SCREENING LINK HEALTH VISITOR
NEWBORN BLOODSPOT SCREENING POLICY
Policy: Screening Link Health Visitor Newborn Bloodspot Screening Policy

Executive Summary:
This policy provides clear guidelines on the Screening Link Health Visitor role and the responsibilities of Health Visiting staff, thus ensuring that ECT complies with Public Health England policies and standards. It aims to deliver a safe and effective screening service for babies requiring repeat samples, with results explained to parents and carers in a clear and timely manner.

Supersedes: Screening Link Health Visitor Newborn Bloodspot Screening Policy 2013

Description of Amendment(s):
New genetic conditions added in line with national screening programme. References updated

This policy will impact on: All Trust Staff

Financial Implications:
No additional financial implications

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<th>Policy Area:</th>
<th>Health Visiting</th>
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<tr>
<td>Version Number:</td>
<td>1</td>
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<tr>
<td>Issued By:</td>
<td>Nicola Greaves</td>
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<td>(Full Job title )</td>
<td>Newborn Bloodspot Screening Co-ordinator</td>
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<td>January 2016</td>
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**APPROVAL RECORD**

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<td>12.1.16</td>
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<tr>
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1. INTRODUCTION

Newborn screening aims to identify babies who are at high risk of having certain serious but rare conditions before they develop symptoms. Screening is not the same as diagnosis: instead it identifies which babies need to go on to have more diagnostic tests to determine whether or not they do have a condition. By detecting these conditions early it is possible to treat them and to reduce their severity.

Newborn blood spot screening is a crucial part of a national child public health programme and is offered to all babies in the United Kingdom.

These are currently the conditions tested for in East Cheshire NHS Trust.

- Congenital Hypothyroidism (CHT)
- Phenylketonuria (PKU)
- Sickle Cell Disorder
- Cystic Fibrosis (CF)
- Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD)
- Maple syrup Urine disease [MSUD]
- Isovaleric acidaemia [IVA]
- Glutaric aciduria type 1 [GA1]
- Homocystinuria [HCU]

CONGENITAL HYPOTHYROIDISM (CHT)

Congenital Hypothyroidism is a condition where there is decreased or no thyroid hormone production. Early diagnosis is important as the effects of hypothyroidism are easy to reverse if left untreated it can lead to the development of severe learning disabilities and growth retardation. If identified early the baby can be treated and can lead a healthy life.

PHENYLKETONURIA (PKU)

Phenylketonuria (PKU) is an inherited metabolic condition where there is a defect in phenylalanine hydroxylase. This enzyme normally converts the phenylalanine in the body into tyrosine. Where there is an enzyme block the phenylalanine accumulates in the body tissues and affects the normal development of the brain causing learning difficulties. If untreated this leads to poor brain development. Early identification allows the baby to be put on a special diet and the brain can develop normally.
HAEMOGLOBINOPATHIES

Sickle cell anemia is an inherited condition where by a haemoglobin S gene is inherited from both parents. If the baby inherits one S gene from one parent this results in the baby being a carrier (The child would have no symptoms)

Sickle cell anemia is a condition that affects the normal oxygen-carrying capacity of the red blood cells. When the cells are de-oxygenated and under stress in sickle cell conditions, they can change from round flexible disc-like cells to elongated sickle or crescent moon shape. The effect of these changes is that the cells do not pass freely through small capillaries and form clusters, which block the blood vessels. The blockage prevents oxygenation of the tissues in the affected areas resulting in tissue hypoxia and consequent pain. Sickle cell disorders are lifelong conditions.

Babies who are healthy carriers of sickle cell trait are also identified through the screening process. Although an infant with sickle cell trait does not have the problems of sickle cell disorder, if his or her parents are both carries they could have another child who does have a sickle cell disorder.

CYSTIC FIBROSIS (CF)

Cystic Fibrosis is a common inherited disease around 1: 25 are carriers of the faulty gene in the United Kingdom. The faulty gene that causes CF is recessive which means that an individual with the disorder has to have acquired a faulty gene from each parent. Carriers do not have the disease but their children may inherit the condition. CF is a condition which affects certain organs in the body, especially the lungs and pancreas, by clogging them with thick sticky mucus. The thick secretions in these organs cause digestive problems and chest infections. Early diagnosis is important as babies with CF are treated vigorously as soon as they are first diagnosed. Treatment of children with CF aims to do two things:

- Improve nutrition by providing supplements containing enzymes to help digestion
- Reduce chest infections with frequent physiotherapy and either occasional or continuous antibiotics.

MEDIUM CHAIN ACYL COA DEHYDROGENASE DEFICIENCY (MCADD)

MCADD is an inherited metabolic disorder where there is lack of an enzyme required to convert stored fat to energy. If MCADD is not identified at an early age, up to a quarter of affected children may die from the condition, with one third of surviving children sustaining significant neurological damage. Treatment involves ensuring that children do not go for long periods without food although periods can increase as the child grows.
MAPLE SYRUP URINE DISEASE (MSUD)

Is an autosomal recessive inherited metabolic disease in which a baby or child has a problem breaking down Leucine, Isoleucine and valine amino acids.

Incidence: 1:116,000 [uk data]

**Early effects**: Many babies with MSUD become unwell when they are a few days old, with poor feeding, vomiting and excessive sleepiness if left untreated leads to coma and permanent damage or death in some cases. In older children a minor illness eg a gastric upset can lead to serious problems.

**Treatment**: A special low protein diet is used to prevent the buildup of harmful amino acids in the blood. A different regime is required when the child is ill, and they may need to be hospitalised.

ISOVALERIC ACIDAEMIA (IVA)

Is an autosomal recessive inherited metabolic disease in which a baby or child has a problem breaking down the leucine amino acid.

Incidence: 1:155,000[EU data]

**Early effects**: vomiting, excessive sleepiness, floppiness and rapid breathing. If untreated can lead to a coma and permanent brain damage or death in some cases. Some babies with IVA have problems within a few days of birth: others become unwell at a few months or years of age, perhaps during a minor illness.

**Treatment**: a special low protein diet, and carnitine and glycine. A different regime is required when the child is ill, and they may need to be hospitalised.

GLUTARIC ACIDURIA TYPE 1 (GA1)

Is an autosomal recessive inherited metabolic disease in which a baby or child has a problem with breaking down lysine and tryptophan amino acids.

**Incidence**: 1:109,191 [EU data]

**Early effects**: In children with GA1, a minor illness such as a chest infection or a tummy upset can lead to serious problems. Early signs may include vomiting, irritability, excessive sleepiness, and floppiness and breathing difficulties. If untreated the child can
go into a coma and be left with neurological damage so immediate treatment is required on identification.

**Treatment:** a special low protein diet and carnitine. A different regime is required when the child is ill, and they may need to be hospitalised.

**HOMOCYSTINURIA (HCU)**

Is an autosomal recessive inherited metabolic disease that prevents the breakdown of the homocysteine amino acid.

**Incidence:** 1:144,000(UK data)

**Early effects:** babies do not have any problems at birth if untreated most children develop learning difficulties and eye problems as a young child. Can also lead to osteoporosis and blood clots or strokes.

**Treatment:** a special low protein diet and extra supplements and medicines.

**Note** Newborn screening only detects the pyridoxine unresponsive form of HCU

### 2. AIMS OF THIS POLICY

- To provide clear guidelines to the Screening Link Health Visitors (SLHV) and members of the Health Visiting Teams
- To comply with the UK Public Health England Newborn blood spot Screening Programme policies and Standards
- To provide a safe and effective screening service for repeat samples
- To deliver all results, ‘not suspected,’ ‘carrier’ and ‘suspected’ result to families in a timely manner
- To detect unscreened babies [under 1 year of age] moving into East Cheshire NHS Trust

### 3. OUTCOMES

- Screening Link Health Visitors and members of the Health Visiting Teams will comply with the UK Newborn Screening Programme Centre policies and standards to reduce the likelihood of late or missed diagnosis.
- All Screening Link Health Visitors will be aware of procedures for handling repeat blood spot samples
- All Screening Link Health Visitors will have clear guidelines for dealing with babies who have been in Special care and babies who move into the area who
do not have any record of blood spot screening recorded these are the children under 1 year of age.

- Improved communication between professionals and between professional and parents
- Screening Link Health Visitors and Health Visitors will have clearly defined roles and responsibilities
- Parents and Carers will receive results in a timely manner

4. **TARGET GROUP**

All members of the health visiting teams designated screening link health visitors and child health employees employed by East Cheshire NHS Trust are required to follow this procedure.

5. **RELATED POLICIES AND DOCUMENTS**

This list is not exhaustive; it highlights the most relevant policies for the safety of patients and staff

- Department of Health (2012) Guidelines for Newborn Blood Spot Sampling
- East Cheshire NHS Trust Newborn Screening Policies April 2012
- East Cheshire NHS Trust Record Keeping Policy
- East Cheshire NHS Trust Infection Control Policy
- East Cheshire NHS Trust Consent Policy

6. **AUDIT, ROLES AND RESPONSIBILITIES OF THE SCREENING LINK HEALTH VISITOR**

The screening Link Health Visitor will be responsible for auditing the request for repeat newborn blood screening tests as part of the Clinical Governance process to feedback at local and regional level.

The screening link health visitor, who has received additional training in screening, is responsible for:
• Following Health Visiting Newborn Blood Spot Screening Policy (East Cheshire NHS Trust 2015)

• Following up referrals for repeat blood spot screening from Alder Hey laboratory and Royal Manchester Children’s Hospital laboratory.

• Contacting the Family Health Visitor when a child has a positive blood spot test for CF. The laboratory in conjunction with the hospital will contact the SLHV and notify them of the time and place for an appointment for the family to attend. The SLHV will arrange to visit the family in the late afternoon the day before the appointment. The SLHV will inform the parent of the positive screening result, discuss and leave the leaflet ‘Cystic Fibrosis is suspected’ and give the date, time and venue for the sweat test and appointment with the Consultant. [NHS England]

• The SLHV will work in conjunction with the Child Health Department in completing any audits.

• Positive MCADD results are followed up by Screening Link Health visitor or midwifery and specialist teams. The SLHV will go out to the family and give them the leaflet Medium-Chain acyl-Coa dehydrogenase deficiency [MCADD] is suspected they will give the family the appointment for the specialist centre, document in the notes and ensure the family Health Visitor and the GP have been informed by the referral form [see appendix]

• The family Health Visitor will record all results in the PCHR and Child Health Records. The SLHV will record all results and information in the PCHR.

7. HEALTH VISITOR RESPONSIBILITIES

• Health Visitors to assess at birth visit/transfer into area visit whether baby has been screened. Untested babies are defined as those babies who do not have documented evidence of screening or a decline notification for each of the conditions for which screening is offered. Any baby identified at the birth visit who has not been screened should be referred to Community Midwife for timely screening to be arranged. The midwife should repeat screening up to 28 days.

• On identification of untested babies, the screening process should be ‘fast-tracked’ for parents wishing to have their child screened and the pre-testing leaflet provided (Newborn Spot Screening for Your Baby NHS 2011)
The Health Visitor will discuss with parents/carers at the birth visit when they will receive the results of the screening tests.

All ‘not suspected’ results received from child health will be discussed with the parents/carers at the 4-6 week contact. Results will be recorded in the Personal Child Health Record (PCHR) and in the Child Health Record if one is open.

If results have not been received by the 6-8 week contact and there has been no contact from any other health professional to indicate that the results are abnormal the health visitor will need to contact the child health department or screening laboratory at Alder Hey Children’s Hospital or the Royal Manchester Children’s Hospital to follow up the results.

Health visitors seeing babies under 1 year of age who have moved into the area and are reported to have been screened, evidence of testing is required. This may take the form of a faxed or written confirmation of the results from child health or regional screening laboratory. Where the health visitor finds there is not proof of testing available, it should be assumed that the baby is untested and retesting discussed with the parents. The Health Visitor Neonatal Screening referral form (Appendix 2) should be completed and sent to the SLHV. If the baby is older than 8 weeks, blood spot screening should be offered for CHT, PKU, Sickle Cell Disorders and MCADD; parent/carer should be informed that screening will not pick up CF as serum levels return to normal after 8 weeks.

Health Visitors receiving results that the baby is a healthy carrier for Sickle Cell Disease or Cystic Fibrosis will need to contact the SLHV to discuss results with parents.

8. CARED FOR CHILDREN

For any child who is looked after by the local authority, consent must be obtained by the person who has parental responsibility i.e. social work manager and fully documented in the Child’s Health Records.

9. PARENTS/CARERS WHO DECLINE

If parents decline retesting, the reason for their decision should be explored and further information offered. However, parents should not be unduly pressured, although they need to be making an informed choice. The SLHV or HV must:
• Document that the parent has declined a retest, including reasons for decision, in the Personal Child Health Records, Health Visitor Child Health Records and the Health Visitor Neonatal Screening Referral form.
• Confirm the parents understand the risks of the baby not being screened.
• Offer further information and who to contact if they change their minds.
• Inform General Practitioner and Child Health Department.

10. PERFORMING THE PROCEDURE

Taking the blood spot involves balancing the need to collect sufficient blood, with the potential for discomfort for the baby and unease for the parents. The following procedures have been drawn from the Newborn blood spot screening in the UK Health Professional Handbook [UK National Screening Committee 2012 www.newbornbloodspotscreening.nhs.uk

11. AFTER TAKING BLOOD SAMPLE

It is important that the laboratory receives the blood sample promptly to ensure that babies with the conditions are seen quickly. Parents also need to know when to expect the results. This will help reduce their concerns about the results, as well as providing an additional safety net in following up missing results.

12. CLINICAL INCIDENTS

Any related incidents arising from carrying out these procedures which may involve clinical error or near miss must be reported following the East Cheshire NHS Trust incident reporting policy.
REFERENCES


East Cheshire NHS Trust [2010]; Infection and control Good Practices Policy for infection Prevention and control

East Cheshire NHS Trust [2011]; Records Management Policy

East Cheshire NHS Trust [2009]; Policy for Consent to Examination or Treatment


ECT [2012] Newborn Bloodspot Guideline
APPENDIX 1
PATHWAY FOR NEWBORN BLOODSPOT SCREENING

Day 5
After birth the midwife takes
the newborn blood spot
sample and sends to screening
labs

Not suspected
Results sent to Child Health
Department who ensure all children
have a result.

Carrier/trait results and repeat blood
tests.
Carrier results for sickle cell and cystic
fibrosis are sent to the Child Health
department and the Screening Link Health
Visitor. Repeat samples are requested by
the Labs.

The screening link Health Visitor will
contact the family Health Visitor to inform
them of the result and get contact details

At the 4 – 8 week contact
The Family Health Visitor ensures the blood
spot result is available. If it isn't the health visitor
should contact Alder Hey labs or The Royal
Manchester Children's Hospital to ensure result
is available. The family Health Visitor then
completes page 24 in Personal Child Health
Record (red book). The original results are documented and
filed in the Health Visiting child health
records. Or contact the SLHV

The Screening Link Health Visitor will
contact the family to arrange a home visit to
discuss the carrier/trait results with them. The
appropriate written information will be given
at this time. The result should be documented
in the Parent Held Record [red book] and the
Childs Health Visiting records should be
completed. A Health Visitor Newborn
Screening information/referral form should
be completed; a copy sent to the GP and copy
sent to the family Health Visitor

TRANSFERS INTO AREA
Family Health Visitors must offer blood spot
screening to any child who transfers into the area
under the age of 12 months who have an
incomplete, or unrecorded, blood spot screening
result. If consent is given, the Family Health
Visitor should contact the Screening Link Health
Visitor to arrange for a sample to be taken.
Please note that this type of screening will not
identify Cystic Fibrosis / trait in a child older than
8 weeks

Any queries about the Newborn Blood Spot
result
The Health Visitor should contact Alder Hey
Labs
0151 252 5489

Child Health sends the results to Family
Health Visitor. The clinic clerk enters the date
that the results are received into the Birth
Book. The health visitor enters it into the
Clinic Profile.

Screening Link Health Visitor Newborn Screening Policy
Screening Link Health Visitors
November 2015
SUSPECTED/POSITIVE RESULTS

PKU and CHT
These are dealt with by the hospital not the Screening Link Health Visitors.

Sickle Cell or other Haemoglobinopathy
Families will be referred to the haemoglobinopathy counsellor / specialist nurse in Liverpool; contact numbers are:
Dorothy Zack-Williams 0151 708 9370
Louise Smith 0151 252 5079

MCADD
If a child has had a positive blood spot test s/he has to be seen the next day for a repeat test.

The hospital/Alder Hey Lab will contact a Screening Link Health Visitor/Midwife and notify the time and place for an appointment for the family to attend the following day.

The Screening Link Health Visitor will then contact the Family Health Visitor (or team) and arrange to go out to visit the family in the late afternoon of that same day. The Screening Link Health Visitor will inform the parents of the hospital appointment and ascertain whether the child is feeding well. The parents should be given the appropriate written information. The Screening link Health Visitor will document in Parent Held Record and Health Visiting Notes. If there are any concerns voiced by parents about the appointment contact should be made with the hospital where the appointment is for.

Cystic Fibrosis Suspected
If a child has had a positive blood spot test s/he has to be seen the next day for a repeat test.

The hospital/Cystic Fibrosis Specialist Nurse will contact appropriate Screening Link Health Visitor and notify them of the time and place for an appointment for the family to attend.

The Screening Link Health Visitor will then contact the Family Health Visitor (or team) and arrange to go out to visit the family in the late afternoon the day before the appointment. The Screening Link Health Visitor will inform the parents of the positive screening result, discuss and leave the leaflet “Cystic Fibrosis is suspected” and give the date, time and venue for the sweat test and appointment with the Consultant. This visit should be documented in the Parent Held Record; a health visitor new born screening referral/information form should be completed and filed in the Health visiting Notes.
### APPENDIX 2
HEALTH VISITOR NEWBORN BLOODSPOT SCREENING
INFORMATION/REFERRAL FORM

**PART 1: TO BE COMPLETED BY THE FAMILY HEALTH VISITOR** [complete all sections: send to appropriate screening link health visitor [SLHV]]

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<tr>
<td>DATE OF BIRTH</td>
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<tr>
<td>ADDRESS</td>
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<tr>
<td>MOTHERS NAME /NHS NUMBER</td>
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<td>TELEPHONE NUMBER</td>
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<tr>
<td>FAMILY GP</td>
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<tr>
<td>HEALTH VISITOR AND CONTACT NUMBER</td>
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<td>REASON FOR REFERRAL</td>
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<td>INTERPRETER REQUIRED</td>
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<tr>
<td>RELEVANT FAMILY AND CLINICAL INFORMATION</td>
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**PART 2: TO BE COMPLETED BY THE SCREENING LINK HEALTH VISITOR**
REPEAT NEWBORN BLOOD SPOT SAMPLE

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<thead>
<tr>
<th>DATE TAKEN</th>
<th>SIGNATURE OF SLHV</th>
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<tr>
<td>PKU</td>
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<tr>
<td>HAEMOGLOBINOPATHIES</td>
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<td>CYSTIC FIBROSIS</td>
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<td>MCAAD</td>
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**RESULTS DISCUSSED FOR:**

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<td>CYSTIC FIBROSIS CARRIER</td>
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<tr>
<td>SUSPECTED MCADD APPOINTMENT AND LEAFLET GIVEN</td>
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<tr>
<td>SUSPECTED CYSTIC FIBROSIS APPOINTMENT AND LEAFLET GIVEN</td>
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**DISTRIBUTION**

Copy to family GP:
Copy to family Health Visitor to file in Child’s notes:
REFERENCES


East Cheshire NHS Trust [2010]; Infection and control Good Practices Policy for infection Prevention and control

East Cheshire NHS Trust [2011]; Records Management Policy

East Cheshire NHS Trust [2009]; Policy for Consent to Examination or Treatment

Equality Analysis (Impact assessment)

Please START this assessment BEFORE writing your policy, procedure, proposal, strategy or service so that you can identify any adverse impacts and include action to mitigate these in your finished policy, procedure, proposal, strategy or service. Use it to help you develop fair and equal services.

Eg. If there is an impact on Deaf people, then include in the policy how Deaf people will have equal access.

1. What is being assessed?

The purpose of this policy is to ensure that there is a robust process in place for East Cheshire Health Visiting Service in the management of the newborn blood spot screening programme for when a baby has not had screening or in response to results that may require further testing.

Details of person responsible for completing the assessment:

- Nicky Greaves Screening Link Health Visitor
- Health Visitor Team
- Team/service: Health Visitors

State main purpose or aim of the policy, procedure, proposal, strategy or service:

(usually the first paragraph of what you are writing. Also include details of legislation, guidance, regulations etc which have shaped or informed the document)

Newborn screening aims to identify babies who are at high risk of having certain serious but rare conditions before they develop symptoms. Screening is not the same as diagnosis: instead it identifies which babies need to go on to have more diagnostic tests to determine whether or not they do have a condition. By detecting these conditions early it is possible to treat them and to reduce their severity.

Newborn blood spot screening is a crucial part of a National Child Public Health Programme and is offered to all babies in the United Kingdom.

It is also offered to babies under one year of age who move into area and have no recorded evidence of the result of the screening test being carried out.

UK National Screening Committee (2012); Guidelines for Newborn Bloodspot Sampling, Nightshift Graphics Ltd.

NSC (2008) Antenatal and Newborn Screening Programme: Standards and Guidelines for Newborn Bloodspot Screening. Newborn Screening Committee
2. Consideration of Data and Research

To carry out the equality analysis you will need to consider information about the people who use the service and the staff that provide it. Think about the information below – how does this apply to your policy, procedure, proposal, strategy or service

2.1 Give details of RELEVANT information available that gives you an understanding of who will be affected by this document

Data collected by Child Health Department, Health Visitor documentation, National screening guidance, Maternity policies East Cheshire Trust

Cheshire East (CE) covers Eastern Cheshire CCG and South Cheshire CCG. Cheshire West & Chester (CWAC) covers Vale Royal CCG and Cheshire West CCG. In 2011, 370,100 people resided in CE and 329,608 people resided in CWAC.

Age: East Cheshire and South Cheshire CCG’s serve a predominantly older population than the national average, with 19.3% aged over 65 (71,400 people) and 2.6% aged over 85 (9,700 people).

Vale Royal CCGs registered population in general has a younger age profile compared to the CWAC average, with 14% aged over 65 (14,561 people) and 2% aged over 85 (2,111 people).

Since the 2001 census the number of over 65s has increased by 26% compared with 20% nationally. The number of over 85s has increased by 35% compared with 24% nationally.

Race:
- In 2011, 93.6% of CE residents, and 94.7% of CWAC residents were White British
- 5.1% of CE residents, and 4.9% of CWAC residents were born outside the UK – Poland and India being the most common
- 3% of CE households have members for whom English is not the main language (11,103 people) and 1.2% of CWAC households have no people for whom English is their main language.

Gender: In 2011, c. 49% of the population in both CE and CWAC were male and 51% female. For CE, the assumption from national figures is that 20 per 100,000 are likely to be transgender and for CWAC 1,500 transgender people will be living in the CWAC area.

Disability:
- In 2011, 7.9% of the population in CE and 8.7% in CWAC had a long term health problem or disability
- In CE, there are c.4500 people aged 65+ with dementia, and c.1430 aged 65+ with dementia in CWAC. 1 in 20 people over 65 has a form of dementia
- Over 10 million (c. 1 in 6) people in the UK have a degree of hearing impairment or deafness.
- C. 2 million people in the UK have visual impairment, of these around 365,000 are registered as blind or partially sighted.
- In CE, it is estimated that around 7000 people have learning disabilities and 6500 people in CWAC.
- Mental health – 1 in 4 will have mental health problems at some time in their lives.
Sexual Orientation:
- CE - In 2011, the lesbian, gay, bisexual and transgender (LGBT) population in CE was estimated at 18,700, based on assumptions that 5-7% of the population are likely to be lesbian, gay or bisexual and 20 per 100,000 are likely to be transgender (The Lesbian & Gay Foundation).
- CWAC - In 2011, the LGBT population in CWAC is unknown, but in 2010 there were c. 20,000 LGB people in the area and as many as 1,500 transgender people residing in CWAC.

Religion/Belief:
The proportion of CE people classing themselves as Christian has fallen from 80.3% in 2001 to 68.9% in 2011 and in CWAC a similar picture from 80.7% to 70.1%, the proportion saying they had no religion doubled in both areas from around 11%-22%.
- Christian: 68.9% of Cheshire East and 70.1% of Cheshire West & Chester
- Sikh: 0.07% of Cheshire East and 0.1% of Cheshire West & Chester
- Buddhist: 0.24% of Cheshire East and 0.2% of Cheshire West & Chester
- Hindu: 0.36% of Cheshire East and 0.2% of Cheshire West & Chester
- Jewish: 0.16% of Cheshire East and 0.1% of Cheshire West & Chester
- Muslim: 0.66% of Cheshire East and 0.5% of Cheshire West & Chester
- Other: 0.29% of Cheshire East and 0.3% of Cheshire West & Chester
- None: 22.69% of Cheshire East and 22.0% of Cheshire West & Chester
- Not stated: 6.66% of Cheshire East and 6.5% of Cheshire West & Chester

Carers: In 2011, nearly 11% (40,000) of the population in CE are unpaid carers and just over 11% (37,000) of the population in CWAC.

2.2 Evidence of complaints on grounds of discrimination: (Are there any complaints or concerns raised either from patients or staff (grievance) relating to the policy, procedure, proposal, strategy or service or its effects on different groups?)

None known

2.3 Does the information gathered from 2.1 – 2.3 indicate any negative impact as a result of this document?

No
3. Assessment of Impact

Now that you have looked at the purpose, etc. of the policy, procedure, proposal, strategy or service (part 1) and looked at the data and research you have (part 2), this section asks you to assess the impact of the policy, procedure, proposal, strategy or service on each of the strands listed below.

RACE:
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, racial groups differently? Yes □ No □X

Explain your response:

There will be the need to have access to translated materials and interpreters to minority groups to ensure they have a full understanding of the screening procedure and information given. Staff who are required to carry out newborn screening should be aware of how to access translator services, and can view the Trust Interpreting Policy on the website. The screening process needs to be aware of populations that do not access or do not know how to access the services.

GENDER (INCLUDING TRANSGENDER):
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, different gender groups differently? Yes □ No □X

Explain your response:

Newborn bloodspot screening and giving of information about the results and follow up information is not affected by gender.

DISABILITY
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, disabled people differently? Yes □ No □X

Explain your response:

The policy does not affect people with a disability differently. It may be appropriate to use BSL interpretation, or information in another format to ensure communication and understanding. Carers will be involved as appropriate.
AGE:
From the evidence available does the policy, procedure, proposal, strategy or service, affect, or have the potential to affect, age groups differently? Yes ☐ No ☑

Explain your response:
The screening tests are offered to children under the age of 12 months who have moved into the area with no documented evidence of a Newborn Blood Spot result in the PCHR or no evidence that a result has been received.

LESBIAN, GAY, BISEXUAL:
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, lesbian, gay or bisexual groups differently? Yes ☐ No ☑

Explain your response:
Newborn bloodspot screening is offered to all regardless.

RELIGION/BELIEF:
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, religious belief groups differently? Yes ☐ No ☑

Explain your response:
Staff have information on beliefs and cultures and are required to access diversity and equality training as part of the Trust’s Mandatory training.

CARERS:
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect, carers differently? Yes ☐ No ☑

Explain your response:
This policy should not affect carers of the children differently. Any information and consent should be directed to the carer with parental responsibility.

OTHER: EG Pregnant women, people in civil partnerships, human rights issues.
From the evidence available does the policy, procedure, proposal, strategy or service affect, or have the potential to affect any other groups differently? Yes ☐ No ☑
Explain your response:

The consent for further testing of the child should be sought from the carer with parental responsibility. In safeguarding cases this may be jointly held with social Services and the parent with parental responsibility.

4. Safeguarding Assessment - CHILDREN

<table>
<thead>
<tr>
<th>a. Is there a direct or indirect impact upon children?</th>
<th>Yes ☑</th>
<th>No ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. If yes please describe the nature and level of the impact (consideration to be given to all children; children in a specific group or area, or individual children. As well as consideration of impact now or in the future; competing / conflicting impact between different groups of children and young people:</td>
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<tr>
<td>The newborn screening is Universal; this is a blood test in the postnatal period by the midwife. A positive result for any of the conditions which are screened for will have an impact on children. They need follow up appointments, potentially more testing and observation and follow up by the appropriate medical team.</td>
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<tr>
<td>The Health Visitor may have to perform a Newborn blood test on older infants if there is no documented evidence of the screening procedure in the notes.</td>
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<tr>
<td>There is an impact on children if the test goes missing, have to be repeated or not obtained in a timely way; this has the potential of missing a positive result. Also if the test is declined.</td>
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<tr>
<td>c. If no please describe why there is considered to be no impact / significant impact on children</td>
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</tbody>
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5. Relevant consultation

Having identified key groups, how have you consulted with them to find out their views and that the made sure that the policy, procedure, proposal, strategy or service will affect them in the way that you intend? Have you spoken to staff groups, charities, national organisations etc?

6. Date completed: 30/12/2015 Review Date:

7. Any actions identified: Have you identified any work which you will need to do in the future to ensure that the document has no adverse impact?
8. **Approval** – At this point, you should forward the template to the Trust Equality and Diversity Lead lynbailey@nhs.net

Approved by Trust Equality and Diversity Lead: [Signature]

<table>
<thead>
<tr>
<th>Action</th>
<th>Lead</th>
<th>Date to be Achieved</th>
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