7.1.1 Antenatal and newborn screening Brighton & Hove JSNA 2015

Why is this issue important?

Around 700,000 women get pregnant in the UK each year and over 95% of these pregnancies result in the birth of a healthy baby. Antenatal and newborn screening identifies diseases or conditions in the mother that may impact on her pregnancy, in the foetus and in the newborn baby.

Table 1: NHS screening programmes in England
Infectious diseases screening is offered to all women in early pregnancy and tests for Hepatitis B, HIV, syphilis and rubella susceptibility.
Fetal anomaly screening (FASP) is offered to all women and includes a test for Down's syndrome and an ultrasound scan to check for physical abnormalities.
Antenatal and newborn sickle cell and thalassaemia[1] **programme** offers a linked programme of screening for all pregnant women and screening for sickle cell disease for all newborn babies.
Newborn and Infant Physical Examination Programme (NIPE) offers all babies an all over physical check and examination of eyes[2], heart[3], hips[4] and testes[5] (boys) at 72 hours after birth and again at 6-8 weeks old.
Newborn bloodspot screening is offered to all parents and screens for phenylketonuria (PKU),[6] congenital hypothyroidism (CHT),[7] sickle cell disease (SCD)[8], cystic fibrosis (CF)[9] and medium-chain acyl-CoA dehydrogenase deficiency (MCADD).[10]
The **newborn hearing screening programme (NHSP)** is offered to all babies aiming to identify moderate to profound permanent bilateral deafness within 4-5 weeks of birth.[11]

[1] Estimated one case of alpha thalassaemia major and 234 pregnant carriers of α thalassaemia each year in England and Wales.
[2] About two hundred children a year are born in the UK with opacity of the lens of one or both eyes - a cataract.
[3] Congenital heart anomalies affect about 8 in 1000 (approx. 1%) newborn babies.
[4] 1 to 2 in 1,000 babies born may have a hip that is dislocated at birth. A slightly larger group have hips which are not safely in the socket or in whom the socket is shallower than it should be
[5] Around one in 20 male babies is born with Cryptorchidism (undecended testicles) which is most common in premature babies. The incidence at the age of one year is around 1%.
[6] About 1 in 10,000 babies born in the UK has phenylketonuria (PKU).
[7] About 1 in 4,000 babies born in the UK has congenital hypothyroidism (CHT).
[8] About 1 in 1,900 babies born in the UK has a sickle cell disease (SCD).
[9] About 1 in 2,500 babies born in the UK has cystic fibrosis (CF).
[10] About 1 in 10,000 babies born in the UK has MCADD.
[11] 1-2 babies in every 1,000 are born with a hearing loss in one or both ears.

Key outcomes

- ***HIV coverage – The percentage of pregnant women eligible for infectious disease screening who are tested for HIV, leading to a conclusive result***
- ***Syphilis, hepatitis B and susceptibility to rubella uptake: The percentage of women booked for antenatal care, as reported by maternity services, who have a screening test for syphilis, hepatitis B and susceptibility to rubella leading to a conclusive result***
- ***The percentage of pregnant women eligible for antenatal sickle cell and thalassaemia screening for whom a conclusive screening result is available at the day of report***
- ***The percentage of babies registered within the local authority area both at birth and at the time of report who are eligible for newborn blood spot screening and have a conclusive result recorded on the Child Health Information System within an effective timeframe.***
- ***The percentage of babies eligible for newborn hearing screening for whom the screening process is complete within 4 weeks corrected age (hospital programmes – well babies, all programmes – NICU babies) or 5 weeks corrected age (community programmes – well babies)***
- ***The percentage of babies eligible for the newborn physical examination who were tested within 72 hours of birth***

(Public Health Outcomes Framework)

Quarterly submission of CCG and Hospital Trust performance against National Key Performance Indicators (KPIs) began in 2011/12. Quality assurance and performance management are an integral part of all national screening programmes.

Impact in Brighton & Hove

The most recent data submission for performance against KPIs is for October - December 2014:

Infectious diseases: Among pregnant women booked for antenatal care during the reporting period, or presenting in labour without previously having booked for antenatal care (excluding:

women who miscarry, opt for termination or transfer out between booking and testing), 99.5% were screened for HIV (Acceptable ≥90%) (ID1). This includes women who were known to be HIV positive at booking and were therefore not retested and women who transfer in for care during the reporting period with documented evidence of a screening test result during the pregnancy (and therefore not retested). All (100%) of hepatitis B positive women at Brighton & Sussex University Hospitals (April – December 2014) were referred and seen by an appropriate specialist within six weeks (Acceptable ≥70%; Achievable ≥90%) (ID2).

Foetal anomaly and Downs syndrome screening: 99.5% of completed laboratory forms at Brighton & Sussex University Hospitals were received within the recommended time frame (Acceptable ≥97%; Achievable 100%) (FA1).

Antenatal sickle cell and thalassaemia: The proportion of eligible women who are tested and have a conclusive result is 99.7% (Acceptable ≥95%; Achievable ≥99%) (ST1). The proportion tested with a conclusive result by 10 weeks gestation was 51.0% (Acceptable ≥ 50%; Achievable ≥ 75%) (ST2). The proportion of samples submitted to the laboratory with a Family Origin Questionnaire was 98.8% (Acceptable ≥90%; Achievable ≥ 95%) (ST3).

Newborn bloodspot: The proportion of screen eligible Brighton & Hove CCG babies with a conclusive result for phenylketonuria recorded on the child health system by 17 days is 75.0% (Performance threshold ≥95%) (NB1). The reason for this performance is still being investigated but it may be related to software issues rather than actual delays in patient care. The avoidable repeat rate at BSUH is 4.5% (Acceptable ≤2%; Achievable ≤0.5%) (NB2). The local hospital is working on improving its processes and pathways and improving staff training. The proportion of results (screen negative for all conditions) available for communication to parents within six weeks of birth in Brighton & Hove is 99.7% (Acceptable ≥95%; Achievable ≥98%) (NB3).

Newborn hearing screening: The proportion of eligible babies in Brighton & Hove CCG area whose screening process is complete by four weeks corrected age is 99.0% (Acceptable ≥95%; Achievable ≥99.5%) (NH1). The percentage of babies referred and receiving their audiological assessment within four weeks is 90.9%, (Acceptable ≥95.0%; Achievable ≥99.5%) (NH2).

NIPE: A national pilot was established in 2011 to better understand how care is delivered and to test the Screening Management and Reporting Tools. Brighton & Sussex University Hospitals was one of the pilot sites and the results of the formal evaluation should soon be available.

Where we are doing well

Most key performance indicators are being met.

Good collaborative working is in place across screening pathways.

Local inequalities

There is no local analysis of screening up-take by deprivation or equalities groups.

Predicted future need

Additional genetic tests may be introduced into the newborn bloodspot following the outcome of the pilot of five additional conditions, which is currently in progress.

The roll out of NIPE (Newborn and Infant Physical Examination Programme) 72 hour screening test will be rolled out shortly.

Inclusion of the six week check in NIPE will impact on child record systems and GP practices in the future.

What we don't know

There is no local analysis of screening up-take by deprivation or equalities groups.

Additionally, there is no local analysis to identify who does not take up the offer of screening.

Key evidence and policy

All potential screening programmes are the subject of a policy review and assessed against a number of criteria before the UK National Screening Committee decides whether a national screening programme is appropriate.

7.1.1 Antenatal and newborn screening

There are national standards and guidelines for each NHS screening programme:

Infectious diseases
http://infectiousdiseases.screening.nhs.uk/standards

Foetal anomaly screening programme
http://fetalanomaly.screening.nhs.uk/standardsandpolicies

Newborn bloodspot
http://newbornbloodspot.screening.nhs.uk/quality

Linked antenatal and newborn screening programme (2011)
http://sct.screening.nhs.uk/standardsandguidelines

Newborn Infant Physical Examination
http://newbornphysical.screening.nhs.uk/cms.php?folder=2366

Newborn hearing screening
http://hearing.screening.nhs.uk/standardsandprotocols

Recommended future local priorities

- Public Heath England screening and immunisations team to ensure that performance data is routinely reported to Brighton and Hove City Council Public Health as part of the requirement in the new public health system for local authorities to lead health improvement including local efforts to protect the health of the population.
- This will enable Public Health in the city to be more actively involved in supporting the performance of these screening programmes if required.
- Brighton and Hove CCG to encourage an improvement in the proportion of women booking by 12 weeks of pregnancy as this impacts on the proportion who have antenatal sickle cell and thalassaemia screening by 10 weeks.

Key links to other sections

- Maternal and infant health

Further information

Commissioning frameworks for all programmes:
http://www.screening.nhs.uk/quality-assurance#fileid9864

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