Public Health Outcome Framework (PHOF) Summary

Outcome Title: Maternal & Infant Screening

Context
The Public Health Outcomes Framework (PHOF) 'Healthy lives, healthy people: Improving outcomes and supporting transparency' sets out a vision for public health, desired outcomes and the indicators that will help us understand how well public health is being improved and protected. The framework concentrates on two high-level outcomes to be achieved across the public health system, and groups further indicators into four 'domains' that cover the full spectrum of public health. The outcomes reflect a focus not only on how long people live, but on how well they live at all stages of life.

Why is Maternal & Infant *Screening* an issue?
Screening tests are offered to apparently healthy individuals to identify if they at increased risk of having a particular condition[1]. It is undertaken to both reduce the impact of future ill health as care can be accessed sooner, and to give information so that further decisions and preparations can be made[2]. Although screening is offered, people must be able to make an informed choice as to whether they wish to undertake the screening[3]. Information should be given about the consequences of testing so that an informed decision can be made[3].

What does the evidence show?
Infectious disease Screening
All women should be offered an infectious disease screen in pregnancy which covers hepatitis B, HIV, syphilis and susceptibility to rubella. This should take place early in the antenatal period so that appropriate treatment can be given and to reduce the risk of transmission to current and potential future children[4]. If the woman does not take up the offer of the infectious diseases screen initially, the option should remain available throughout pregnancy[4]. If a woman is identified as hepatitis B positive they should be referred and seen by an appropriate specialist within six weeks from identification, currently because of the small number of cases involved, data on this KPI is not available[5]. The most recent data for Norfolk and Waveney shows that HIV screening coverage is above the national standard of 90% for 2013/14 Quarter 3[5].

Sickle Cell and Thalassaemia
Within the first ten weeks of pregnancy women should also be screened for sickle cell disease and thalassaemia. In areas of low prevalence, such as Norfolk, women will be screened using the Family Origin Questionnaire (FOQ) which identifies whether the mother or father are from a high risk group for haemoglobin variants[6]. If living in a high risk area, or if a woman scores highly on the FOQ, further tests will be offered.

Antenatal sickle cell and thalassaemia screening coverage is above the acceptable level (95%) across Norfolk and Waveney providers in the third quarter of 2013/14[7]. Across Norfolk and Waveney results are also being received within 10 weeks of gestation in over 70% of women, above the 50% acceptable level[7]. All of the provider trusts have also met the 90% acceptable level for sending sickle cell and thalassaemia samples with a completed FOQ to the laboratory in 2013/14 (Q3)[7].

Down's Syndrome Screening
During the antenatal period women will be offered Down's Syndrome screening. If they present within the first trimester they will be offered the combined test that requires a maternal serum sample (blood test) and an ultrasound scan. If the pregnant woman presents to primary care between 14+2 weeks and 20+0 weeks then they will instead be offered the quadruple test[8] (blood test only). The tests give a woman a risk assessment of the likelihood that the unborn baby will have Down's syndrome[8]. A result of 1 in 150 or above is considered high risk; the mother will then be offered a diagnostic test[8], further information can be found on the national screening committee website (www.screening.nhs.uk/uknsc). Nationally a target is set for at least 97% of laboratory request forms for a Down's Syndrome screen to include complete data prior to screening analysis and submitted within the recommended timeframe (10+0 to 20+0 weeks)[9]. The majority of Norfolk providers are reaching the 97% level in the most recent data reports; however, one area is achieving a slightly lower level, but still in excess of 95%.[5]

Newborn Screening

Newborn Blood Spot
Between five and eight days after a child is born a Midwife will collect a blood sample via a heel-prick test. This test screens for phenylketonuria, congenital hypothyroidism, sickle cell disease, cystic fibrosis and medium-chain acyl-CoA dehydrogenase deficiency. A new national fail safe system has been put into place whereby the Child Health Record Department, who receives laboratory results, notifies the maternity unit if no result has been recorded within 14-17 days birth[10]. The maternity unit can then follow this up. The Health Visitor should also check that parents have received the result within 8 weeks[10].

Across Norfolk and Waveney a coverage level of over 97% is being achieved in the most recent data for newborn blood spot screening (2013/14 Q3); above the 95% acceptable level[7]. In addition, negative results (for all 5 conditions) are available to communicate with parents by 6 weeks in over 99% of cases. However, there are slightly higher than 2% of tests being repeated due to an avoidable failure in the sampling process in some areas of Norfolk, and data has not been submitted for all areas[9].

Newborn Hearing Screening
Within the first few days after a baby is born they should be offered a hearing screen which aims to identify moderate to profound permanent hearing impairment[11]. Early detection can ensure that appropriate support is given to develop adapted language and communication skills[11]. An automated oto-acoustic emission (AOAE) test is carried out in the first instance, and if no clear response is achieved then an Automated Auditory Brainstem Response (AABR) test is carried out on the child[11]. If the AABR is not clear then the patient will be referred to the Audiology department for further testing. Initial hearing screening can either be hospital based (in the maternity department) or community based[11]. In Norfolk and Waveney, two providers offer hospital based services, whereas the provider covering the eastern areas offers a community based service.

In Norfolk and Great Yarmouth & Waveney newborn hearing screening coverage in the third quarter of 2013/14 was above 98%, therefore exceeding the 95% acceptable level[5]. Data for timely assessments following a screening referral (receiving an audiological assessment within four weeks of referral/44 weeks gestational age)[9] is not available quarterly, it is released annually to protect patient confidentiality.[5]

Newborn Infant and Physical Examination (NIPE)
Within the first 72 hours of birth, all parents should be offered a physical examination for their baby if clinically safe to do so[12]. Midwives or doctors complete a thorough full body examination and screen the child's heart, hips, eyes and testes. Another physical examination will be offered at 6-8 weeks after the birth by a GP. Currently there is no information available on the NIPEs because

the national programme's IT database for completion of the KPI is undergoing a national rollout[13]. Data will become available once this rollout is complete.

Vision Screening
A recent audit of vision screening in Norfolk has been undertaken following a review in November 2013 by the National Screening Committee (NSC) covering vision screening for children aged four to five years. A critical period for correction of vision defects is generally considered as before the age of seven years, vision screening enables these defects to be identified within this time period[14]. Vision defects include amblyopia (also known as 'lazy eye') and refractive error (e.g. astigmatism). These may affect a child's ability to learn if left untreated, for example with difficulty seeing the teacher at the front of a classroom[14]. The prevalence of vision problems in the UK is unclear, in the 2013 NSC review a large UK based study reported a prevalence of amblyopia of 3.6% in children at age seven, this is within the reported ranges from other countries, with between 1% and 4% of children aged less than six years old affected by amblyopia[14].

In Norfolk there are three school-based screening programmes; in east and central Norfolk screening is provided by the school nursing team with support from orthoptists, whereas in the west of Norfolk screening is carried out by the orthoptists. In the recent vision screening audit conducted by Norfolk County Council in 2013/14, 893 children were screened; 4.3% of which were referred on to secondary care. This did vary considerably across localities though, potentially because re-testing is offered by some providers, and not others[14]. It should be noted that there were issues with data quality so some data had to be excluded from the audit, therefore this is an approximate snapshot of vision screening in Norfolk[14]. The review highlights the need to improve data collection and reporting, potentially through the nationally run audit[14]. Furthermore, the report suggests giving guidance on staff training as currently there is no national guidance available on how vision screening programmes should be monitored and run[14].

Further information about national screening programmes can be found on the UK National Screening Committee website: http://www.screening.nhs.uk/uknsc.

What can we do to increase uptake?
Research suggests that there may be socio-demographic factors linked to uptake[15], for example lower uptake in South Asian women has been noted in a number of studies[16,17]. Potential reasons for this disparity in uptake in antenatal screening programmes are access, communication and late presentation to antenatal care[18]. It is also possible that for antenatal infectious disease screening that those at a higher risk of being infected, are the least likely to get checked[19], the reasons for this are not entirely clear.

For more information on this subject
Public Health Outcomes Framework**:**
http://www.phoutcomes.info/

The spreadsheets to use for graphs are in:
G:\6. Health Intelligence\Secure\Work Areas\Vaccs and Imms

---

[1] Public Health England (2013) UK screening portal – What is screening? http://www.screening.nhs.uk/screening (Accessed July 2014).
[2] Pencheon, D. et al./Raffle et al. [part 3.6] (2006) Oxford Handbook of Public Helath Practice 2nd Ed. Pp 258 Oxford University Press: New York.
[3] UK National Screening Committee. Programme Appraisal Criteria. http://www.screening.nhs.uk/criteria (Accessed July 2014).

[4] NHS England/Department of Health (2013) Public health functions to be exercised by NHS England: Service specification No.15 NHS Infectious Diseases in Pregnancy Screening Programme.
[5] Public Health England (2014) Screening KPIs Q3 2013-14 Screening KPI Summary Publication v1_1.
[6] NHS England/Department of Health (2013) Public health functions to be exercised by NHS England: Service specification No.18 NHS Sickle Cell and Thalassaemia Screening Programme
[7] Public Health England (2014) Screening KPIs Q3 2013-14 Screening KPI Summary Publication v1_1.
[8] NHS England (2013) Public health functions to be exercised by NHS England: Service specification No.16 NHS Down's Syndrome Screening (Trisomy 21) Programme.
[9] NHS Screening Programmes (2013) UK National Screening Committee: Key Performance Indicators for Screening 2013-14 Version 1.12.
[10] NHS England (2013) Public health functions to be exercised by NHS England: Service specification No.19 NHS Newborn Blood Spot Screening Programme.
[11] Department of Health/NHS England (2013) Public health functions to be exercised by NHS England Service: specification No.20 NHS Newborn Hearing Screening Programme.
[12] Department of Health/NHS England (2013) Public health functions to be exercised by NHS England: Service specification No.21 NHS Newborn and Infant Physical Examination Screening Programme.
[13] NHS Screening Programmes (2013) IT-NIPE SMART http://newbornphysical.screening.nhs.uk/it (Accessed July 2014)
[14] Hams, R. [Norfolk County Council, Public Health] (2014) Service Review: Vision screening in 4-5 year olds across Norfolk (confidential due to commercially sensitive data). A summary may be available upon request.
[15] Dormandy et al. (2005) Low uptake of prenatal screening for Down syndrome in minority ethnic groups and socially deprived groups: a reflection of women's attitudes or a failure to facilitate informed choices? *Int. J. Epidemiol*. 34 (2): 346-352.
[16] Rowe et al. (2005) Ethnic minorities' access to antenatal screening. *British Journal of Midwifery* 13 (2): 101-104.
[17] NICE (2009) Reducing differences in the uptake of immunisations: NICE public health guidance 21.
[18] Yu, J. (2011) Review: A systematic review of issues around antenatal screening and prenatal diagnostic testing for genetic disorders: women of Asian origin in western countries. *Health and Social Care in the Community* (2012) 20(4), 329–346.
[19] Boxall et al. (2004) Antenatal screening for HIV; are those who refuse testing at higher risk than those who accept testing? *Journal of Public Health* 26(3): 285-287.