
  - increased maternal body mass index (BMI)
  - uterine fibroids
  - abdominal scarring
  - sub-optimal fetal position
- where providers are able to arrange the fetal anomaly scan later within the recommended window and have a pathway to facilitate referrals for further investigations and options for pregnancy choices in a timely manner and within the required national timeframes. Ongoing audit of practice should be in place to monitor conformity. The screening pathway must be completed by 23<sup>+0</sup> weeks of pregnancy
- who present to service at ≥ 20<sup>+6</sup> weeks of pregnancy where the sonography department are able to offer a screening scan appointment and complete screening by 23<sup>+0</sup> weeks of pregnancy

'As a screening co-ordinator preparing KPI reports has become a regular activity and I am aware of the terminology involved. We were already able to identify our booking cohort having worked with a data analyst in the IT department who prepares the data for me.

When FA2 came in I worked with the admin/data collection person in radiology - to identify a way to collect and report on this KPI.

I now receive a spread sheet listing all women booked within the specified timeframe. Alongside this will be information from scan reports detailing the gestation the anomaly scan was performed.

From here it is easy to identify women who appear not to have had a scan and those who were scanned later in the pregnancy. I can access the electronic records for these women to identify why scans were performed later than 23<sup>+0</sup> weeks gestation.

The spread sheet also includes details for those women who have moved out of the area and those who have had a termination or miscarriage since the dating scan. (This will not usually be present for those who are cared for by cross-border midwives).

The spread sheet then leaves a much smaller number of women who are unaccounted for. Reading entries on the electronic record usually explains the reason a scan was performed (such as declined) or was performed at a later gestation (such as booked later in pregnancy).'

# Collecting the data – women who did not attend the appointment

It is a common belief that women always attend for this scan appointment and whilst this is true for most women, we discovered women during the pilot that did not attend their ultrasound appointment. The number of women in this group was much higher than expected.

'felt that there were no surprises in terms of coverage but I was surprised at the number of women who DNA and do not present for anomaly scan.'

'This is a useful KPI and has been well received by our Trust. It has also highlighted a gap in our failsafe for DNA's to anomaly scans which has now been rectified but may not have been identified as a gap had we not taken part in the pilot.'

'We are an inner city provider and do have women that DNA their ultrasound appointments. We have a process where these women are followed up by the community midwife and GP.'

'As the local screening coordinator I would also look on the hospital IT system to see if there had been any admissions to gynaecology, early pregnancy unit and accident and emergency before making any further enquires.'

See appendix 4 for an example of a provider's DNA policy.

# Collecting the data – women who are unaccounted for

The difference between the denominator and numerator is equal to the number of women unaccounted. Five providers taking part in the pilot found that they had women in the unaccounted category.

When investigated the unaccounted women fell into the following broad categories:

- had scans abroad
- had scans at another provider
- had scan at tertiary centre as fetal anomaly identified at dating scan
- needed follow up scan to complete but had intrauterine death before the scan could be completed
- did not attend
- lost to follow up

'As a result of taking part in the pilot we found 4 women were not screened in the screening timeframe due to:

- booking error (1 did not have appointment booked, error realised when patient attended for 28 week growth
- 1 patient booked with midwife at 20<sup>+2</sup> but was not booked anomaly scan in the correct timeframe
- 2 patients booked early but were not given appointment for anomaly scan in the correct timeframe no explanation found for this)'

One provider outlined the step by step approach they take to ascertain what has happened to the women in the unaccounted category:

- 1. Check ultrasound system
- 2. Check maternity care records (either electronic or paper)
- 3. Check with community midwife
- 4. Check re: letters that might have been sent for example from gynaecology

# Reporting

There can be a delay between booking and completing the fetal anomaly scan which makes reporting more challenging. For example it is possible that a woman who is 6 weeks pregnant booking for care in quarter 1 (April to June) may not complete screening until October.

When setting up a query/search you should allow an additional 23 weeks in each quarter. For example when interrogating the IT system for scans completed for women booking in Q1 (1 April to 30 June) the search criteria should include scans undertaken between 1 April to 11 November (1 April to 30 June +23 weeks).

Quarter	Dates	KPI submission window to accommodate lag
		time
Q1	1 April to 30 June	1 to 31 December
Q2	1 July to 30 September	1 to 31 March
Q3	1 October to 31 December	1 to 30 June
Q4	1 January to 31 March	1to 30 September

# Summary

Assurance that all eligible women are offered screening and those accepting screening complete the screening pathway is a measure of quality. There is evidence from the pilot and from screening safety incidents show that women can miss the offer or do not complete the screening pathway.

This KPI provides a mechanism of tracking and detecting when things are going wrong in the pathway so it can be fixed. However processes need to be put in place locally to be able to track the women through the pathway. Checks need to be done in a timely manner if they are to provide a failsafe.

We hope that some of the learning from pilot sites will help you at the very least get started.

#### Acknowledgements

We are extremely grateful to all providers who participated and gave their time and commitment to make this pilot a success.

# Appendices

## Appendix 1: providers participating in the pilot

- Stockport NHS Foundation Trust (Buxton)
- Stockport NHS Foundation Trust (SHH)
- North Tees & Hartlepool NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust
- Sherwood Forest Hospitals NHS Foundation Trust
- Nottingham University Hospital NHS Trust
- Bolton Hospitals NHS Foundation Trust
- Great Western Hospitals NHS Foundation Trust (Swindon)
- Liverpool Women's Hospital
- Hull and East Yorkshire Hospitals NHS Trust

# Appendix 2: example of a standard operating procedure

#### FASP KPI Collection Procedure – FA2



## Appendix 3: example of ultrasound codes used by one provider

#### Dus40: dus40:

Synechie noted. All fetal parts are free of the band. No follow up scans will be required.

**Dus41: dxus41:** Nuchal translucency measurement was obtained for 1<sup>st</sup> trimester Down's syndrome screening with patient consent. The patient was directed to antenatal clinic for screening bloods to be taken. A fetal anomaly scan was offered. 20 weeks on xxxxxx

#### Dus42: dxus42:

Verbal consent to screening was obtained from the patient prior to undertaking the ultrasound scan. NT measurement could not be obtained due to technical difficulties. The patient was directed to antenatal clinic to organise a QUAD test. A fetal anomaly scan was offered. 20 weeks on xxxxxxxx

#### Dus43: dxus43:

The patient has been referred to FMU as per FASP pathway for raised NT equal or greater than 3.5mm.

#### Dus44: dxus44:

Verbal consent to screening was obtained from the patient prior to undertaking the scan element of combined screening. Gestational age is greater than 14 weeks 1 day, therefore out of limits for this screening test. The patient was directed to antenatal clinic to organise a QUAD test. A fetal anomaly scan was offered. 20 weeks on xxxxxx

#### Dus45: dxus45:

Verbal consent to screening was obtained from the patient prior to undertaking the scan element of combined screening. Gestational age is too early. CRL is less than 45mm. A repeat appointment has been arranged.

#### Dus46: dxus46:

Verbal consent to screening was obtained from the patient prior to undertaking the ultrasound scan element of combined screening. Screening was not undertaken due to fetal demise.

#### Dus47: dxus47:

Verbal consent to screening was obtained from the patient prior to undertaking the fetal anomaly scan. Your baby appears to be developing normally. As you know, most babies are born healthy and with no physical problems. However, there is a small chance that your baby may still have a problem that is hard or impossible to see using ultrasound.

#### Dus48: dxus48:

Verbal consent to screening was obtained from the patient prior to undertaking the fetal anomaly scan. We were unable to complete all the checks today as your baby was lying in a position which made it more difficult to look at your baby. A repeat scan has been booked.

#### Dus49: dxus49:

Verbal consent to screening was obtained from the patient prior to undertaking the fetal anomaly scan. We were unable to complete all the checks today as you are above average weight and this made looking at your baby more difficult because the images were not as clear. A repeat scan has been booked.

#### Dus50: dxus50:

Repeat anomaly scan, all anomaly checks have now been completed. Your baby appears to be developing normally. As you know, most babies are born healthy and with no physical problems. However, there is a small chance that your baby may still have a problem that is hard or impossible to see using ultrasound.

#### Dus51: dxus51:

Repeat anomaly scan. We were unable to complete all our checks of your baby today due to sub-optimal imaging. The patient has been informed that no further scans will be undertaken.

**Dus52: dxus52:** The fetal anomaly screening scan is undertaken between the gestational ages of 18 weeks and 20 weeks and 6 days (FASP 2010). This scan was carried out outside these dates because (state reason)

#### Dus53: dxus53:

The fetal anomaly screening scan is undertaken between the gestational age of 18 weeks and 20 weeks 6 days (FASP 2010). The patient has been informed that, because the scan has been carried out after 20 weeks 6 days, fetal anomaly screening is less effective. Gestational age cannot be accurately assessed after 25 completed weeks (BMUS 2009). EDD has been estimated by head circumference (HC).

#### Dus54: dxus54:

Please discuss with / refer to the fetal medicine unit.

#### DUS55: dxus55:

Other finding:

#### DUS56: dxus56:

Rebook at 16 weeks to obtain a more accurate EDD using the head circumference.

**DUS57: dxus57:** Declined first trimester screening. A fetal anomaly scan was offered. 20 weeks on xxxxxx

## Appendix 4: example of a did not attend policy

# STANDARD OPERATING PROCEDURE

## 1. Purpose of guidance

To ensure all staff are aware of and follow the correct procedures for booking routine ultrasound scans in pregnancy, that is, first trimester screening or dating and the routine 20 week anomaly scan

- to ensure the correct audit trail is in place
- to ensure targets are not breached by ensuring effective control measures
- to ensure examinations are vetted and so are appropriate and to avoid duplicate requests
- to ensure that referrers are informed if patients do not attend for examination

## 2. Principles

#### First Trimester Screening (FTS) and Dating scan

- **2.1** Ultrasound request form is completed by the Community midwife clearly indicating screening choice:
  - screening declined (dating scan only)
  - T13/18 screening only
  - T21 screening only
  - all T13/18/21 screening

# Midwife must sign the request form to confirm the patient has given consent to FTS.

**2.2** Paper request form is faxed to the ultrasound department by community midwife on fax number xxxx xxx xxxx.

A copy of the request form is also posted to the ultrasound department and an information sticker is placed on the patients handheld notes requesting them to contact the ultrasound department if an appointment has not been received by 12 weeks – *failsafes to ensure that requests are not lost or misplaced.* 

**2.3** Paper requests are scanned and pended onto the CRIS system as soon as they are received.

- 2.4 Patient is booked an appointment between 12 and 14 weeks by LMP. (Combined screening can be performed between 11weeks 4 days- 14weeks 2days). The community midwife should state when the patient is 12weeks gestation on the request form. Any discrepancies or incomplete forms should be discussed with the community midwife via telephone or a Sonographer.
- **2.5** FTS appointments are 30mins and booked in the FTS clinic diary as blood test is performed after the scan. If a patient books late (over 14 weeks) with community midwife, the next available appointment is given; quadruple test can be offered if too late for FTS.

If a patient is 13+ weeks at time of booking, then best endeavors should be taken to offer an appointment before 14 weeks, however this may not always be possible. Next available appointment should then be given.

Dating – appointments are 20mins and booked in the obstetric diary.

## 20 week anomaly scan

The anomaly scan is booked with the patient immediately after the Dating/FTS scan where possible.

**Midwife signs request form to confirm the patient has given consent.** This is requested at the same time as FTS consent.

2.7 The woman is booked between 19 weeks and 20 weeks 6 days (scan can be performed between 18 weeks and 20 weeks 6 days). The sonographer should calculate the date range for the anomaly scan and should be clearly written on the front of the request form so the admin staff can book appropriately.

This is accurately calculated by the sonographer on the "Examination Data" page in Viewpoint. Select the "Overall Diagnosis" box, at the bottom of the page, and enter 19<sup>+0</sup> and 20<sup>+6</sup> weeks into the "Gestational Age boxes"

- **2.8** Appointment slots are 35mins, or 45mins for multiple pregnancies.
- **2.9** Sonographer hands scan referral form to Booking Appointments and asks the patient to make their anomaly scan appointment before they leave (referral form is placed in the black tray on reception 2 if receptionist is unavailable).

If we are unable to make the appointment on the same day (for example patient unable to wait or diary unavailable) then the request is pended onto CRIS and appointment is sent to the patient in the post.

#### Completion of anomaly scan

If a follow up appointment is required to complete the anomaly scan, a scan should be offered by 22<sup>+0</sup> weeks (local policy). This appointment should be arranged ideally by the sonographer whilst the patient is in the department, or arranged by the admin staff (sonographer to inform when the scan is to be booked by) and the patient is contacted via telephone call

#### 3. Did Not Attends (DNAs)

**3.1** Record on CRIS that the patient has failed to attend for the appointment (this is automatically generated).

The community midwife is contacted in the first instance, to check the patient has not miscarried or moved out of the area and that the scan is still required. The patient details are also checked and confirmed.

- **3.2** If the scan is still required, the patient is contacted via telephone to rearrange appointment. Wherever possible, the next available appointment is offered.
- **3.3** All communication with the patient should be recorded on CRIS, that is, attempts to arrange appointment, patient requests or similar.
- **3.4** If patient DNA's a second time then the community midwife is informed.

## 4. Rearranging appointments/communications with patients

- **4.1** Admin staff should always speak to the patient directly. If communication is difficult then an appointment letter should be sent to the patient.
- **4.2** Admin staff should record on CRIS any notes or communications with patients regarding their appointment that is, cancellations at patients request, specific times.

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## 5. Interpreters

Interpreters should be booked in advance by xxxxxxx.

All women with language difficulties should be offered an interpreter, and relatives should not be used unless the patient declines.

## 6. Assumptions

Staff are fully familiar with the Trusts expectation of them regarding the use of CRIS, Viewpoint and have received training in how to use these systems where applicable

## 7. Scope

- **7.1** This SOP addresses the protocols to be followed to manage u/s appointments for routine ultrasound scans in pregnancy.
- 7.2 The SOP identifies the staff groups responsible for booking these appointments.