NHS antenatal and newborn screening programmes London region report 2009-10

Nadia Permalloo nadia.permalloo@nhs.net
Jean Chapple jean.chapple@westminster-pct.nhs.uk
Regional screening coordinators, London region
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Summary of recommendations

Complete and robust data

- Trusts and commissioners need accurate data collection processes and systems to monitor screening programmes. This is especially important as the National Screening Committee proposes the introduction of key performance indicators (KPIs) from 2011. The variable quality of data is highlighted throughout this report. The provision of accurate booking data is a priority.

Coordination of local screening programmes

- Trusts and commissioners without a local antenatal and newborn screening coordinator should address this gap urgently. Administrative support is essential for these roles especially with the move to a formal national quality assurance process.

Local guidelines

- Trusts and commissioners must ensure that they have newborn bloodspots guidelines that cover requests for repeat samples and for ensuring that all babies less than one year of age, including babies who have moved into a locality, are offered blood spot screening. This should be completed as soon as possible.

Screening for sickle cell and thalassaemia in pregnancy

Trusts and commissioners

- Early screening by 10 weeks of pregnancy needs to be actively implemented with accurate data capture to report on performance against this standard. This differs from the 'Vital Signs' target of booking by 12 weeks and 6 days.
- Uptake of partner testing needs to improve in many areas. Commissioners are asked to look at the pathways for achieving this.

Maternity units

- The two outstanding maternity units must implement the Family Origin Questionnaire (FOQ) by December 2010.
- All maternity units must ensure 100% accurate compliance of completion of the FOQ.
- All units should explore options of an electronic FOQ.

Neonatal units

- Neonatal units should take a pre-transfusion/ admission sample on all babies to ensure that a full screen for sickle cell disease can be performed without resorting to less effective and more expensive DNA methods. The regional guidelines to be followed can be found at http://www.screening.nhs.uk/getdata.php?id=9763

Screening for Down's syndrome

Maternity units and commissioners

- The one outstanding unit must implement the quadruple test as soon as possible to meet national standards and policy recommendations.
- All units should offer twin pregnancies combined screening for Down's syndrome in line with national policy.

Screening for Infectious diseases in pregnancy

- Commissioners need to ensure the Personal Child Health Record is commissioned appropriately so that every mother in London can receive a copy in hospital before

discharge irrespective of which borough she resides in or which GP she is registered with. This will help to ensure that babies born to mothers infected with hepatitis B receive a full course of immunisations.

- Trusts with low coverage rates are asked to address this with urgency.
- Maternity units must resolve any issues around MMR coverage and ensure all rubella susceptible women receive the first dose of MMR in hospital before discharge.

Fetal anomaly ultrasound screening

- All ultrasound departments must offer the mid trimester scan within the time frame and in line with standards specified by the national programme i.e. 18+0 to 20+6 weeks by April 2011.

Newborn bloodspot screening

- Good progress has been made on use of the baby's NHS number on all bloodspot cards and this must continue. Particular attention should be paid to cards from neonatal units.
- All outstanding maternity units must implement bar code labels for newborn bloodspot screening as per national specification. If systems suppliers are not able to support this it should be highlighted as an area of risk to clinical governance leads locally.

Acknowledgements
Thanks to all local screening coordinators, specialist midwives, sonographers, haemoglobinopathy specialist nurses, fetal medicine departments, screening laboratories and all who provided data or contributed to local reports and who continue to work hard to improve services for women and their families each year.

Nadia Permalloo
Jean Chapple
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1. Introduction

This report covers the financial year 1st April 2009 to 31st March 2010. This report builds on two previous reports covering 07/08 and 08/09 http://www.screening.nhs.uk/london and provides comparative data that measures performance against key national standards. It focuses on the antenatal screening programmes as performance data relating to newborn bloodspot and the hearing screening programmes are collected and reported separately. Directors of public health and commissioners with responsibility for the quality of screening programmes should note the recommendations and areas for improvement in their local service.

2. Response rate

For the first time in three years 100% (n=27) of maternity units returned a report. However many units had gaps in data and these are highlighted where they occur. This regional report gives an overview of the local screening programmes. Local reports provide more detailed information and local action plans and are available from the regional and local screening coordinators. PCT public health leads and commissioners are asked to look at both regional and local reports.

3. Activity

Booking data are important to assess coverage of the antenatal screening programmes. Booking data are used as the denominator as data on the 'offer' of screening is almost impossible to extract from current maternity systems and most maternity units do not collect this information electronically. Therefore the best estimate for coverage at this time is bookings. Maternity units therefore need to ensure accurate booking data are provided. We asked maternity units to indicate the source of booking data and this is shown in Table 1. The majority of units use a maternity information system to generate booking data but it is of interest to note that some units use a combination of systems some of which are manual systems.

A proportion of bookings do not result in births in the booking unit because of miscarriages and women moving. The wide variation in attrition rates across London is shown in Table 1 (2% at Epsom & St Helier compared to 24.3% at Barking, Havering & Redbridge University Hospital). The average attrition rate across the region was 15.3% (compared to 18.6% in 08/09). This is a reflection of booking women at earlier gestations and therefore more women are captured at booking who subsequently miscarry. For women who transfer care during pregnancy there is a potential risk that their screening results are not communicated

to the referral unit. Matenrity units need to ensure that screening results are transferred with women so that appropriate care can be continued.

Table 1: Booking and birth activity 09/10

Maternity unit	Total number of bookings 09/10	Total number of deliveries (live births + still births) 09/10	Attrition rate 09/10	Attrition rate 08/09	Source of booking data 09/10
Barnet & Chase Farm	7685	6818	11.3% (867)	6.6% (480)	MIS
North Middlesex	3956	3358	15.1% (598)	14.1% (579)	MIS
Royal Free	4009	3206	20% (803)	8.8% (315)	Manual count
UCLH	6409	5308	17.2% (1101)	XXX	MIS
Whittington	4706	4021	14.6% (685)	13.7% (598)	PAS
BHRT-Queen's Hospital	13038	9872	24.3% (3166)	13.4% (1464)	MIS
Homerton	5325	4643	12.8% (682)	18.5% (1077)	MIS
Newham	6581	5262	20% (1319)	XXX	EPR
Royal London	5695	4616	19% (1079)	25.4% (1469)	MIS + manual systems as MIS data is not reliable
Whipps Cross	6868	5375	21.7% (1493)	26% (1825)	PAS
Chelsea & Westminster	6526	5611	14% (915)	16.8% (1071)	MIS
Ealing	3666	3031	17.3% (635)	17.3% (624)	MIS
Hillingdon	4585	4225	7.9% (360)	21.5% (1228)	ireporter
NWL Hospitals	6243	4840	22.5% (1403)	19.8% (1200)	PAS
Imperial- QCCH	6140	5510	10.3% (630)	17.7% (1107)	Booking office data, labour ward audit reports
Imperial- St Mary's	5090	4806	5.6% (284)	4% (187)	MIS
West Middlesex	5346	4389	17.9% (957)	22% (1119)	MIS
Guys & St Thomas	7506	6844	8.8% (662)	3.1% (233)	Healthware
Kings College	6886	5804	15.7% (1082)	16.4%(1074)	MIS
Lewisham	3649	3491	4.3% (158)	17.2% (727)	MIS
Princess Royal	4544	4005	11.9% (539)	16.2% (722)	MIS
Queen Elizabeth	4912	4203	14.4% (709)	13.1% (621)	HISS- joint PAS, maternity and pathology system
Queen Mary's	3405	3141	7.8% (264)	XXX	MIS
Epsom & St Helier's	5280	5167	2% (113)	10.5% (598)	MIS
Mayday	5820	4492	22.8% (1328)	XXX	MIS
St Georges	6575	5188	21.1% (1387)	15% (869)	MIS
Kingston	6789	5923	12.7% (863)	22.3% (1676)	Laboratory, maternity system and manual
Total	**157234**	**133149**	**15.3% (24085)**	**18.6% (25542)**	

MIS- Maternity Information System (supplier unspecified)
EPR- Electronic Patient Record
PAS- Patient Administration System

4. Local structure & accountability of screening

Coordination of screening programmes at a local level is essential if programmes are to be managed effectively. This requires a coordinator at Trust level as well as at PCT level with all stakeholders fully engaged.

The UK National Screening Committee (NSC) recommends 1 WTE screening coordinator per 4,000 deliveries per annum with support by a deputy and administrative help. Most maternity Trusts in London have a screening coordinator in place but there are a few gaps that must be addressed locally by commissioners and trusts.

- Kings College is the only Trust in London without a screening coordinator.

- There are gaps in terms of adequate number of dedicated hours at Barnet & Chase Farm and St Thomas.

- Since the last report Whipps X and the newly merged South London Healthcare NHS Trust (Queen Mary's, Queen Elizabeth & Princess Royal) have appointed full time screening coordinators. This is commendable and will help to move their services forward.

It is important that coordination covers all screening programmes i.e. both antenatal and newborn as traditionally these posts have been solely focused on the antenatal screening programmes. In the last few months the need to have administrative support for these posts was highlighted by a number of requests for assurances and investigation of serious incidents. Trusts are asked to ensure deputies to cover for periods of leave and adequate administrative support are in place.

Each maternity unit/ NHS Trust should also have a multidisciplinary clinical screening steering group that meets regularly to examine audit reports and oversee the management and quality of the antenatal and newborn screening programmes. The group should be accountable and report to the Chief Executive of the Trust.

Coordination is needed from within PCTs to ensure all stakeholders are fully engaged and that there is equitable care for all women living in a PCT regardless of the Trust providing care. The amount of resource and time available for PCT coordination is not known but needs to be assured. Good PCT coordination makes maximum use of resources and benefits both PCTs and maternity trusts – for example, SW London has developed one newborn blood spot screening guideline to cover the whole sector.

5. Local screening guidelines

The presence of local guidelines is a basic requirement of any screening programme. These ensure that all members of the multidisclipnary team are aware of the local procedures and their specific roles in the programme and demonstrates to patients and commissioners the level of service to expect.

5.1 Antenatal screening programmes

Table 2 shows the presence or absence of local guidelines for each of the antenatal screening programmes. There are only a few gaps to address.

Table 2: Local antenatal screening guidelines in place in 09/10

Maternity unit	SCT	HIV	Hep B	Syphilis	Rubella	FASP (Downs)	FASP (USS)
Barnet & Chase Farm	Yes	Yes	Yes	Yes	Yes	Yes	Yes
North Middlesex	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Royal Free	Yes	Yes	Yes	Yes	Yes	Yes	Yes
UCLH	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Whittington	Yes	Yes	Yes	Yes	Yes	Yes	Yes
BHRT-Queen's Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Homerton	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Newham	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Royal London	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Whipps Cross	**National policy**	Yes	Yes	Yes	**NO**	Yes	Yes
Chelsea & Westminster	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ealing	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hillingdon	Yes	Yes	Yes	Yes	Yes	Yes	Yes
NWL Hospitals	Yes	Yes	Yes	Yes	Yes	XXX	XXX
Imperial-QCCH	Yes	Yes	Yes	Yes-	Yes	Yes	Yes
Imperial-St Mary's	Yes	Yes	Yes	Yes	Yes	Yes	Yes
West Middlesex	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Guys & St Thomas	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kings College	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lewisham	Yes	Yes	Yes	Yes	**NO**	Yes	Yes
Princess Royal	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Queen Elizabeth	Yes	Yes	Yes	Yes	Yes	**NO**	Yes
Queen Mary's	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Epsom & St Helier's	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mayday	Yes	Yes	Yes	Yes	Yes	**NO**	Yes
St Georges	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kingston	Yes	Yes	Yes	Yes	Yes	Yes	Yes

XXX- no answer given
SCT- sickle cell & thalassaemia

5.2 Newborn screening programmes

There are more gaps in existing guidelines for the newborn screening programmes as shown in Table 3.

Newborn hearing screening guidelines are patchier and this is most likely as a result of the links between hearing screening and maternity services. Hearing screening follows a different pathway and is coordinated by dedicated hearing screening coordinators. More robust links are needed between the local antenatal and newborn screening coordinators and hearing screeners in order to have a seamless service for mothers and babies. Some Trusts indicated that the national policy is used which is positive but local guidelines may be needed to complement and to provide clarity on roles and responsibilities.

Midwives have an important role in promoting hearing screening prior to discharge from hospital and their role should be incorporated into local guidelines and training initiatives. Hearing screeners should be members of the local antenatal and newborn steering groups.

Although the newborn physical examination takes place this is often seen as part of routine postnatal care as opposed to a formal screening programme. As the national screening programme is rolled out from 2011, units will need to ensure robust guidelines are in place.

Local guidelines for the newborn bloodspot screening programme must be a priority area of work for London. London PCTs were asked to develop local guidelines two years ago and this is still not in place for all areas although many are progressing. Many maternity units have guidelines in place but this only covers a limited part of the programme and there must be an overall local guideline covering the whole screening pathway. This should incorporate babies up to one year of age and include ‘movers in’. The bloodspot programme spans different organisations and health professional boundaries and therefore a high risk area. Local guidelines need to clarify roles and responsibilities of all those involved in the programme. Areas where guidelines are in place should ensure they are disseminated to all relevant stakeholders, implemented and embedded in local practice. There is also a need to monitor compliance at regular intervals. It may also be helpful if these guidelines could be available on a local websites for easy access. There are good examples of guidelines from NHS City & Hackney and NHS Westminster that have been shared with other PCTs across London.

Table 3: Local newborn screening guidelines in place in 09/10				
Maternity unit	**NHSP**	**NIPE**	**NBBS**	
			Newborn Bloodspot- maternity unit aspects only	**PCT led newborn bloodspot guideline - covers the whole programme and includes babies up to 1 year old**
Barnet & Chase Farm	Yes	Yes	Yes- Barnet & Enfield guidelines	
North Middlesex	Yes	Yes	Yes	Haringey guidelines in progress
Royal Free	Community model	Yes	Yes	Yes- Camden guidelines
UCLH	XXX	Yes	XXX	
Whittington	Community model	Yes	Yes- Islington guidelines	
BHRT-Queen's Hospital	Yes	**NO**	BHR guidelines in progress	
Homerton	**NO**	**NO**	Yes- City & Hackney guidelines	
Newham	National policy	Yes	Newham guidelines in progress	
Royal London	Yes	Yes	Yes	Tower Hamlets guidelines in progress
Whipps Cross	National policy	Yes	Waltham Forest guidelines in progress	
Chelsea & Westminster	Yes	Yes	Yes	**Kensington & Chelsea guidelines needed**
Ealing	Yes	Yes	Yes	Ealing ?? In draft
Hillingdon	Yes	Yes	Yes	Yes- needs updating to incorporate 2008 national standards
NWL Hospitals	National policy	XXX	Yes	Brent & Harrow working on joint policy
Imperial-QCCH	Yes	Yes	Yes	**Hammersmith & Fulham guidelines needed**
Imperial-St Mary's	National policy	**NO**	Yes- Westminster guidelines	
West Middlesex	Yes	Yes	Yes	**Hounslow guidelines needed**
Guys & St Thomas	Yes	Yes	Yes	Southwark & Lambeth working on a joint guideline
Kings College	Yes	Yes	Yes	
Lewisham	Yes- draft	Yes	Lewisham guidelines in progress	
Princess Royal	PCT led	Draft	Yes- Greenwich & Bromley have guidelines in place- need to be brought together as newly formed Trust	
Queen Elizabeth	**NO**	Yes		
Queen Mary's	**NO**	Yes		
Epsom & St Helier's	Yes	Yes	Yes- South West London guidelines	
Mayday	XXX	Yes		
St Georges	National policy	Yes		
Kingston	Yes	Yes		

NHSP- Newborn hearing screening programme
NIPE- Newborn & Infant physical examination
NBBS – Newborn bloodspot screening programme
XXX- no answer given

6. Screening for sickle cell and thalassaemia in pregnancy

This programme is linked with newborn bloodspot screening for sickle cell diseases. The antenatal screening programme is reported here.

The data collection tool for this report was agreed with the national programme to minimise duplication of data collection as the national programme collects data annually from the screening laboratories. It is therefore not possible to report on the number of carriers here but publication of the national data reports for 08/09 and 09/10 are expected later this year. London data is presented in Table 4 below.

6.1 Coverage

Coverage is generally high across the region but there are a number of problems with obtaining accurate data. The source of booking data and the number of tests are usually from different sources, the former generated from maternity information systems whilst the latter laboratory generated. This year for the first time we asked units to document the source for each data item to help us understand the data challenges. In three units the number of tests performed was greater than the number of bookings. This may be due to counting repeat tests and women who may be screened before booking and subsequently miscarry. In some units it would also appear that the number of women declining screening is large but these may be attributed to late transfers and a discrepancy between booking and laboratory data as opposed to a true reflection of women declining the test. A number of units have set up manual data collection systems to capture true declines.

6.2 Testing women in subsequent pregnancies

There is also variation in the re- screening policy and the rationale for the local policy, while some laboratories do not re-screen women who have been previously screened others do. Units were asked to describe their local policy this year and the responses can be seen in Table 5. Haemoglobinopathy screening is a genetic test which means that an individual's status does not change so there is no need to re-screen women who have previously been tested and there is documented evidence of the result. Antenatal screening laboratories need to adopt new national guidance published in October 2009 regarding testing women in subsequent pregnancies.

The national policy http://sct.screening.nhs.uk/cms.php?folder=2493 recommends that women need not be tested again in the same or a subsequent pregnancy provided that:-

- the original result is unequivocal and well documented
- the red cell indices remain the same

- the patient identification has three or more matching data items eg:-
    - name, date of birth and hospital number
    - name, date of birth and address
    - Hospital number, date of birth and address (if woman confirms name change)
    - Name, date of birth and haemoglobinopathy card.

6.3 National standards

6.3.1 National standard: 50% of all pregnant women are offered screening by 10 weeks of pregnancy.

15 units were able to report against this standard; this is an improvement from last year when only eleven units were able to. Five additional units reported data by 'booking by 12 weeks' (as these data are being collected for vital signs statistics) and Lewisham reported on bookings by 10 weeks and six days. Some also reported separate audit data to demonstrate performance against this standard. Of the 15 units responding rates ranged from 0.9% at Homerton to 76% at Queen Charlottes. Overall three units currently meet this standard but it should be recognised that there have been huge improvements in booking women by 12 weeks across London. Reporting on this standard is extremely challenging for units as they do not have information systems that they can easily extract these data from. PCTs required data on bookings by 12 weeks and 6 days as part of 'Vital Signs' monitoring and maternity units gave priority to collecting these data. It is recognised that many units are investing a lot of time into manual data collection systems even where they have electronic information systems in place.

6.3.2 National standard: 50% of all couples/women defined as 'at high risk' are identified before the end of 11 weeks of pregnancy. This requires timely and complete (as far as possible) partner testing.

Based on the responses the coverage of partner testing remains very variable across London (41.9% at Homerton to 97% at Queen Mary's). Hillingdon also maintains a consistently high partner testing rate of 93.5% this year. Comparative data are available for 18 units (08/09 data compared to 09/10) and these demonstrate that in eight units partner testing improved compared to ten units where the uptake of partner testing decreased. The estimated average uptake across the London region is 61.4% (compared to 66% in 08/09). It should be noted that data are missing from some areas so may in fact be an over estimate. National data shows that 57% of partners were tested in 07/08. This is an area of concern as it means that the risk assessment for many couples is incomplete. Commissioners need

to ascertain reasons for local uptake rates and units should learn from those areas where rates are better. Commissioners should explore the process of inviting partners for testing. Some of the issues to consider are as follows:

- How is contact made with partners- if letters are sent are they clear and stress the timeliness and importance of attending?

- How are DNAs (those who fail to attend) followed up- this appears to be problematic in some areas of London?

- In areas where specialist nurses manage this part of the care pathway what is the interface with maternity services (many of these women are accessing maternity care and attending for a 18- 20 week fetal anomaly scan – women tend not to miss scan appointments and this may be a missed opportunity)?

- Are appointments for partners flexible in terms of the venue and timings (can partners who work access services in the evening?)

- Are bloods (from partners who consent to screening) taken at the counselling appointment or is another appointment required for this?

6.3.3 National standard: 50% of all prenatal diagnoses are performed before the end of the 12th week of pregnancy

Based on the reported data (which is incomplete for some areas) there were a total of 586 (537 in 08/09) couples 'at risk' of having a child with a haemoglobinopathy disorder. 24.4% (143/586) of couples knew their 'at risk' status prior to pregnancy. 202/586 (34.5%) of couples opted to have prenatal diagnosis; this is an increase to the 22% uptake rate last year and is slightly higher than national picture of 22% reported in 07/08. Of those having prenatal diagnoses only 16.8% (34/202) of invasive tests in London were performed by the 12th week of pregnancy. This shows that the national standard is clearly not being met in London and suggests that the majority of at risk couples are not offered a timely service. The reasons for this must be addressed as a priority – are at risk couples being identified late because partners cannot be reached or are not available for testing, are couples wanting more time to consider the pros and cons of an invasive test, or are services unable to meet the time scales?.

6.4 Implementation of the Family Origin Questionnaire (FOQ)

High prevalence areas were instructed to implement the FOQ following successful implementation in low prevalence areas. All maternity units in London with the exception of Queen Mary's and Queen Elizabeth have implemented this. These two units are addressing this urgently and should have in place by the end of 2010.

As with any implementation process there needs to be monitoring process in place to ensure success. For the FOQ this is measured via antenatal data returns from the screening laboratories to the national programme. However all units were asked to complete a snap shot audit following implementation to ascertain success. The findings from units that have completed local snap shot audits are found in Table 6.

These data shows that compliance is very poor in some cases and means that some requests for partner testing are inappropriate and may increase parental anxiety unnecessarily. As discussed above partner testing rates requires improvement; the FOQ must be used to positively to reduce the overall number of partner testing requests facilitating targeted and concentrated efforts into screening those partners where screening is clinically indicated.

There needs to be good communication links between the screening laboratory and the antenatal screening coordinator to ensure poor practice with individual midwives is addressed. This is an area maternity units and laboratories may wish to audit regularly.

The snap shot audit also indicates that having an electronic version of the FOQ where the fields are mandatory increases compliance as is the case at Newham and Queen Charlotte's, however as the Hillingdon audit indicates close scrutiny is still necessary to ensure midwives complete the categories accurately.

Table 4: Antenatal screening for sickle cell and thalassaemia 09/10

Maternity unit	No. of bookings	No. of women screened	No. of women screened by 10 weeks	No of women not screened as screen before	No of women declining screening	No. of partners offered screening	No. of partners screened	No. of at risk couples Previously known	No. of at risk couples Diagnosed in this pregnancy	No. of at risk couples opting for prenatal diagnosis	No. of prenatal tests performed by 11 weeks + 6 days	No of affected babies identified through prenatal diagnosis	No of women choosing termination of pregnancy
Barnet & Chase Farm	7685	92%	62% booked by 12/40	0	5	630	367 (58.3%)	7	35	14 (33.3%)	0	0	0
North Middx	3956	100%	28.9% (1144)	0	0	346	263 (76%)	0	23	13 (56.5%)	0	4	1
Royal Free	4009	4061	N/A	0	N/A	193	146 (75.7%)	0	14	4 (28.6%)	0	0	0
UCLH	6409	100%	70% booked by 12/40	0	0	477	393 (82.4%)	6	10	5 (31.3%)	2 (40%)	1	1
Whittington	4706	99.7%	23.5% (1100)	0	16	272	173 (63.6%)	7	13	7 (35%)	1 (14.3%)	4	1
BHRT-Queen's	13038	96.5%	N/A	1795	N/A	1924	1082 (56.2%)	19	76	17 (18%)	XXX	5	3
Homerton	5325	100%	0.9% (49)	0	0	454	190 (41.9%)	5	24	11 (38%)	2 (11.2%)	4	3
Newham	6581	100%	35.2% (2317)	0	0	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX
Royal London	5695	100%	N/A	41	XXX	292	271 (92.8%)	5	18	2 (8.7%)	2 (100%)	1	0
Whipps Cross	6868	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX
Chelsea & Westminster	6526	96%	40% (2506)	0	260	159	96 (60%)	4	3	1 (14.3%)	0	0	0
Ealing	3666	99.9%	6.5% (238)	3	N/K	142	109 (76.8%)	4	8	6 (50%)	N/K	2	1

Maternity unit	No. of bookings	No. of women screened	No. of women screened by 10 weeks	No of women not screened as screen before	No of women declining screening	No. of partners offered screening	No. of partners screened	No. of at risk couples Previously known	No. of at risk couples Diagnosed in this pregnancy	No. of at risk couples opting for prenatal Diagnosis	No. of prenatal tests performed by 11 weeks + 6 days	No of affected babies identified through prenatal diagnosis	No of women choosing termination of pregnancy
Hillingdon	4585	97.5%	70.5% of carriers	N/A	112-to be clarified	153	143 (93.5%)	4	3	3	3	0	0
NWL Hospitals	6243	100%	44% (2742)	0	0	311	201 (64.6%)	5	18	7	3	2	1
Imperial-QCCH	6140	89%	76% (3296)	1127	3	180	125 (69%)	13	15	17 (60.7%)	4 (23.5%)	4	4
Imperial- St Mary's	5090	96.8%	30.6% (1344)	165	0	227	99 (43.6%)	10	6	7 (43.8%)	0	1	0
West Middx	5346	100% (to clarify)	57% (3051)	990	103 (to clarify)	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX
Guys & St Thomas	7506	9089	39* but 41.9% booked by 12/40	All are re-screened	0	799	349 (44.7%)	XXX	XXX	9	1 (11%)	5	3
Kings College	6886	98.8%	29% (1796)	604	86	267	148 (55.4%)	12	31	6 (13.9%)	6 (100%)	2	1
Lewisham**	3649	4754	47.8% (1718) bkd by 10+6	XXX	XXX	121	77 (63.6%)	XXX	38	21 (55.3%)	3 (14.3%)	2	2
Princess Royal	4544	71.6%	N/K	N/K	N/K	49*	27* (55%)	2*	3*	0*	0*	0*	0*
Queen Elizabeth	4912	N/K	N/K	N/K	N/K	670	359 (53.6%)	N/A	51	28 (54.9%)	N/K	4	4
Queen Mary's	3405	N/K	3.2% (109)	N/K	3	163	158 (97%)	1	5	0	0	0	0
Epsom & St Helier's	5280	96.6%	11.4% (580)	1527 pr. screened but re-screened	0	98	67 (68.4%)	2	4	1 (16.7%)	0	0	0
Mayday	5820	96.4%	57% (local audit)	0	N/K	369	231 (62.6%)	24	32	15 (26.8%)	4 (26.7%)	4	2

Maternity unit	No. of bookings	No. of women screened	No. of women screened by 10 weeks	No of women not screened as screen before	No of women declining screening	No. of partners offered screening	No. of partners screened	No. of at risk couples Previously known	No. of at risk couples Diagnosed in this pregnancy	No. of at risk couples opting for prenatal diagnosis	No. of prenatal tests performed by 11 weeks + 6 days	No of affected babies identified through prenatal diagnosis	No of women choosing termination of pregnancy
St Georges	6575	91.6%	12.4% (621)	1016	1	207	158 (76.3%)	9	11	6 (30%)	1 (16.7%)	3	2
Kingston	6786	100%	16.3% (1103)	1513	0	134	73 (54.5%)	4	2	2 (33.3%)	2 (100%)	1	1

XXX- no answer given
N/A- data not available
N/K- not known
*incomplete data set
** Data supplied by specialist nurses used but differs from laboratory and fetal medicine data

Table 5: London antenatal screening laboratories practice on retesting women	
Maternity unit	**Antenatal sickle cell & thalassaemia re-screening policy in place- comments from units**
Barnet & Chase Farm	All women are re-screened in case the partner changes
North Middlesex	All are re-screened
Royal Free	All are re-screened
UCLH	Women who have previously been screened are offered screening again. If they are known to be carriers and there is no evidence of the result they are screened again. All results must be from a UK laboratory (this includes partners)
Whittington	In order to rule out any possibility of error, all women are retested even when there is documented evidence of a previous result
BHRT-Queen's Hospital	All are re-screened as laboratory cannot identify women who were screened previously
Homerton	Screening is not offered again if status is already known
Newham	No answer given
Royal London	All women are retested in each pregnancy, unless they carry a haemoglobinopathy card, even then most are retested
Whipps Cross	All are re-screened
Chelsea & Westminster	All are re-screened
Ealing	Women are not retested if there is a definite result with a legible laboratory number. If taken abroad retesting is recommended. If the previous result was a query or borderline and/or was taken more than 3 years ago they will be offered a retest
Hillingdon	If women have been tested at Hillingdon they will not be re-screened. Any woman not previously tested at Hillingdon will be retested.
NWL Hospitals	No answer given
Imperial-QCCH	Women who have been screened before and a normal result is available are not re-tested
Imperial-St Mary's	All women are re-screened at present but the unit plans to review this policy
West Middlesex	If a normal result is available for the midwife to see then screening is not repeated.
Guys & St Thomas	All are re-screened
Kings College	All women are re-screened unless there is a written report from a UK laboratory
Lewisham	All women are re-screened as bookings take place in the community and the midwife does not have access to previous results
Princess Royal	Women previously tested and results are on pathology system are not retested. Transfers in who have results from a UK laboratory are not re-screened.
Queen Elizabeth	All are re-screened
Queen Mary's	Women who have been tested before are not re-screened
Epsom & St Helier's	All are re-screened
Mayday	Samples are retested due to false identities, time consuming to filter those who have been screened before and screening acts as a trigger for partner testing
St Georges	Women are not rescreened if they have a previous result
Kingston	Women are not rescreened if they have a previous result

Table 6: Snap shot audits showing compliance of FOQ completion	
Maternity units	**FOQ audits**
Barnet & Chase Farm	No audit data supplied
North Middlesex	No audit data supplied
Royal Free	Planned for Nov 10
UCH	No audit data supplied
Whittington	**72%**
BHRT- Queen's Hospital	Unable to undertake at present as short staffed in lab
Homerton	No audit data supplied
Newham	**100%**
Royal London	**11.6%**
Whipps Cross	TBC- in progress
Chelsea & Westminster	No audit data supplied
Ealing	**85.6%**
Hillingdon	**100% but the family origin was stated as 'not known' in 20%**
NWL Hospitals	**98% - CMH** **90% - NPH**
Imperial- QCCH	**100%**
Imperial – St Mary's	**91.3%**
West Middlesex	No audit data supplied
Guys & St Thomas	No audit data supplied
Kings College	**76.2%- audit of electronic requests only, paper requests audit in progress**
Lewisham	No audit data supplied
Princess Royal	**95.4%**
Queen Elizabeth	Yet to implement policy
Queen Mary's	Yet to implement policy
Epsom & St Helier's	Unable to determine from data supplied
Mayday	**76%**
St Georges	**65%**
Kingston	Planned for Nov 10

7. Screening for Down's syndrome

7.1 Coverage

National standards recommend screening tests for Down's syndrome should be offered to all pregnant women presenting for maternity care, before twenty weeks of pregnancy http://fetalanomaly.screening.nhs.uk/standardsandpolicies#fileid11059

The combined test is the test of choice. All London units offer the combined test as the primary screening method. The recommended test for late bookers is the quadruple test. In 2009-10 some units in London offered the triple test but all units with the exception of Barking, Havering and Redbridge NHS Trust now offer the quadruple test as recommended. A breakdown is shown in Table 7.

There are no national targets for uptake as this screening programme requires women to be given information and supported to make a choice about whether they wish to have screening or not. http://fetalanomaly.screening.nhs.uk/standardsandpolicies#fileid11059 (Pages 43-44)

The average uptake of screening across the region was 73.3% (70.2% in 08/09). Uptake ranged from 49% at The Royal London to 98% at Guys & St Thomas. The Royal London despite having the lowest uptake rate in London this year increased from last year's 37.5%. The West Middlesex's uptake rate has also increased from 27% (08/09) to 69.5% (09/10). West Middlesex attributes this to better understanding by local users and improved effectiveness of counselling by midwives and sonographers. This is perhaps as a result of more dedicated hours for local screening coordinators seen at the West Middlesex this year.

It is worth noting that data collection is also challenging for this programme and the use of bookings as the denominator may not give a true refection as women booking late for care who are illegible for screening are included. The Whittington is the only unit that is currently able to calculate uptake based on eligible women due to the help of a data analyst at the Trust. Guys & St Thomas and Queen Charlotte's calculate uptake rates by extrapolating from the number of declines as opposed to using bookings. But not all units capture declines on an information system.

The coverage data also demonstrates that the majority of women having screening are having first trimester combined screening so this gives a good indication of early access to maternity care.

These data also show that there are some women in the region who were having nuchal translucency (NT) only screening tests in this timeframe. The NSC does not support NT only screening.

- The high number of NT only tests at Barnet & Chase Farm needs to be clarified as this was not the screening policy in that unit at the time.
- The Homerton and Newham offered and continue to offer twins NT only screening which is outside national policy.
- Chelsea & Westminster, St Georges and Guys & St Thomas' also offered NT only screening to twins but have since changed practice to combined screening as recommended.

There are also a few women who were found to have an increased NT and were offered an invasive test based on that finding which is within the national policy.

The average uptake of prenatal diagnosis for Down's syndrome was 60.8% (range of 27.4% at Barnet & Chase Farm to 87% at Epsom & St Helier's).

7.2 Screen positive rates

The estimated average screen positive rate for the combined test was 3.14% (5.0% in 08/09). The change in the national cut off that occurred during this time frame appears to have had the desired effect of reducing the screen positive rate.
The average screen positive for the triple test was 6.6% and 5.8% for the quadruple test.

Trust should ensure that they have failsafe systems in place to ensure all eligible women are offered appropriate screening and that uptake rates (whether high or low) are reflective of women making informed choices.

Table 7: Down's syndrome screening programme 09/10

Maternity unit	Bookings 1/04/09 - 31/03/10	No of primary screening tests	Primary screening tests (% of overall tests)- an indication of % of 1st trimester tests	No of high risk results from primary screening test	No of secondary screening test i.e. screening for late bookers	No of high risk results from secondary screening tests	No of NT only tests	No of high risk NT only	Overall uptake of Down's syndrome screening	Uptake of prenatal diagnosis for Down's syndrome	Total number of babies born with Down's syndrome in timeframe	No. of terminations of pregnancy for Down's syndrome
Barnet & Chase Farm**	7685	3864**	74.4%**	110 (2.9%) **	989**	116 (11.7%)	38	-	67.5%**	27.4%	1	36 TOPS in total
North Middlesex	3956	2312	79.3%	60 (2.6%)	605	44 (7.3%)	-	-	73.7%	55.8%	6	1
Royal Free	4009	4037	96.8%	106 (2.6%)	131	10 (7.6%)	4	1	Unable to calculate as tests > Bkgs	81.2%	5	4
UCLH	6409	5012 CT 314 IT	83%	294 (5.9%) 6 (1.9%)	365	15 (4.1%)	0	0	88.8%	75%	0	55 in total but includes external referrals
Whittington	4706	2391	80.7%	104 (4.4%)	571	31 (5.4%)	0	0	63%	53%	8	10
BHRT- Queen's Hospital	13038	8130	86%	197 (2.4%)	1320	85 (6.4%)	0	0	72.5%	N/K	2	13
Homerton	5325	3055	84.7%	89 (2.9%)	448	35 (7.8%)	105	13	67.8%	53.7%	6	11
Newham	6581	3255	66%	32 (1%)	1642	33 (2%)	27	1	74.8%	35%	1	0
Royal London	5695	2369	85.3%	57 (2.4%)	409	21 (5.1%)	0	0	49%	58%	2	2
Whipps X	6868	3370	82%	123 (3.7%)	741	36 (5%)	0	0	59.9%	75.5%	2	23

Maternity unit	Bookings 1/04/08 - 31/03/09	No of primary screening tests		No of high risk results from primary screening test	No of secondary screening test i.e. screening for late bookers	No of high risk results from secondary screening tests	No of NT only tests	No of high risk NT only	Overall uptake of Down's syndrome screening	Uptake of prenatal diagnosis for Down's syndrome	Total number of babies born with Down's syndrome in timeframe	No. of terminations of pregnancy for Down's syndrome
Chelsea & Westminster	6526	4558	91.9%	125 (2.7%)	326	6 (1.8%)	75	26	76%	81%	1	9
Ealing	3666	1865	80.8%	63 (3.4%)	438	23 (5.3%)	6	5	63%	55%	1	6
Hillingdon	4585	2286	80%	47 (2%)	577	22 (3.8%)	0	0	62.4%	49.3%	4	6
NWL Hospitals	6243	2812	78%	56 (2%)	797	43 (5.4%)	0	0	57.8%	72%	2	XXX
Imperial- QCCH	6140	4141 (3718 CT + 107 CT for Twins) 316 IT	91.6%	86 CT (2.3%) 10 IT (3.2%) 2 CT twins (1.9%) Overall 2.5%	358	21 (5.9%)	21	1	94.3%	54.4%	8	33
Imperial- St Mary's	5090	2162 CT +IT 2162 CT +IT	76.8%	58 (2.7%)	655	50 (7.6%)	0	0	55.3%	47%	6	XXX
West Middlesex	5346	2678	88.6%	68 (2.5%)	345	37 (10.7%)	0	0	56.5%	69.5%	2	8
Guys & St Thomas	7506	5907	78.7%	235 (4%)	658	41 (6.2%)	329 twins & triplets	42	98%	52.5%	7	18
Kings	6886	5318	89.4%	226 (4.3%)	628	25 (4%)	0	0	86.4%	66.5%	0	12
Lewisham	3649	2551	80.5%	95 (3.7%)	619	35 (5.7%)	0	14	87%	35.4%	3	7

Maternity unit	Bookings 1/04/08 - 31/03/09	No of primary screening tests		No of high risk results from primary screening test	No of secondary screening test i.e. screening for late bookers	No of high risk results from secondary screening tests	No of NT only tests	No of high risk NT only	Overall uptake of Down's syndrome screening	Uptake of prenatal diagnosis for Down's syndrome	Total number of babies born with Down's syndrome in timeframe	No. of terminations of pregnancy for Down's syndrome
Princess Royal	Included in Kings data											
Queen Elizabeth	4912	3121	85.2%	116 (3.7%)	541	38 (7%)	0	0	74.6%	XXX	XXX	XXX
Queen Mary's	3405	2390	93%	91 (3.8%)	180	13 (7.2%)	1	0	75.5%	86.5%	1- awaiting confirmation	2
Epsom & St Helier's	5280	4915	97%	123 (2.5%)	158	11 (7%)	0	3	96.1%	87%	6	5
Mayday	5820	2882	81%	91 (3.2%)	675	44 (6.5%)	0	0	61.1%	63%	3	6
St Georges	6575	5395	93.2%	211 (3.9%)	232	15 (6.5%)	160	46	88%	49.6%	1	8
Kingston	6786	5312	94.5%	192 (3.6%)	307	18 (5.9%)	2	0	82.8%	74.7%	5	11
Total		Average SPR Combined test 3.14%			Average SPR Triple test 6.6%		Average SPR Quadruple test 5.8%		Average 73.3%	Average 60.8%	82	Incomplete therefore total not calculated

XXX- no answer given

***BCFH supplied two data sets from different sources the averages of these were used so not a true reflection of coverage etc.*

8. Screening for infectious diseases in pregnancy

All pregnant women were offered and recommended screening for HIV, hepatitis B, syphilis and rubella susceptibility in each pregnancy in line with current national recommendations. Maternity Trusts report uptake rates and surveillance to the Health Protection Agency (HPA) London on a quarterly basis. At Homerton, Whipps Cross, The Royal London, Guys & St Thomas, and Epsom & St Helier's the number of women screened exceeds the number of women booked. This may be due to the fact that data on screened women are laboratory generated and may contain women who are screened prior to 'booking' and who subsequently miscarry, non pregnant women and/or repeat test. These data issues must be addressed locally. Booking data for the infectious diseases is also generated from the laboratory at Hillingdon, Lewisham and Kingston. Maternity units must be able to generate accurate booking data to monitor screening programmes and other aspects of care.

8.1 Prevalence

Table 8 below shows the prevalence based on data submitted for these annual reports over a three year period.

Table 8: Prevalence of infections in London (data based on annual reports)

Infection	London prevalence in 07/08	London prevalence in 08/09	London prevalence in 09/10
Syphilis	0.36%	0.41%	0.38%
Hepatitis B	1.04%	1.02%	1.02%
HIV	0.39%	0.39%	0.46%
Rubella	4.15%	5.0%	4.6%

8.2 Coverage

Coverage is good across London for all infections a shown in Table 10.

- Syphilis 84.5 -100% (average 96.7%)
- Hepatitis B 84.2-100% (average 96.8%)
- HIV 83.4 – 99.8% (average 95%)
- Rubella susceptibility 82.4-100% (average 96.7%)

Coverage is lowest for all infections at Barking, Havering and Redbridge NHS Trust and falls short of the national standards. In additional HIV screening coverage is less than the recommended 90% at The Royal Free and The Royal London.

8.3 Hepatitis B

Previous regional audits show that babies born to Hepatitis B positive mothers do not always receive complete protection i.e. only 45% of babies received all four doses of the vaccination [*I. Giraudon, N Permalloo et al / Vaccine 27 (2009) 2016–2022 linkinghub.elsevier.com/retrieve/pii/S0264410X08017258].* Maternity units are, on the whole, good at giving the first dose of vaccine but completion of the course relies on good links to primary care. The main barriers for incomplete vaccination were identified and these as well as solutions were highlighted to London PCT in May 2009 via a letter from Dr Pratibha Datta, NHS London immunisation lead (a copy is available from the regional coordinators). Maternity units, commissioners and immunisations leads are asked to address the issues highlighted in this letter.

8.3.1 Use of the Personal Child Health Record (PCHR)

One recommendation to improve complete vaccination is the use of the PCHR (red book) as a means of communication and information transfer from maternity services to primary care. In May 2009 a new standardised national version of the PCHR became available.

Maternity units were asked to use the national version of the PCHR and ensure each woman receives a copy of the PCHR before discharge from hospital with the relevant pages completed, including the hepatitis B page regardless of maternal status. The relevant completed copies can be sent to the local child health record department to support scheduling further vaccination appointments and to provide information to health visitors.

Please note when ordering the PCHR the person placing the order MUST specifically request books with the hepatitis B pages.

In 2009/10 the regional team asked all PCTs/ commissioners to support this.

Table 9 highlights where gaps still exist.

Table 9: Use of PCHR by maternity units in London	
Maternity units	**Use of PCHR**
Barnet & Chase Farm	Thanks to Kathryn Collins, NCL Maternity Project Manager this was commissioned on a sector level as is now in place for all units in North Central London.
North Middlesex	
Royal Free	
UCH	
Whittington	
BHRT- Queen's Hospital	In place for all
Homerton	**Yes but only for City & Hackney patients**
Newham	**?**
Royal London	**NO**
Whipps Cross	**NO-** in progress
Chelsea & Westminster	The maternity unit has taken the initiative and ordered PCHRs
Ealing	**Yes but Hep B pages needed**
Hillingdon	In place for all
NWL Hospitals	?
Imperial- QCCH	**Yes but only for Hammersmith & Fulham patients and Hep B pages needed**
Imperial – St Mary's	**Yes but only for Westminster patients**
West Middlesex	**Yes but Hep B pages needed**
Guys & St Thomas	**NO**
Kings College	**NO**
Lewisham	**NO**
Princess Royal	**Awaiting delivery of new books for Bromley patients only**
Queen Elizabeth	**Reported as inconsistent use**
Queen Mary's	**NO**
Epsom & St Helier's	**NO**
Mayday	In place
St Georges	**NO**
Kingston	**NO**

8.4 Rubella susceptibility

This is an important public health issue and concerning as most units in London do not have robust systems in place to ensure all susceptible women were vaccinated. NICE postnatal guidelines recommend pregnant women susceptible to rubella should be offered vaccination in hospital prior to discharge home http://guidance.nice.org.uk/CG37. This must be considered as a priority area for London Trusts and PCTs. Many maternity units are not able to report on the coverage of MMR vaccination to susceptible women and worryingly include those units with the highest susceptibility rates as shown in Table 10. Commissioners are asked to performance manage maternity units against this as a key area.

8.5 Revised national standards

Publication of the new UK NSC standards is imminent but a pre publication version of the programme standards and laboratory handbook can be found at http://infectiousdiseases.screening.nhs.uk/standards. Implementation of the new standards will begin across London from April 2011.

Table 10: Screening for infectious diseases in pregnancy programme 09/10

Maternity unit	Bookings	Uptake of Syphilis	No. of positive cases- Syphilis	Uptake of Hepatitis B	No. of positive cases- Hep B	Uptake of HIV	No. of positive cases- HIV (total)	No. of NEW HIV cases only	Uptake of Rubella	No. of Rubella susceptible women	No. of rubella susceptible women given MMR vaccination prior to discharge from hospital
Barnet & Chase Farm	7685	91.8%	27 (0.4%)	92.2%	63 (0.89%)	91.4%	10 (0.14%)	6	93.7%	134 (1.9%)	183#
North Middlesex	3956	100%	37 (0.94%)	100%	95 (2.4%)	99.8%	59 (1.5%)	41	99.9%	282 (7.1%)	43.3% (122)
Royal Free	4009	92.8%	35 (0.94%)	94%	33 (0.88%)	88.4%	16 (0.45%)	0	91.8%	189 (5.1%)	XXX
UCLH	6409	92.5%	5 (0.08%)	93.8%	45 (0.75%)	92.3%	22 (0.37%)	XXX	95.4%	211 (3.5%)	52.6% (111)
Whittington	4706	99.2%	12 (0.26%)	99.3%	63 (1.4%)	99.3%	15 (0.32%)	4	99.8%	249 (5.3%)	92.4% (230)
BHRT- Queen's Hospital	13038	84.5%	66 (0.6%)	84.2%	118 (1.07%)	83.4%	32 (0.3%)	XXX	82.4%	127 (1.18%)	0
Homerton*	5325	103.6%	23 (~0.43%)	105.2%	92 (~1.7%)	101.8%	39 (~0.73)	6	103.8%	226 (~4.2%)	75.5% (107) Of those delivered
Newham	6581	98.8%	53 (0.82%)	98.8%	97 (1.5%)	98.7%	50 (0.77%)	19	98.5%	336 (5.2%)	XXX
Royal London*	5695	5731	0	5744	70 (~1.2%)	88%	23 (0.46%)	0	5718	253 (4.4%)	XXX
Whipps X*	6868	7370	35 (~0.5%)	7370	86 (~1.25%)	7370	15 (~0.2%)	6	7370	598 (8%)	XXX
Chelsea & Westminster	6526	96%	19 (0.3%)	96%	36 (0.6%)	96%	22 (0.35%)	3	96%	369 (6%)	XXX
Ealing	3666	97.4%	11 (0.3%)	97.2%	30 (0.84%)	95.3%	15 (0.43%)	4	97.4%	224 (6.3%)	XXX
Hillingdon**	4788	100%	8 (0.17%)	100%	38 (0.8%)	91.1%	5 (0.1%)	1	100%	165 (3.5%)	94.6% (156)

Maternity unit	Bookings	Uptake of Syphilis	No. of positive cases- Syphilis	Uptake of Hepatitis B	No. of positive cases- Hep B	Uptake of HIV	No. of positive cases- HIV (total)	No. of NEW HIV cases only	Uptake of Rubella	No. of Rubella susceptible women	No. of rubella susceptible women given MMR vaccination prior to discharge from hospital
NWL Hospitals	6243	99.9%	24 (0.39%)	99.9%	79 (1.3%)	99.8%	27 (0.43%)	3	99.9%	471 (7.6%)	88% (415)
Imperial- QCCH	6140	99.9%	9 (0.15%)	99.9%	34 (0.55%)	99.8%	5 (0.8%)	4	99.9%	228 (3.7%)	91.2% (208)
Imperial- St Mary's	5090	96%	27 (0.6%)	95.3%	41 (0.86%)	94.4%	36 (0.75%)	5	95.1%	150 (3.1%)	52.7% (79)
West Middlesex	5436	99.4%	7 (0.13%)	99.4%	30 (0.57%)	96.8%	14 (0.27%)	3	99.5%	160 (3%)	41.9% (67)
Guys & St Thomas*	7506	8446	35 (0.41%)	8455	99 (1.2%)	8425	45 (0.53%)	33	8456	xxx	xxx
Kings College	6886	94.4%	48 (0.74%)	94.4%	111 (1.7%)	93.5%	66 (1%)	23	94.5%	199 (3.1%)	57.3% (114)
Lewisham**	4618	99.8%	30 (0.65%)	100%	64 (1.4%)	99.1%	28 (0.61%)	10	100%	418 (9.1%)	0
Princess Royal	4544	96.5%	5 (0.11%)	96.6%	27 (0.62%)	95%	6 (0.14%)	1	96.6%	208 (4.7%)	31.3% (65)
Queen Elizabeth	4912	xxx	xxx	xxx	xxx	xxx	xxx	xxx	xxx	xxx	xxx
Queen Mary's	3405	100%	5 (0.15%)	100%	21 (0.62%)	97.6%	0	0	100%	252 (7.4%)	xxx
Epsom & St Helier's*	5280	5348	9 (0.17%)	5340	19 (0.36%)	5343	8 (0.15%)	3	5354	138 (2.6%)	78.3% (108)
Mayday	5865	99.9%	8 (0.14%)	99.9%	64 (1.1%)	99.8%	33 (0.56%)	1	99.9%	284 (4.9%)	xxx
St Georges	6575	91.2%	19 (0.32%)	91%	33 (0.55%)	91%	26 (0.43%)	4	91%	145 (2.4%)	76.2% Of those delivered
Kingston**	6786	100%	4 (0.06%)	100%	28 (0.41%)	99.6%	11 (0.16%)	5	100%	163 (2.4%)	20.3% (33)
Total (average)		**96.7%**	**0.38%**	**96.8%**	**1.02%**	**95%**	**0.46%**	**185**	**96.7%**	**4.6%**	

This figure needs to be clarified as number of women receiving MMR is greater than the number of susceptible women xxx- no data supplied
*units where the number of test exceeds the number of bookings ** units where the denominator booking data is laboratory generated

9. Fetal anomaly ultrasound screening

National standards recommend all women should be offered two scans in pregnancy http://fetalanomaly.screening.nhs.uk/standardsandpolicies

All pregnant women in London are offered two scans, a dating and a fetal anomaly scan. This includes women who book for care late and are at an appropriate gestational age. The gestational age recommended by the UK NSC for mid trimester fetal anomaly scans is 18 weeks and zero days to twenty weeks and six days (18+0 to 20+6). Only seven units in London are currently meeting this standard, the remaining units all perform the anomaly scan at later gestational ages.

The national fetal anomaly ultrasound menu and standards published in January 2010 reiterates the gestational age range for performing the anomaly scan and outlines the structures that should be examined at the fetal anomaly ultrasound scan http://fetalanomaly.screening.nhs.uk/getdata.php?id=11218 Ultrasound departments are required to implement the core standards outlined by April 2011.

9.1 Coverage

Although it appears that coverage is 100% in most instances it is evident from the data submitted that it is a challenge to accurately report coverage for dating and anomaly scans (See Table 12). This is due to difficulties with an appropriate denominator as when 'booking' is used some women miscarry between having a dating and an anomaly scan and women who transfer or book late may have a dating and anomaly scan at the same time.
Dating scans in London are performed at the same time as offering first trimester combined screening for Down's syndrome i.e. between 11 and 13 weeks and 6 days.

9.2 The fetal anomaly screening programme (FASP) auditable conditions

As part of the national standards for the 18+0 to 20+6 week anomaly scan the national programme defines 11 conditions that ultrasound departments are required to monitor themselves against from April 2010. Departments are required to report on the detection rates for these conditions listed in Table 11 below. We asked ultrasound departments to report on these for 09/10 if they were able to, to gauge how many units have the ability to do this. Of the 27 units, 2 provided data on detection rates, 10 could provide data on the number of cases identified and the remaining 15 units did not provide data.

Table 11: FASP auditable conditions (from April 2010)		
Conditions	**Number of cases identified**	**Detection rates**
Anencephaly		
Open spina bifida		
Cleft lip		
Diaphragmatic hernia		
Gastroschisis		
Exomphalos		
Serious cardiac abnormalities		
Bilateral renal agenesis		
Lethal skeletal dysplasia		
Edwards syndrome (T18)		
Patau's syndrome (T13)		

Table 12: Fetal anomaly ultrasound screening programme 09/10

Maternity unit	Gestational age range for dating scans (weeks + days)	Gestational age range for anomaly scan (weeks + days)	No. of bookings 08/09	No. of dating scans	Uptake of dating scans	No. of anomaly scans	Uptake of anomaly scans	No. of Anencephaly's diagnosed	No. of other neural tube defects diagnosed	No. of gastroschisis diagnosed
Barnet & Chase Farm	11-13+5	19-22	7685	8577	~80%	8000	XXX	3	6	2
North Middlesex	11-13+6	19-21+6	3956	3335	84%	3772	94%	1	1	1
Royal Free	11- 13+6	19- 20+6	4009	4453	100%	3995	99.7%	1	0	0
UCLH	11- 13+6	20- 22+6	6409	>4947	XXX	>4947	XXX	1	XXX	11
Whittington	11-13+6	18-20+6	4706	4560	96.8%	4170	88.6%	1	8	1
BHRT-Queen's Hospital	11-13+6	20+6-22+6	13038	9846	76%	11086	85%	XXX	XXX	XXX
Homerton	11+2- 13+6	18- 20+6	5325	4505	84.6%	4441	83.4%	2	5	3
Newham	10-18	20-23	6581	XXX	72%	5502	84%	0	2	1
Royal London	11-14	18-20+6	5695	4390	85.1%	5237	100%	2	0	9
Whipps Cross	10-19	20-22+6	6868	1026 dating only	91.3%	5400	95.1%	2	1	5
Chelsea & Westminster	11-13+6	18-20+6	6526	5872	90%	4637	71%	4	1	1
Ealing	12	20-22	3666		83%	XXX	74%	5	2	1
Hillingdon	11-13+6	18-20+6	4585	4835	~100%	5156	99%	0	3	2
NWL Hospitals	Up to 20+5	18-21	6243	5359	85.8%	5291	~90%	2	0	4

Maternity unit	Gestational age range for dating scans (weeks + days)	Gestational age range for anomaly scan (weeks + days)	No. of bookings 08/09	No. of dating scans	Uptake of dating scans	No. of anomaly scans	Uptake of anomaly scans	No. of Anencephaly's diagnosed	No. of other neural tube defects diagnosed	No. of gastroschisis diagnosed
Imperial- QCCH	11-13+6	18-20+6	6140	XXX	100%	XXX	100%	2	1	1
Imperial- St Mary's	11-13	19-21	5090	5101	100%	4729	100%	2	0	1
West Middlesex	11-13+6	20-20+6	5346	Currently unable to extract data				1	0	1
Guys & St Thomas			7506	6565		6822	100%	6	8	13 exomphalos
Kings College	11-12+6	20-22+6		5318	99.7%	5072	95%	3	1	2
Lewisham		19-20	4226	4372	100%	3640	100%	1	2	3
Princess Royal	11- 13+6	20+4	4544		XXX	4157	91.4%	0	0	0
Queen Elizabeth	11-14	18-20+6	4912	4635	94.4%	4710	95.9%	XXX	XXX	XXX
Queen Mary's	11-13+4	20-20+6	XXX	XXX	XXX	XXX	XXX	XXX	XXX	XXX
Epsom & St Helier's	11+2-13+6	19-23	5280	4808	91%	5109	96%	1	2	4
Mayday	11-14+1	18-21+6	5820	4379	75.2%	4217	72.5%	2	1	0
St Georges	11-13+6	20-21	6575	5627	85.5%	6729	100%Kings+	7	23	11
Kingston	11+ 5-13+ 6	20-22	6786	6685	98%	6584	97%	3	1	0
Total								52	68	77

XXX- no answer given

10. Prenatal diagnosis

There were 15 centres in London where chorionic villi sampling (CVS) procedures were performed, seven of which were also referral centres (St Mary's only have referrals from North West London hospitals) as shown in Table 13. Newham started performing CVSs in December 2009. All but three units undertook amniocenteses in house. There was an estimated total of 4590 invasive procedures performed in London in 2009/10 with a 56.7% - 43.3% split between CVSs and amniocenteses as shown in Table 14.

The data presented in Table 14 is an estimate as there may be some double counting of women who are referred to tertiary centres for invasive procedures. It is important for referring units to monitor the outcomes for women sent to tertiary units. The annual report template for 2010/11 should be revised to capture more accurate data in order to accurately assess the provision of services across London as there may be a case to centralise these services both in terms of safety and cost. The RCOG guidance states that competency should be maintained by carrying out at least 30 ultrasound guided procedures a year and there is evidence that operator experience is important, with better outcomes for operators who perform over 100 procedures each year http://www.rcog.org.uk/files/rcog-corp/GT8Amniocentesis0610.pdf.

Table 13: London invasive testing and referral centres 09/10 (*Referral centres are in bold text)				
Maternity Trusts	**CVS performed in house**	**Referral centre (s)**	**Amniocentesis Performed in house**	**Referral centre(s)**
Barnet & Chase Farm	No	UCH	Yes	N/A
North Middlesex	No	UCH, Homerton, St Georges & Kings	Yes	N/A
Royal Free	Yes	N/A	Yes	N/A
UCLH*	Yes	N/A	Yes	N/A
Whittington	Yes	UCH for sickle	Yes	N/A
Queen's Hospital	Yes	Kings for sickle	Yes	N/A
Homerton*	Yes	N/A	Yes	N/A
Newham	Yes	N/A	Yes	N/A
Royal London	Yes	N/A	Yes	N/A
Whipps Cross	No	Homerton, Kings	Yes	N/A
Chelsea & W'minster	Yes	N/A	Yes	N/A
Ealing	No	QCCH	Yes	N/A
Hillingdon	No	QCCH, UCH & Kings	Yes	N/A
NWL Hospitals	No	QCCH, St Mary's UCH for sickle	Yes	N/A
Imperial- QCCH*	Yes	N/A	Yes	N/A
Imperial- St Mary's*	Yes	N/A	Yes	N/A
West Middlesex	No	QCCH	No	QCCH
Guys & St Thomas*	Yes	N/A	Yes	N/A
Kings College*	Yes	N/A	Yes	N/A
Lewisham	Yes	Kings for A/L cover	Yes	N/A
Princess Royal	No	Kings, St Thomas	No	Kings, St Thomas
Queen Elizabeth	No	Kings, St Thomas	No	Kings, St Thomas
Queen Mary's	No	Kings	Yes	N/A
Epsom & St Helier's	Yes	N/A	Yes	N/A
Mayday	No	St Georges	Yes	N/A
St Georges*	Yes	N/A	Yes	N/A
Kingston	No	St Georges, Kings	Yes	N/A

Table 14: Number and indication of invasive procedure performed per centre 09/10 (*Referral centres are in bold text)						
Maternity Trusts	**Total no. of CVSs**	**Total no. of Amniocenteses**	**No. of prenatal diagnoses by screening programme**			
			Sickle Cell & Thalassaemia	**FASP (Down's syndrome)**	**FASP (Ultrasound**	**Other reasons**
Barnet & Chase Farm	24	**52**	XXX	62	XXX	14
North Middlesex	49	**36**	13	59	11	2
Royal Free	**95**	**59**	4	95	18	37
UCLH*	**553**	**334**	86	511	146	144
Whittington	**61**	**58**	0	71	24	24
BHRT-Queen's Hospital	**122**	**110**	XXX	XXX	XXX	XXX
Homerton*	**203**	**36**	27	182	19	11
Newham	**1**	**73**	XXX	59	15	1
Royal London	**24**	**52**	2	45	6	23
Whipps X	83	**37**	XXX	2	0	0
Chelsea & Westminster	**116**	**124**	1	134	30	75
Ealing	25	**44**	6	47	7	8
Hillingdon	20	**35**	3	34	12	6
NWL Hospitals	13	**71**	7	72	XXX	12
Imperial- QCCH*	**190**	**325**	17	181	207	108
Imperial- St Mary's*	**35**	**74**	8	51	34	16
West Middlesex	64		9	17	34	4
Guys & St Thomas*	**144**	**184**	9	167	51	101
Kings College*	**212**	**30**	6	167	XXX	69
Lewisham	**17**	**31**	5	26	16	1
Princess Royal	XXX		XXX	XXX	XXX	XXX
Queen Elizabeth	XXX	XXX	XXX	66	XXX	XXX
Queen Mary's	XXX	XXX	XXX	90	XXX	XXX
Epsom & St Helier's	**73**	**70**	1	117	16	9
Mayday	XXX	XXX	15 (Kings)	XXX	XXX	XXX
St Georges*	**758**	**133**	12	708	84	87
Kingston	182	**18**	2	157	20	21
Total	**2604**	**1986**				

11. Newborn bloodspot screening

Sector reports on the performance of newborn bloodspot screening (2005-2009) are also available and can be accessed from http://www.screening.nhs.uk/london
These will up updated by November 2010 to incorporate more recent data.

Much work and training has taken place this year to implement the mandate for the Baby's NHS on bloodspot cards. Generally there is good compliance from most areas. South West and South East London laboratories now only have about 5 bloodspot cards with missing NHS numbers per week, and Great Ormond Street laboratory has seen a reduction from 300 cards without NHS numbers a week to approximately 15 per week and we would like to thank midwives, neonatal units and all staff responsible for this improvement.

Neonatal units must remember that both the admission/pre-transfusion cards must be completed fully including documentation of the Baby's NHS number.

To help achieve 100% compliance of NHS numbers bar code labels for bloodspots has been recommended and implementation is being supported by the national programme.

Table 15 shows implementation progress for newborn bloodspot bar code labels. Success is dependent on system suppliers and maternity/Trusts IT departments. Trusts failing to achieve this are falling short of meeting national standard which states that **95% of blood spot cards received by the laboratory should have a label that includes the information standard board (ISB) approved bar-coded babies' NHS number (April 2010).**

The ability of Trusts to issue bar coded labels depends on the electronic maternity system used in the trust. Cerner is significantly delaying six Trusts from achieving this standard and a solution from Cerner is unlikely to be imminent. This puts Trusts at significant risk by not meeting the national standards but more importantly put babies at potential risk as midwives and screening laboratories are relying on hand written NHS numbers and these are subject to transcription errors.

Table 15: Newborn bloodspot bar code labels- London's implementation progress

Status as of 13th October 2010

Maternity unit	Maternity system	Status
Barnet & Chase Farm	CMIS	Live
West Middlesex	CMIS	Live
NWLH	CMIS	Live
St Mary's	CMIS	Live
Chelsea & Westminster	CMIS	Labels to be verified
North Middx	Protos	Live
PRUH	Protos	Live Sept 10
Epsom & St Helier's	Protos	Upgrade happened 30/08/10 Expected to go live soon
Mayday	Protos	Awaiting upgrade of maternity system
Queen Elizabeth	Mc Kesson Star	Live
Whittington	PAS- INNS	Live
Whipps X	PAS- INNS	Live
Queen Charlottes	PAS- INNS	Live
GSTT	Terranova	Live
Lewisham	Terranova	Live
Portland	Meditech- INNS	Live
Kings	Euroking E3	Live Sept 10
Hillingdon	Euroking E3	Live
BHRT	Euroking E3	Live
Ealing	Euroking K2	Live
Queen Mary's	Euroking K2	Live
UCH	Eclipse	Awaiting upgrade of maternity system Oct 2010
Royal Free	Cerner	
Royal London	Cerner	
Kingston	Cerner	
Homerton	Cerner	Testing possible solution but need resolution from Cerner for bar code label
Newham	Cerner	Testing possible solution but need resolution from Cerner for bar code label
St Georges	Cerner (Euroking)	Interface between Euroking & Cerner in progress

12. Education & Training

A detailed education and training report covering the regional and training activities in 2009/10 can be accessed from http://www.screening.nhs.uk/getdata.php?id=9956. These data are shared with the Care Quality Commission (CQC). The local screening coordinators and all those who support them to deliver education and training at a local level must be highly commended as training activities continues to increase under challenging conditions. This will in no doubt improve the quality of screening programmes.

13. Acknowledgements

Thanks to all local screening coordinators, specialist midwives, sonographers, haemoglobinopathy specialist nurses, fetal medicine departments, screening laboratories and all who provided data or contributed to local reports and who continue to work hard to improve services for women and their families each year.

If you have any comments about this report and particularly how it may be improved please pass on your comments to nadia.permalloo@nhs.net

14. Priorities for improvement

Although services for women and their families are continuously improving, we need to keep screening programmes running well and safely and to ensure risks are managed effectively. This section highlights priorities for 2011.

41.1 Complete and robust data

Accurate data collection processes and systems are needed. The variable quality of data is highlighted throughout this report. Provision of accurate booking data is a priority. The UK NSC are about to formally published key performance indicators (KPIs) for the non cancer screening programmes (including antenatal and newborn screening programmes) and a decision has been made that where data fails to meet the strict definitions Trusts will be expected to provide a nil (blank) return. Some of the KPIs are very dependent on accurate booking data. This should be addressed urgently as the collections of KPIs are due to commence later this year. More information abut the KPIs can be found at http://www.screening.nhs.uk/kpi

As a pre-amble to the formal launch of the KPIs we tested one of the KPIs in this reporting period and the results can be seen in Appendix 1.

14.2 Coordination of local screening programmes

As the UK NSC moves from implementation to quality assurance maternity units may find that they come under more scrutiny and as such local programmes need to be able to measure against national quality standards. Trusts that are yet to invest in a local screening coordinator and adequate support for those roles may find that they are left behind. Trusts and commissioners should address gaps where they exist urgently. Administrative support is crucial for these roles especially with the expectation of KPIs and possible quality assurance visits.

14.3 Local guidelines

Newborn bloodspots guidelines that cover the all babies less than one year of age must be in place for each locality. This should be completed as soon as possible.

14.4 Screening for sickle cell and thalassaemia in pregnancy

There are a number of areas for improvement:

14.4.1 Early screening by 10 weeks of pregnancy needs to be actively implemented and data capture to report on performance against this standard is required.

14.4.2 Uptake of partner testing needs to improve in many areas and commissioners are asked to look at the pathways for achieving this. This needs to be done in a timely manner as only 16.8% of prenatal diagnoses were performed by the recommended 11 weeks and 6 days of pregnancy.

14.4.3 Family origin questionnaire
14.4.3.1 The two outstanding units must implement by December 2010.
14.4.3.2 All maternity units must ensure 100% accurate compliance of completion of the FOQ
14.4.3.3 All units should explore options of an electronic FOQ

14.5 Screening for Down's syndrome
14.5.1The one outstanding unit must implement the quadruple test as soon as possible to meet national standards and policy recommendations.
14.5.2 All units should offer twin pregnancies combined screening for Down's syndrome in line with national policy.

14.6 Screening for Infectious diseases in pregnancy
14.6.1 Commissioners need to ensure the PCHR is commissioned appropriately so that every mother in London can receive a copy in hospital before discharge irrespective of which borough she resides in or which GP she is registered with. The model used in North Central London can be mirrored.
14.6.2 Trusts with low coverage are asked to address this with urgency.
14.6.3 Maternity units must resolve any issues around MMR coverage and ensure all rubella susceptible women receive the first dose of MMR in hospital before discharge.

14.7 Fetal anomaly ultrasound screening
14.7.1 All ultrasound departments must offer the mid trimester scan within the time frame and in line with standards specified by the national programme i.e. 18+0 to 20+6 weeks
14.7.2 Monitoring the FASP auditable conditions will be a challenge for ultrasound departments in London as there is no regional congenital malformation register and therefore it is not possible to provide accurate detection rates. There are also some ambiguities with the criteria as it is unclear in cases where a baby has multiple abnormalities whether this should be recorded based on the main abnormality so the baby is captured once or whether the every abnormality should be recorded. The term serious cardiac abnormality also needs to be defined to have consistent reporting.

14.8 Newborn bloodspot screening

14.8.1 Continued use of the baby's NHS number on all bloodspot cards is required. This particularly applies to neonatal units and to pre-transfusion/ admission samples.

14.8.2 All outstanding maternity units are to implement bar code labels and if systems suppliers are not able to support this it should be highlighted as an area of risk to clinical governance leads locally.

Appendix 1: Example of key performance indicator for infectious diseases		
Maternity units	**Total number of Hepatitis B positive (HbsAg) mothers**	**Number of Hepatitis b positive mothers referred for specialist assessment within 6 weeks of identification**
Barnet & Chase Farm	XXX	XXX
North Middlesex	Not available	Not available
Royal Free	33- 11 new cases	11 All known cases already in care
UCLH	XXX	XXX
Whittington	XXX	XXX
BHRT-Queen's Hospital	118	Data collection put in place for 2010/2011
Homerton	92	80 women referred before delivery. Unable to specify time of referral. Insufficient data is available to confirm referral to gastroenterology of the remaining 12 women
Newham	97	97
Royal London	Meeting with hepatologist to discuss	
Whipps Cross	86	86
Chelsea & Westminster	36	36
Ealing	XXX	XXX
Hillingdon	38	38
NWL Hospitals	79	79
Imperial- QCCH	34	All referred but not necessarily within 6 weeks
Imperial- St Mary's	41	23, the other women all had previous referrals or refused a referral
West Middlesex	30	28 +2 already in care
Guys & St Thomas	XXX	XXX
Kings College	109	109
Lewisham	64	Data not available
Princess Royal	27	All women referred to an obstetrician at diagnosis. At present we have no specialist hepatologist.
Queen Elizabeth	Not known	Not known
Queen Mary's	21	21
Epsom & St Helier's	19	0 (7 already in care)
Mayday	XXX	XXX
St Georges	33	20 referred within 6 weeks 3 women under the care of hepatology from referrals in previous pregnancies. 9 women referred between 7-10 weeks
Kingston	28	19 (+ 9 already in care)