





# Health Screening in Cumbria: a Public Health Service

January 2011

A report commissioned by:



## Foreword

The recent service failure of breast screening in North Cumbria has thrown the spotlight on a service which is estimated to save around 1,400 women's lives in England each year. That service has now been restarted with a commitment from NHS Cumbria to provide a high quality and robust screening for all those women eligible in the county.

What comes out from an incident like this is a realisation that there is widespread ignorance of the extent of NHS screening programmes and of the issues raised by the proposal to introduce a new service. There is a feeling at a community level that all screening must be a good thing. In practice there is a rigorous framework for evaluating the positive and negative aspects of any attempt to identify early or pre-symptomatic

disease in a whole population with the intention of saving life or reducing ill health.

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This report, which has been commissioned from the North West Public Health Observatory at the Centre for Public Health, Liverpool John Moores University with input from Public Health Cumbria, is intended as a reference work and source of information on the current state of screening programmes in the county. I hope that this will lead to a greater level of popular understanding of the scope and potential benefits of these very modern public health interventions and lead to informed debate within the county on any issues that arise in the coming years.

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#### Section 1: Introduction

### What is screening?

Screening is an important public health service which has the potential to save lives, reduce risk to health and prevent illness and disease.

The UK National Screening Committee defines screening as:

"...a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition."<sup>1</sup>

As the NHS Screening Timeline (launched in April 2010) illustrates, the NHS currently offers at least eleven established screening programmes nationwide right from before birth (for a mother or her unborn/new baby) through to older age (including testing of both young people and adults [Figure 1]). There are also a number of further screening programmes, which although not formally agreed by the UK National Screening Committee, are available across England. Everyone registered with a doctor should receive an automatic invitation for screening at the relevant time or be screened 'opportunistically' when attending a particular venue during their daily life, such as their GP surgery or supermarket (see www.screening.nhs.uk/england).

Screening can involve answering a simple guestion/s or undergoing a clinical test (for example, providing a sample of blood or urine). Although no screening test is 100% accurate, before any programme is introduced it must meet a range of internationally recognised criteria (see www.screening.nhs.uk/criteria). The UK National Screening Committee is responsible for ensuring the quality and effectiveness of screening programmes nationally. As part of this, there are already national standards for each of the cancer screening programmes and a series of performance indicators or standards are available or being developed for the non cancer screening programmes (see www.screening.nhs.uk/about).

#### **Outline of the report**

In the *Cumbria 2010* annual report, the Director of Public Health noted that while screening services are generally performing well locally (with high levels of uptake and a wide coverage among at risk groups) there is potential for some programmes and some areas to do better.<sup>2</sup> This *Health Screening In Cumbria* report forms part of a response to a request at the beginning of October 2010 from the Regional Director of Public Health, Dr Ruth Hussey, for primary care trusts to review all local screening programmes (by the end of December 2010). The report focuses upon the programmes that are currently available throughout a person's lifetime in Cumbria:

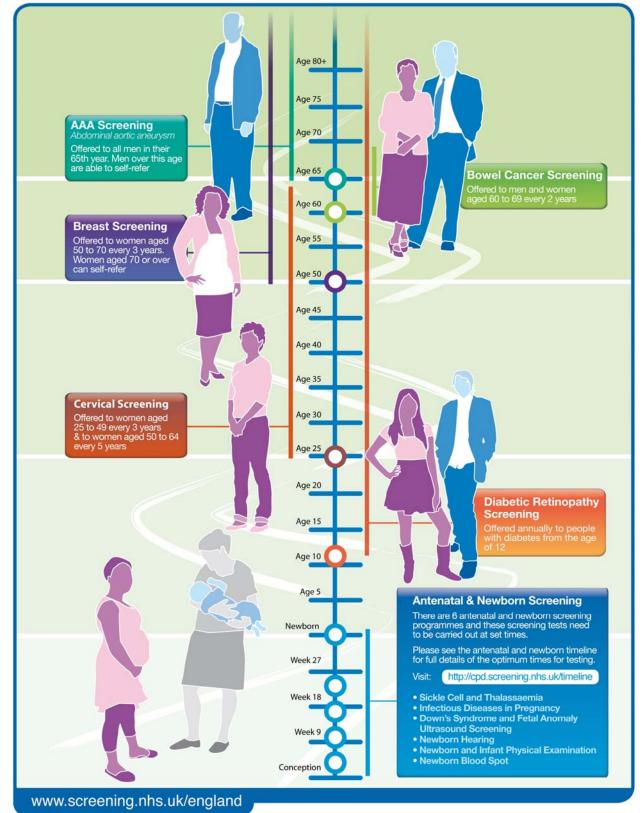
- Antenatal and newborn screening (for infectious diseases in pregnancy, sickle cell and thalassaemia, Down's syndrome and foetal anomalies, newborn blood spot, newborn hearing and newborn and infant physical exam)
- Diabetic retinopathy;
- Cancer screening; (for cervical, breast and bowel cancer);
- Abdominal aortic aneurysm screening;
- NHS health check (formerly the vascular check); and
- Chlamydia screening.

The latter two opportunities for testing are not officially part of the nationally agreed screening programmes, but are generally available across the county.

The report briefly outlines each of the screening programmes and their importance before providing national context, such as when the programme started, who is targeted and how, any future developments and, where available, data showing outcomes or achievements.

Details about how the programmes are organised, delivered and performing locally is then presented. For example, the number of people in Cumbria who take up the offer of screening, the extent to which national or local targets are being met and how the programmes may develop in the future. Brief details are also included about emerging screening opportunities in relation to alcohol misuse and the risk of prostate cancer. A distinction must be drawn between screening and case-finding. In general, population-based screening programmes as described above come under the direction and supervision of the Public Health Service, whereas case-finding is part and parcel of good clinical practice.

#### Figure 1: The NHS Screening Timeline



Source: UK National Screening Committee and NHS National Screening Programmes (www.screening.nhs.uk/nhs-timeline)

### Section 2: NHS Screening Timeline Antenatal and newborn screening



For the purpose of this report the antenatal and newborn screening programme has been split into two sections.

### **Antenatal screening**

During pregnancy, a mother is offered a number of screening opportunities to allow her to access appropriate treatment for herself, to plan for the baby's treatment soon after its birth or to allow her to receive advice to help her make an informed choice about whether to continue with the pregnancy.<sup>3</sup>

The antenatal screening programme encompasses three separate tests:

- Before birth, as part of the NHS Infectious Disease in Pregnancy Screening Programme<sup>4</sup> a blood sample is taken from the mother to see if she has one of four conditions that can cause considerable harm to her unborn child (hepatitis B, HIV, rubella or syphilis [Figure 2]).
- The NHS Sickle Cell and Thalassaemia Screening Programme<sup>5</sup> involves taking a blood test (before 10 weeks of pregnancy) to help identify whether a baby is at risk of one of the serious blood disorders.
- 3. All pregnant women are also offered tests (including a minimum of two ultrasound scans) at around 10-20 weeks into the pregnancy as part of the *NHS Fetal Anomaly Screening Programme*<sup>6</sup> (previously the *NHS Fetal Anomaly Ultrasound Screening Programme* and the *Down's syndrome Screening Programme*) to check the general health of the developing baby.



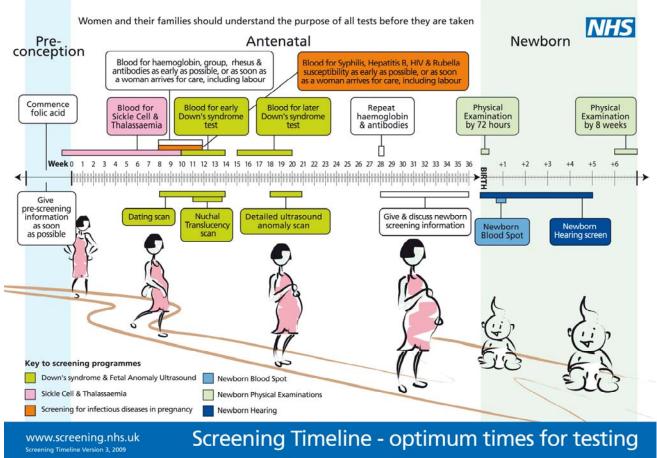
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The anomaly screening as a whole therefore includes:

- a dating scan at 8 to 14 weeks;
- a Nuchal Translucency<sup>i</sup> Scan at 11 to 14 weeks of pregnancy;
- a detailed ultrasound anomaly scan at 18 to 21 weeks of pregnancy;
- a blood for early Down's syndrome test at 10 to 14 weeks of pregnancy; and
- a blood for later Down's syndrome test at 15 to 20 weeks of pregnancy (Figure 2).

The future life chances and health of an unborn child can be at significant risk if its mother catches or already has an infection during her pregnancy.<sup>7</sup> For example, a baby whose mother contracts rubella in early pregnancy risks being born with brain, heart, eyes or hearing problems (even immunised mothers are not guaranteed full immunity) while a baby who catches Hepatitis B from its mother can experience recurring health infections, which at worst could lead to serious liver problems in later life.7 There are also a number of conditions in the baby (some of which are hereditary) that can harm his/her development and future health.<sup>8</sup> For example, the spine of babies with spina bifida does not develop correctly,9 babies with Down's syndrome will have learning difficulties and physical impairments<sup>10</sup> and babies with the inherited blood disorder thalassaemia. in its most severe form, will need a lifetime of blood transfusions.<sup>11</sup>

<sup>&</sup>lt;sup>i</sup> Refers to fluid behind the neck of the fetus



Source: NHS Fetal Anomaly Screening Programme (http://fetalanomaly.screening.nhs.uk/cms.php?folder=2442)

### Organisation of antenatal screening in Cumbria

Figure 2: Antenatal screening timeline

The antenatal programme screening lead for North Cumbria is based at North Cumbria University Hospitals NHS Foundation Trust and the programme operates across three maternity units or so called satellite sites:

- Cumberland Infirmary;
- Penrith Hospital; and
- West Cumberland Hospital.

The screening lead in South Cumbria is based at the University Hospitals of Morecambe Bay NHS Trust. The Ante and Neonatal Screening Co-ordinator is a new post for the Morecombe Bay area and the programme covers three sites:

- Furness General Hospital;
- Royal Lancaster Infirmary; and
- Westmorland General Hospital.

Screening for infectious disease during pregnancy across the North West and in Cumbria began in 2003.<sup>7</sup> Screening for infectious disease (including syphilis, Hepatitis B and HIV) is offered to all mothers who consent to testing. Sickle cell and thalassaemia screening has been offered in Cumbria since 2007, while screening for foetal anomalies among all women has been available since 2008 (including blood test screening for Down's syndrome).

#### Programme performance

The Cumbria and Lancashire Health Protection Unit, one of three regionally, organises collection of infectious disease in pregnancy outcomes data from its ten maternity units on a quarterly basis (on behalf of the North West Health Protection Agency).<sup>7</sup> The 2010 annual report of infectious diseases (including data from January - December 2009) shows that all Cumbria and Lancashire maternity units submitted 100% of infectious disease data returns each quarter.<sup>7</sup> However, the North West Health Protection Agency notes that there could be inconsistencies in the infectious disease data as many maternity units regionally struggle to compile and validate their data due to time and resource constraints.<sup>7</sup>

Cumbria and Lancashire achieved the highest uptake rates overall for Hepatitis B, HIV, syphilis and rubella of any unit regionally, with the highest being for rubella (99.82%). Cumbria and Lancashire also had the lowest rates of declined screening for each infection and positive test results for Hepatitis B, HIV and syphilis (Table 1).

### Table 1: Infectious diseases national targets

	January - December 2009			
		Cumbria and Lancashire Health		
	North	Protection	North	National
	Cumbria	Unit	West	target
Annual uptake -Hepatitis B -HIV -syphilis -rubella	99.0% 97.5% 100.0% 100.0%	98.52% 97.79% 99.54% 99.82%	95.83% 93.75% 96.82% 96.31%	100.0% ≥90.0% 100.0% 100.0%
Declined screening -Hepatitis B -HIV -syphilis -rubella	1.0% 2.5% 0.0% 0.0%	1.38% 2.11% 0.27% 0.03%	4.07% 6.18% 3.12% 2.97%	
Pregnant women with known Hepatitis B referred to an appropriate specialist (in six weeks)	* (data for South Cumbria: shows 100.0%)	*	*	≥ 70.0%

Source: Health Protection Agency, University Hospitals of Morecambe Bay NHS Foundation Trust and North Cumbria University Hospitals NHS Trust

\*No accurate data available for the time period

### South Cumbria is generally meeting or exceeding national performance targets for sickle cell and thalassaemia, and fetal anomalies screening (Table 2 and Table 3).

### Table 2: Sickle cell and thalassaemia national targets

	2009		
	North Cumbria	South Cumbria	National target
Coverage (i.e. the proportions of eligible mothers who receive a conclusive screening test)	* (01/12/09- 31/08/10 data shows 99.34%)	99.0%	≥ 95.0%
The timeliness of testing (conclusive results by 10 weeks gestation)	82.5% (approx.)	50.0%	≥ 50.0%
The proportion of samples submitted to the laboratory with a Family Origin Questionnaire	* (01/12/09- 31/08/10 data shows 99.5%)	99.85%	≥ 85.0%

Source: University Hospitals of Morecambe Bay NHS

Foundation Trust and North Cumbria University Hospitals NHS Trust \*No accurate data available for the time period

### Table 3: Fetal anomalies national targets

	2009		
	North Cumbria	South Cumbria	National target
<b>— — — — — — — — — —</b>	Gumbha	Cumbria	larger
Testing for foetal			
anomalies in the			
timeframe among	100%	99.9%	≥ 90.0%
women who accept			
screening			
The completion of lab			
forms for Down's in	100%	100.0%	≥ 97.0%
the timeframe			

Source: University Hospitals of Morecambe Bay NHS Foundation Trust and North Cumbria University Hospitals NHS Trust

### Planned/future developments

### North Cumbria University Hospitals NHS Trust has yet to fund a maternity IT system and while South Cumbria has had such a system for over ten years, only some antenatal and neonatal screening tests can be input into this.

Planning is underway to implement the first trimester combined test for Down's syndrome from January 2011 among all women expecting a single baby who are booked to have an early pregnancy scan on or after that date at North Cumbria University Hospital NHS Trust. The combined test includes an ultrasound screen (such as the nuchal translucency) and a blood test between 11<sup>+2</sup> and 14<sup>+1</sup> weeks' gestation. The regional screening laboratory combines test results with the details about the mother's age, weight, ethnicity and smoking status, stage of pregnancy and related factors to calculate the risk of Down's syndrome.

This new test is expected to detect up to nine out of ten (90%) of pregnancies affected by Down's syndrome. However, two or three in one hundred women (2-3%) will be identified as at 'higher' risk when their child could be unaffected (also called the 'screen positive' rate). As for other programmes, all results will be reported and followed up with those women identified as 'higher risk' being able to discuss their results and healthcare options (such as having an amniocentesis diagnostic test at the local maternity units) with a relevant professional. The second trimester quadruple test will still be available for women who access maternity services later in pregnancy or where, for maternal or fetal reasons, it is not possible to complete the combined test. GPs are asked to urge every pregnant patient to contact their midwife promptly as the timeframe for completing the test is fairly short. Women having

more than one child will continue to be offered screening for Down's syndrome at the Fetal Medicine Unit (at the Royal Victoria Infirmary in Newcastle).

There is a marked variation in uptake of screening for Down's syndrome risk nationally, and on different sites within Cumbria, although the cause of the variation requires further investigation.

A key challenge for rolling out the Combined Test for Down's syndrome is providing the additional resources required (such as for ultrasound and maternity care support workers).

A method of collecting data for the newborn and infant physical examination will be in place across South Cumbria with effect from January 2011 and now the area has a designated Antenatal and Neonatal Screening Coordinator/Screening Lead, collection of data and quality assurance will be prioritised. All babies undergo a general check of their physical health soon after birth as part of the *NHS Newborn and Infant Physical Examination* programme

(http://newbornphysical.screening.nhs.uk). This is followed by a more detailed examination (usually in hospital) within three days of birth, including tests of a baby's eyes, heart, hips and in boys, testes. The same tests are then repeated after six to eight weeks once the baby has developed further.

Each mother in England is also given the opportunity to have a small sample of blood taken from her baby's heel between the fifth and eighth day after birth as part of the *NHS Newborn Blood Spot Screening Programme* (http://newbornbloodspot.screening.nhs.uk) to identify if they have a rare but serious health condition. The UKNSC recommend testing for phenylketonuria, congenital hypothyroid, sickle cell disorders,<sup>ii</sup> cystic fibrosis and medium acyl-CoA dehydrogenase (MCADD)<sup>iii</sup>.

Some babies will need treatment after birth (such as an operation) to correct their health problem. For example, around one in 200 will need treatment for heart problems and one or two in 1,000 for hip problems. A very small number of babies will be born with a rare but dangerous condition such as cystic fibrosis which affects about one in 2,500 babies born in the UK and requires treatment throughout life. However, many children with these conditions go on to enjoy a high quality of life, given appropriate care and support.

There are a number of further screening options available in the first few weeks or months of life. Every parent in England is invited to have their child's hearing tested as part of the *NHS Newborn Hearing Screening Programme* and the programme is said to have one of the best clinical IT systems across the NHS, screening over 1,700 baby's daily

(http://hearing.screening.nhs.uk). The screening includes the Otoacoustic Emission One and Otoacoustic Emission Two tests and an Automated Auditory Brainstem Response test. The Otoacoustic Emission tests involve inserting a small probe into the baby's ear to measure soundwaves when clicks or tones are played into it, while the Automated Auditory Brainstem Response test measures the hearing nerve's response when sounds are played through soft earphones (the nerve's response is recorded by placing three electrodes on the outside of the baby's head).

In the UK, one to two babies in every 1,000 will be born with hearing loss in one or both of their ears.<sup>12</sup> It is estimated that without screening, 400 of the 900 children born each year in the UK with permanent deafness would already be 18 months of age before a problem is detected, by which time their ability to learn language and to do well at school and in later in life could already be significantly affected.<sup>13</sup>

### Organisation of newborn screening in Cumbria

The newborn blood spot was introduced in Cumbria in 1968. Every newborn is offered the screening for one of five different conditions (each was introduced at different points over the last 30 years): phenylketonuria and congenital hypothyroid testing both from 1980, haemoglobinopathies (such as sickle cell) from 2005, cystic fibrosis testing from October 2007 and screening for MCADD most recently, in 2008.14 Midwives collect the sample with informed consent on day five to eight. Babies born in South Cumbria or within the University Hospitals of Morecambe Bay NHS Foundation Trust area have samples sent to Manchester, while the rest of Cumbria uses the Newcastle laboratory. The success of the screening programmes relies upon a high quality initial blood sample as this helps to reduce the likelihood of a repeat test, worry among parents, additional pain for the baby as well as additional workload for health staff.<sup>14</sup>

The county of Cumbria employs three health visitors who act as informal screening links. In South Cumbria, for example, the screening link obtains repeat blood samples at home where there is a clinical need and delivers any out of the ordinary results to parents at home face-toface and with immediate follow up by the appropriate health professional. For example, if screening suggests that cystic fibrosis is suspected, the screening link will visit parents anywhere in South Cumbria, explain what the screening indicates and advise them of the next steps - which will involve an appointment for confirmatory testing the following day and a paediatric review. This can be a very difficult visit

<sup>&</sup>lt;sup>II</sup> Part of the haemoglobinopathy disorders

<sup>&</sup>lt;sup>II</sup> MCADD is a rare inherited disorder where the body cannot break down (metabolise) fat properly

to undertake as parents are often distressed but on reflection they do welcome the personal service. The screening lead can also deliver and explain carrier results for cystic fibrosis and haemoglobinopathies.

The newborn hearing screening programmes across Cumbria are largely community based. This means that hearing tests are generally done at home by a health visitor during their first visit, between 10 and 14 days after birth. However, if babies are unwell, testing can also be carried out by specially trained hospital staff at the Special Care Baby Unit or Neonatal Intensive Care Unit.<sup>15</sup>

In North Cumbria, there is a Local Co-ordinator/Manager (employed by Cumbria Primary Care Trust) and two part time hearing

- screeners covering babies born in the:
- Cumberland Infirmary;
- Penrith Hospital; and
- West Cumberland Hospital.

In South Cumbria there are two members of staff (based at Carnforth Clinic, employed by NHS North Lancashire) who share the job of Local Co-ordinators for the Newborn Hearing Screening Programme in the Morecambe Bay site (covering Lancaster and/or Morecambe and South Cumbria) and testing babies born in:

- Furness General Hospital (Barrow);
- Royal Lancaster Infirmary (Lancaster); and
- Westmorland General Hospital (Kendal).

The Otoacoustic Emission One and Two tests (if necessary) are performed by health visitors in the home and the Automated Auditory Brainstem Response test, if required, is performed at home by a Local Co-ordinator (the same system operates in the north).

Testing, as part of the Neonatal Intensive Care Unit Protocol, relates to babies who have spent a minimum of 48 hours in the unit. Dedicated screeners specifically in the Neonatal Intensive Care Units of Furness General Hospital and Royal Lancaster Infirmary have been trained to do the screening. As part of the protocol, babies have both the Otoacoustic Emission and Automated Auditory Brainstem Response screening tests. The standard includes that babies are not to be tested until over 34 weeks gestation and screening is to be completed by 44 weeks gestation. The Community Paediatric Audiology service also provides follow up and support throughout the child's time in school. In North Cumbria, for example, each child is also screened for hearing problems during reception year at primary school (with their parent's permission).<sup>15</sup>

### Programme performance

### Limited data are available to measure outcomes from the Newborn and Infant Physical Examination and Blood Spot screening programmes (Table 4 and Table 5). For the physical examination, there were a small number of 'well babies' in East Cumbria who were tested but not within the 72 hour timeframe, however, all were tested by five days of age. The Newborn and Infant Physical Examination for well babies is largely done by

Examination for well babies is largely done by community midwives in East Cumbria and workload pressures had led to these delays. This issue will be addressed following the outcomes of a national mapping of physical examination services.

### Table 4: Newborn and infant physicalexamination national targets

		2009	
	North	South	National
	Cumbria	Cumbria	target
Coverage: eligible babies tested within 72 hours of birth.	*	*	≥ 95.0%
Timely assessment: babies with a possible abnormality of hips who undergo ultrasound assessment within two weeks of birth.	100.0%	*	≥ 95.0%

Source: University Hospitals of Morecambe Bay NHS Foundation Trust and North Cumbria University Hospitals Trust \*No accurate data available for the time period

### Table 5: Newborn blood spot nationaltargets

2009			
North	South	National	
Cumbria	Cumbria	target	
95.1%	99.9%	≥ 95.0%	
* (usually 2.0%)	2.0%	≤2.0%	
*	99.0%	≥95.0%	
	Cumbria 95.1% * (usually 2.0%)	North South Cumbria Cumbria 95.1% 99.9% * (usually 2.0%)	

Source: University Hospitals of Morecambe Bay NHS Foundation Trust and North Cumbria University Hospitals Trust \*No accurate data available for the time period The most recent newborn hearing screening data for Cumbria relates to the period 1<sup>st</sup> April -30<sup>th</sup> June 2010 and is taken from the e-Screening Plus database and compiled by the Programme Centre for the NHS National Hearing Screening Programme in Manchester. **The data shows that many of the national quality standards for the programme have already been reached or surpassed in both areas of Cumbria** (Table 6).

### Table 6: Newborn hearing screeningnational targets

	1 <sup>st</sup> April 2010 - 30 <sup>th</sup> June 2010		
	North Cumbria	South Cumbria/ Morec. Bay	National target
Screens offered (total)	99.8%	99.7%	≥ 99.0%
Screens started (total) - Well babies - Neonatal intensive care unit babies	99.8% 99.7% 100.0%	99.7% 99.7% 100.0%	≥ 98.0% ≥ 98.0% ≥ 98.0%
Screens declined	0.2%	0.0%	≤ 0.1%
Screens completed by four weeks (neonatal intensive care unit babies)	100.0%	100.0%	≥ 95.0%
Screens completed by five weeks (community sites)	98.6%	98.6%	≥ 95.0%
Screens completed by three months	99.7%	99.6%	≥ 95.0%
Screening outcome set within three months	99%	99.6%	≥ 99.0%

Source: National Hearing Screening Programme Quality Standards Headline Report A (by primary care trust) produced on 15<sup>th</sup> October 2010

### Planned/future developments

Key challenges include the lack of an IT system, the absence of a team leader over the last three years and the age of the equipment being used, as it is over five years old.

In 2010, all trusts nationally provided information towards a national mapping of newborn and infant physical examination services (a similar review of the infectious disease and sickle cell and thalassaemia screening programmes was conducted in 2008). Until two years ago, there were no national standards for the physical examination, however, these have since included the timeliness of the test and time of referral for children with suspected problems. The aim of the mapping exercise is therefore to gather evidence about what key gaps might exist and what works well, with a view to sharing best practice. Alongside this, a national pilot of a screening management system (including Newcastle's Royal Victoria Infirmary site) was completed last year with a view to rolling this out nationally (similar to the current national newborn hearing screening programme system) to help improve the tracking and follow up of babies tested (see

http://newbornphysical.screening.nhs.uk/cms.ph p?folder=2419).

The UK National Screening Committee is considering offering screening for more conditions, probably starting with congenital adrenal function problems (screening for Duchene's is being considered as it is offered in some regions) and the usual tests of reliability, specificity<sup>iv</sup> and so on, will be applied before screening is introduced (there is no fixed date for introducing this in South Cumbria).

North Cumbria University Hospitals NHS Trust implemented the use of barcoded NHS number baby labels in March 2010. In South Cumbria, staff are awaiting arrival of compatible software before this can be introduced and hope to commence with the barcoded labels in early 2011.

New hearing machines called Otoports have been used since February 2010 and feedback from the health visitors is excellent (previously used Echocheck machines). The hearing screen machines used in South Cumbria are called Accuscreen, which although different do the same job, but are around five years old.

Staff in south Cumbria now use a new Screening Equipment Data Quality system (introduced in 2010) to upload their hearing screening results directly from their screening machines. This system was brought in to speed up the transfer of data from equipment to database thus reducing errors and increasing accuracy and security of data. Health visitors can now download patient data from their screening machines daily. This has been very successful in improving the achievement of the quality standards. In south Cumbria, the 34 pieces of equipment, owned by the Morecambe Bay site, were upgraded and all computers were fitted with intermediate software. Training sessions took place over three days for over 60 health

<sup>&</sup>lt;sup>10</sup> Specificity refers to the percentage of people who test negative for a specific disease among a group of people who do not have the disease. No test is 100% specific because some people who do not have the disease will test positive for it (false positive)

visitors and neonatal intensive care unit screeners.

As part of the planned re-commissioning of Sure Start children's centres, NHS Cumbria are developing contracts covering performance monitoring and quality assurance measures around the newborn blood spot and newborn hearing screening programme, which will include agreement of robust county wide pathways.<sup>16</sup>

### **Examples of local successes**

During the most recent national quality assurance visit (in April 2009) the newborn hearing screening part of the programme was rated as above average. The next round of quality assurance questionnaires have just been submitted and another visit could follow in Spring 2011 depending on the assessment of the information for the site.

#### **Diabetic retinopathy screening**

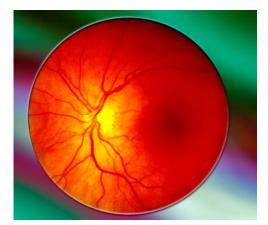


The aim of the *English National Screening Programme for Diabetic Retinopathy,* launched in 2003, is for fewer diabetics to lose their eyesight by ensuring earlier identification of people potentially at risk from the disease and quicker treatment.<sup>17</sup> The test involves taking a digital photo of the retina, which is assessed to determine the likely risk of developing the condition.

A total of 2.8 million people in the UK are currently diagnosed with diabetes and an estimated 500,000 more people have the condition without knowing it.<sup>18</sup> Diabetes is characterised by high levels of glucose (a form of sugar) in a person's blood because his/her pancreas does not produce enough insulin (a hormone) to help the body use glucose properly.<sup>18</sup> Diabetes can affect both children and adults.

There are a number of complications associated with diabetes, one of which is diabetic retinopathy. This is where the group of blood vessels linked to the retina (the area of the inner eye which is light sensitive) become blocked or leak which in turn can lead to blurred vision or at worst, loss of sight.<sup>19</sup> The condition is also the main reason for blindness among people of working age in the western world.<sup>20</sup> Diabetic retinopathy can present relatively few symptoms until it is fairly advanced, however, if caught early enough laser treatment can be used to reduce risk of sight loss and better management of diabetes itself can prevent risk from diabetic retinopathy or slow the disease's progress.

Each year, around one in twenty pregnant women in England and Wales will have diabetes.<sup>21</sup> Left untreated, diabetic retinopathy can become considerably worse during pregnancy (especially among mothers who already had the condition or those who have



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persistently high blood pressure). The national screening programme therefore makes a number of recommendations about screening pregnant women in line with national guidelines (produced by the National Institute for Health and Clinical Excellence in 2008) about the management of diabetes in pregnancy.<sup>21</sup>

Since 2006, each diabetic retinopathy screening programme nationally has produced an annual report showing the services available along with general details about the programme to help measure performance against service objectives and national quality assurance standards.<sup>22</sup> From October 2008, all programmes now submit annual report data online through a new Electronic Annual Reporting System (see https://ears.retinalscreening.nhs.uk). However, at present these are not available to view online at regional or national level for comparison.

The National Service Framework Delivery Strategy for Diabetes, produced in 2003, committed to ensuring that at least 80% of people with diabetes would be offered screening by 2006 for the early detection (and treatment if needed) of diabetic retinopathy, increasing to 100% coverage of those at risk of retinopathy by the end of 2007.<sup>23</sup>

To help maintain the quality of retinal screening, there is a programme of quality assurance visits, led by a National Quality Assurance Director and Regional Quality Assurance Managers. The visits are also supplemented by peer review and close liaison with the regional Directors of Public Health. The process should also be supported by ongoing internal reviews (including regular assessment of any statistical data). The Regional Quality Assurance Managers' key role includes analysing local data (such as provided in the annual report) and supporting local hospital trusts, primary care trusts and strategic health authorities to share standards and good practice, to help build the quality of their programmes

(see www.retinalscreening.nhs.uk/pages/default. asp?id=4).

The quality of services and treatment available for diabetics is currently being independently reviewed.<sup>17</sup> Local screening programmes are also under review to ensure that they are achieving the national target that all people with diabetes are offered retinopathy screening each year. The National Quality Assurance Manager for the North West (who also covers the North East) visited all programmes across the region during the last two years and suggested a number of improvements across most of the schemes; three cases in the North West were reported as serious incidents.<sup>59</sup>

### Organisation of diabetic retinopathy screening in Cumbria

The Cumbria programme includes a Diabetes Service Manager (who is the main screening contact) along with a Screening Team Leader and Programme Manager.

Diabetic retinopathy screening services in Cumbria also cover North Lancashire, as part of an agreement jointly commissioned by NHS Cumbria and North Lancashire Primary Care Trust.<sup>24</sup> Until 2005, screening was the responsibility of the opticians service and until October 2009, the North West Ambulance Service operated the retinal screening service across Cumbria and North Lancashire with two teams of staff (one for North Cumbria and another for South Cumbria and North Lancashire).<sup>25</sup> Since 1<sup>st</sup> October 2009, this service has become one, and comprises four teams of staff, each being mobile serving their community and operating with the Closer to Home<sup>v</sup> agenda. Together, they operate in 30 different clinics and screen on average 400 patients per week.

#### Programme performance

Disease register and prevalence data, for April 2009 - March 2010 (from the most recent Quality and Outcomes Framework<sup>vi</sup>), shows that

21,888 people aged 17 years and over in the Cumbria Primary Care Trust area are recorded as having diabetes, including details of whether the patient has Type 1 or Type 2 diabetes, equating to a prevalence rate of 5.2% (one of the lowest levels of prevalence in the North West).<sup>vii</sup> This is slightly below the prevalence rates for the North West and England (5.7% and 5.4% respectively).

As noted, all people with diabetes in England are to be offered testing each year, although this is not currently being achieved across Cumbria (Table 7).

### Table 7: Diabetic retinopathy national targets

		April 2009 -	March 201	0
		North		
	Cumbria	Lancs.		
	Primary	Primary		
	Care	Care	North	
	Trust	Trust	West	England
Patients with				
diabetes who				
received retinal	87.4%	90.5%	91.2%	90.9%
screening in the				
past 15 months				

Source: Quality Outcomes Framework

At a practice level, there is a wide variation in achievement across Cumbria and North Lancashire Primary Care Trust, ranging from 66.0% in some practices to 100.0% in others (Figure 3 and Figure 4); one practice in Cumbria Primary Care Trust achieved 100.0%, but this had only one patient with diabetes.

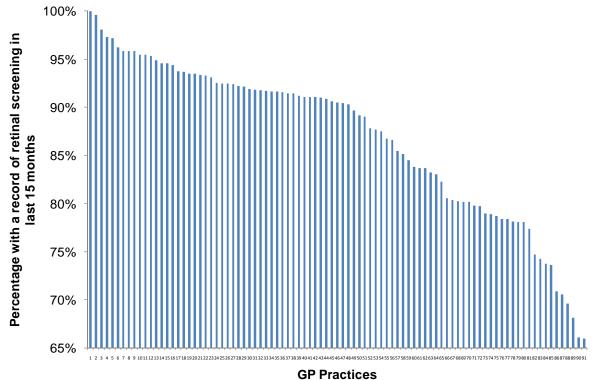
Some retinal screening data from the English programme is also available from the Health Needs Assessment Tool which is downloadable via the National Diabetes Information Service website (see https://dhna.ic.nhs.uk). However, no data is currently available for Cumbria Primary Care Trust and there is a note on the website that reports by individual primary care trust will only be possible when the relevant software is developed, or where there is a single Diabetic Retinopathy Screening Programme providing services for a single primary care trust.

<sup>&</sup>lt;sup>v</sup> See www.cumbria.nhs.uk/YourLocality/C2HNorth.aspx

<sup>&</sup>lt;sup>vi</sup> A voluntary incentive scheme for GP practices in the UK which rewards them for how well they care for patients (and against which practices score points according to their level of achievement) - a total of 91 GP practices across Cumbria participate in the national Quality Outcomes Framework

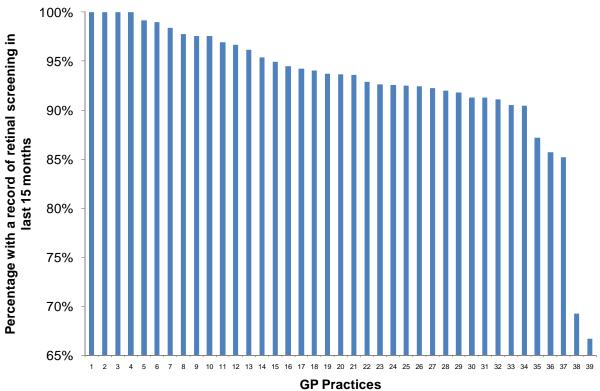
<sup>&</sup>lt;sup>vii</sup> See the full list of data tables: www.ic.nhs.uk/statistics-and-datacollections/supporting-information/audits-and-performance/the-quality-andoutcomes-framework/qof-2009-10/data-tables





Source: Quality Outcomes Framework. NB: Although individual GP practices are numbered here, actual names are available online for information

Figure 4: The percentage of GP patients with diabetes who have a record of retinal screening in the previous 15 months. North Lancashire Primary Care Trust, April 2009 - March 2010.



Source: Quality Outcomes Framework. NB: Although individual GP practices are numbered here, actual names are available online for information

viii Taken from Quality Outcomes Framework Diabetes Indicator 21

Further relevant data sources include the National Diabetes Audit, started in 2003.<sup>ix</sup> This provides data and intelligence on over 1.7 million diabetics in England and Wales, and helps to share good practice, show progress towards national targets and identify gaps in commissioning. There are also plans to establish a national register of children and young people with diabetes.

#### **Planned/future developments**

### Providing complete data can be difficult due to the cross boundary working

**arrangements** (for this reason the most recent annual report from 2008/09 was missing some data).

To date, there have also been a number of delays or problems with the programme (including the length of time that people wait for testing and receiving results);<sup>24</sup> however, as of January 2011 these issues had largely been resolved.

#### **Examples of local successes**

The retinal screening service's mobile camera testing equipment is particularly well suited to reaching even the most hard to reach, such as elderly people living in rural areas.<sup>25</sup>

<sup>&</sup>lt;sup>k</sup> See www.ic.nhs.uk/services/national-clinical-audit-support-programmencasp/diabetes

#### **Cancer screening programmes**





There are three major NHS cancer screening programmes - breast, cervical and bowel (colorectal) which have been grouped together for the purposes of this report. The NHS breast and cervical cancer screening programmes are well established, having been introduced in 1988, while the bowel cancer screening programme was more recently introduced in 2006.<sup>26</sup> Each of the three programmes is discussed in detail in the following sections.

One of the eight goals as set out in *NHS Cumbria's Strategic Plan 2010*<sup>27</sup> is to '*Reduce premature mortality due to cancer'*. Improving the coverage and uptake of screening programmes that are in place across Cumbria will assist in achieving this goal as well as providing an opportunity to reduce health inequalities. The Commissioning Strategy for Cancer Services in Cumbria 2010-2013<sup>28</sup> has been developed to support and develop the Strategic Plan.

#### **Cervical cancer screening**



The aim of the *NHS Cervical Screening Programme* is to reduce the number of women who:

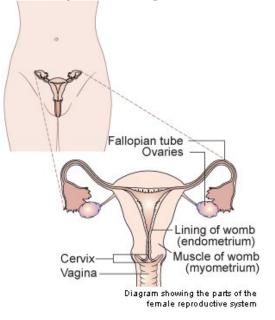
- 1. develop invasive cervical cancer (incidence); and
- 2. die from it (mortality).

Cervical screening does not test for cancer; rather it looks for early abnormalities which, if left untreated, could lead to cancer in the cervix, also known as the neck of the womb (Figure 5).<sup>29</sup>

The test involves taking a small sample of cells from the surface of the cervix and placing them in a preservative fluid, a process called liquid based cytology. This fluid is sent to a laboratory to be examined and any abnormal cells that are found are reported.

Each year in the UK, around 2,800 women are diagnosed with cervical cancer.<sup>30</sup> It is the second most common cancer among women under the age of 35 years.<sup>30</sup> Cases of cervical cancer are declining, having fallen by over ten per cent in the last ten years. Over half of new cases of cervical cancer are diagnosed in women aged 50 years or less.<sup>31</sup>

### Figure 5: Location of the cervix in the female reproductive system



Source: Cancer Help UK (www.cancerhelp.org.uk/type/cervicalcancer/about/the-cervix)

Under the national programme, the screening test (known as a cervical smear) is offered to all women who are deemed 'at risk' i.e. those aged 25 to 64 years. Screening is done at different intervals, depending on age (Table 8).

Women who are registered with a GP will be invited to attend for a cervical smear under the NHS call and recall system. This system also monitors any follow-up investigations, and, if all is well, recalls the woman for screening at the appropriate time. For this reason it is important for all women to inform their GP about any changes in their personal details including name and address.

#### **Table 8: Intervals for cervical screening**

	······································
Age	Call for screening
24 years and 4 months	First invitation
25-49 years	Every three years
50-64 years	Every five years
Over 65 years	Those who have never been screened or have had recent abnormal results

Source: Cervical Screening Pocket Guide 2009

Since its introduction, the NHS Cervical Screening Programme has screened over 64 million women and detected more than 400,000 significant abnormalities, saving an estimated 4,500 lives per year.<sup>32</sup> In 2010, the programme invited around 4.1 million women in England and 66,201 in Cumbria for cervical screening.<sup>33</sup>

The programme's effectiveness is also judged by coverage i.e. the percentage of women in the target age group (25-64 years) who have been screened in the last five years. A target of 80% coverage of the eligible population in the last five years has been set by the NHS Cervical Screening Programme.<sup>35</sup>

Evidence has suggested that if an overall coverage of 80% is achieved, it would be possible to reduce death rates by an estimated 95% in the long term. In 2009/10 the coverage of eligible women was 78.9% across England. The North West had the second lowest coverage rate in England (78.4%), with only London being lower (73.9%).<sup>33</sup>

The human papilloma virus is a family of viruses affecting the skin and moist membranes that line the body. Over 100 types of human papilloma virus exist, and research has found that some types can lead to cervical cancer.<sup>34</sup>

The national human papilloma virus vaccination programme, introduced in September 2008, offers the vaccine (also known as the 'cervical cancer jab') to all girls aged 12-13 years. At the same time, a three-year 'catch-up' campaign was also introduced, offering the vaccination to older girls, aged 17-18 years. The majority of primary care trusts aim to complete the catch-up programme within two years.<sup>34,35</sup> Delivered mainly through secondary schools, the vaccination programme provides three injections of the human papilloma virus vaccine Cervarix over a three month period (although they may be given over a 12 month period). Between September 2008 and July 2010, over four million doses of Cervarix were given.

In combination with cervical screening, the human papilloma virus vaccination plays an important role in the fight against cervical cancer. In the UK, an estimated 400 lives per year could be saved as a result of vaccinating girls against human papilloma virus. It is important that vaccinated women continue to attend for cervical screening appointments as the vaccination will not prevent all types of cervical cancer.  $^{\mbox{\tiny 35}}$ 

In the future, computer assisted detection of cervical abnormalities may also be possible.<sup>35</sup>

### Organisation of the cervical screening programme in Cumbria

Cumbria is a large geographical area and is England's second largest county. This presents challenges when it comes to organising the cervical screening programme. The Cumbrian programme is overseen by the Deputy Director of Public Health and there is one part-time Cervical Screening Advisor. There are two screening agencies responsible for the call and recall system; one for North Cumbria and Lancashire and the other (the Lancashire and South Cumbria Agency) for South Cumbria.

The majority of cervical samples are taken in primary care with only a small percentage performed in community clinics. **During 2010** the laboratory facilities have altered in the county and all samples are now sent to the Central Manchester Hospital Laboratory for processing. This means that samples may now also have human papilloma virus testing if appropriate. This has improved the service offered to Cumbrian women.

There are five hospital sites offering colposcopy,<sup>×</sup> two in the north at Carlisle and Whitehaven. These have had a direct referral system in place for a few years which means that women are not waiting to be referred for an appointment if an abnormality is discovered at screening. The three hospitals in Morecambe Bay in the South are in Kendal, Barrow-in-Furness and Lancaster. Each is in the process of introducing a direct referral system which will again improve the patient pathway for women with abnormalities.

### Programme performance

Cervical Screening Programme data (KC53 returns) shows that cervical screening coverage in Cumbria is consistently higher than regional and national averages (Table 9 and Figure 6).

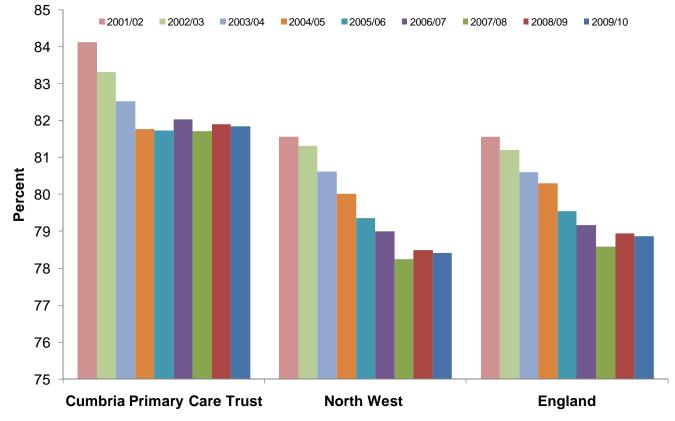
<sup>&</sup>lt;sup>x</sup> A colposcopy is a procedure (using a low powered microscope) carried out after an abnormal cervical screening test

### **Table 9: Cervical screening national targets**

	2009/10		
	Cumbria Primary Care Trust	North West	England
At least 80% of eligible women tested	81.8%	78.4%	78.9%
All women should receive their test result in two weeks	24.4%	33.4%	44.6%
Achievement of waiting time targets for patients with suspected cancer	*	*	*

Source: NHS Information Centre and NHS Cervical Screening Programme \*No accurate data available

Figure 6: Cervical screening coverage among women aged 25-64 years. Percentage for whom it is less than five years since last test. Cumbria Primary Care Trust, North West and England 2005/06 - 2009/10.



Source: NHS Information Centre and NHS Cervical Screening Programme

Data from the Quality Outcomes Framework for 2009/10 again **shows that Cumbria Primary Care Trust achieved higher cervical screening coverage (86.3%) than both the North West (83.1%) and England (83.7%) averages.** Across the 91 GP practices in Cumbria Primary Care Trust, cervical screening coverage ranged from 72.7% to 100.0%, <sup>xi</sup> with 83 practices achieving the target coverage of 80.0%. Therefore, more GP practices are meeting the target now than stated in the cervical screening programmes *2009 Annual Report* when only 64 practices were meeting the target.<sup>36</sup>

In 2009/10, the number of women in Cumbria receiving their test results within two weeks more than doubled compared to 2007/08 (from 10.5% to 24.4% - Figure 7). However, the proportions in 2009/10 were still well below the regional and England averages (33.4% and 44.6% respectively). Therefore while Cumbria is making progress in this area, there is a long way to go to achieve the target of all women receiving their results within two weeks.

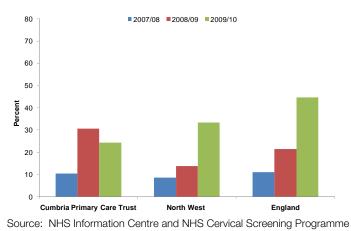
The time women waited to receive their results in 2008/09 posed a particular challenge due to the increase demand on the service following the media coverage of Jade Goody's<sup>xii</sup> treatment and tragic death due to cervical cancer. This was monitored throughout that time and information cascaded to practitioners via the GP Bulletin sent out from the Communications Team at Cumbria Primary Care Trust. This enabled practitioners to inform women of the delay when samples are taken.

<sup>&</sup>lt;sup>xi</sup> April 2009 - March 2010. Cervical Screening Indicator one: Percentage of patients aged 25 to 64 whose notes record that a cervical smear has been performed in the last five years. Available from The NHS Information Centre

<sup>&</sup>lt;sup>xii</sup> Jade Goody was a young television personality made famous through her appearance on the Channel 4 TV programme Big Brother in 2002. She was diagnosed with cervical cancer in 2008 at the age of 26 years and sadly lost her life in 2009. Her high profile battle with the disease raised awareness of cervical cancer, particularly among women aged 25-64 years

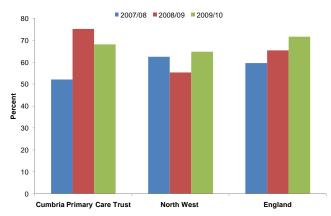
### Figure 7: Timeliness of receiving cervical screening test results. Cumbria, North West and England, 2007/08 - 2009/10.

### i) Less than two weeks



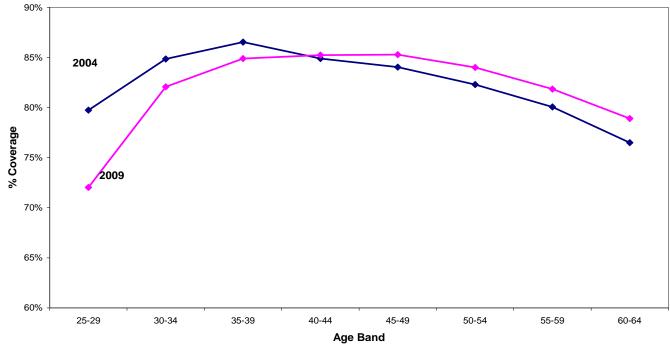
In Cumbria, the number of young women entering the screening programme at age 25 has decreased (Figure 8). In 2009, 72% of women aged 25-29 years were screened; this is around

### ii) Less than four weeks



7% less than in 2004. Nationally, the number of women aged 25-29 years attending for screening dropped from 66% in 1998 to 62% in 2009.

## Figure 8: NHS Cervical Screening Programme coverage (%)<sup>xiii</sup> among women aged 25-64 years (less than five years since last test) by age. Cumbria Primary Care Trust, 2004 and 2009.



Source: Cumbria Primary Care Trust

<sup>&</sup>lt;sup>∞</sup> Data are taken from KC53 returns

### Planned/future developments

All cervical screening laboratory work has been transferred to the Central Manchester Laboratory and it is hoped that this will help towards meeting the two week target in January 2011.

A standard has been set for training of all sample takers and an audit has been undertaken to identify all smear takers and mentors for trainee sample takers within Cumbria. This data is being merged with information about all those attending three yearly updates in line with the Quality Assurance Reference Centre recommendations. This work is done by the Cervical Screening Advisor.

Closer work is also being undertaken with underperforming practices to increase uptake of screening for cervical cancer.

A number of improvements to Cumbria's cervical screening programme have been made, for example:

- In line with Quality Assurance North West recommendations, all doctors and nurses involved in cervical cytology must now take part in the recognised training, with three yearly updates;
- A rolling programme of training for new GP and nurse sample takers;
- A rolling programme of cervical screening updates (180 practitioners attended a half day update during 2010);
- Increasing the number of mentors for trainee sample takers to cover the large geographical area and training;
- Improved access to cervical screening for women with learning difficulties through the introduction of a resource pack for professionals, along with leaflets and information designed specifically for this group;
- The introduction of a 'Cervical Screening Dashboard'. This will provide six monthly data on access to screening, laboratory turnaround times, results and colposcopy waiting times. An annual report is also being produced and circulated to all GP Practices via the GP Bulletin (and all practices have a

cervical screening resource pack which is updated via the intranet); and

 A colposcopy direct referral system has been in place in North Cumbria for some time and this is now being implemented in South Cumbria. This system ensures that once the laboratory issues a report advising that a colposcopy referral is required, a copy is automatically sent to colposcopy and an appointment is either sent, or the woman can ring for an appointment directly. This reduces the waiting time and any unnecessary anxiety for the woman.

### **Examples of local successes**

Uptake of the human papilloma virus vaccination programme is higher across Cumbria than the national average.<sup>37</sup> During 2008/09, Cumbria Primary Care Trust had higher uptake of first, second and third doses across young people ages 12-13 years (routine cohort) and 17-18 years (catch-up cohort) than the North West and England averages (Table 10).

### Table 10: Human papilloma virus vaccineuptake for first, second and third doses

	3	31 <sup>st</sup> August 2009		
	Cumbria Primary Care Trust	North West	England	
Ages 12-13 (Year 8) Uptake rates:				
Dose 1	93.1%	91.0%	88.1%	
Dose 2	90.8%	89.6%	86.0%	
All 3 doses	90.2%	87.6%	80.1%	
Ages 17-18 (Year 13) Uptake rates:				
Dose 1	75.2%	63.2%	62.2%	
Dose 2	70.5%	52.7%	54.2%	
All 3 doses	55.3%	23.6%	31.8%	

Source: Health Protection Agency and Department of Health

#### Breast cancer screening



In 1986, the *Forrest Report*<sup>38</sup> recommended the introduction of a *NHS Breast Screening Programme* offering three yearly mammography to women aged 50-64 years. In 1988, the world's first national breast screening programme was set up in England.

In the UK, free breast screening is offered every three years to women aged 50 years and over, with around 1.5 million women screened each year. The age range of women eligible for breast screening is currently being extended to those aged 47-73 (as part of the 2007 *Cancer Reform Strategy*) on a phased basis with full coverage of this group to be achieved from 2012.<sup>39</sup> There are currently 82 UK screening units, some of which are based in hospitals, others are mobile or sited in convenient locations such as shopping centres. Each unit will invite eligible women (aged 50-70 years) through their GP practice register.

Not all women will receive an invitation for screening as soon as they turn 50, however they will receive it before their 53<sup>rd</sup> birthday. Those women who have reached the upper age limit for routine invitations are encouraged to make their own appointment.

Breast cancer is the most common cancer in the UK. In 2007 there were 45,972 new cases diagnosed in the UK, over 99% of which were in women (45,695), whilst less than 1% (277) were in men. Nearly a third of all new cancers in women are breast cancers. It is estimated that one in 9 women and one in 1,014 men in the UK will develop breast cancer in their lifetime.<sup>40</sup>

The risk of breast cancer is strongly linked to age, with nearly half (48%) of breast cancer cases being diagnosed among women aged 50-69 years. It is this age group, along with those aged 70 years, who are targeted by the national screening programme. While very few cases of breast cancer are diagnosed in women in their teens or early twenties, breast cancer is the second most commonly diagnosed cancer among women under the age of 35.<sup>40</sup>

In the UK during 2008, breast cancer claimed the lives of around 12,000 women and 70 men. Survival rates have, however, been improving, and women diagnosed with breast cancer are twice as likely to survive for at least ten years than those diagnosed 40 years ago.<sup>41</sup> There is probably no single reason for this improvement, with a combination of factors likely to be involved. These include earlier diagnosis and increased awareness of breast cancer and its symptoms. Breast cancer screening with mammography is a particularly important element in increased survival.<sup>32</sup>

The breast screening programme aims to detect breast cancer at a very early stage through the use of a low dose x-ray of each breast (known as a mammogram). The mammogram can identify small changes in breast tissue that are too small to be felt by the woman or her doctor.

All screened women are sent written results. For some women, the mammogram is inconclusive and they are invited for further tests at assessment centres run by the screening programme's multidisciplinary teams. In England during 2008/09, 8.6% of women attending for their first screen and 3.2% of those attending a subsequent screen were recalled.<sup>42</sup> Further investigations may include another mammogram, clinical breast examination, ultrasound, core biopsy, fine needle aspiration (cytology) or surgical biopsy. Figure 9 shows what happens at a breast screening unit.

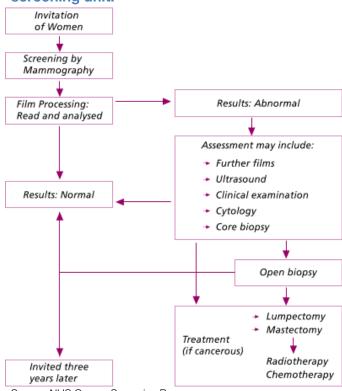
Work carried out in Denmark by the Nordic Cochrane Centre has questioned the value of breast cancer screening.<sup>xiv</sup> Their work suggests that even at the age of 60 years, when the risk of dying from breast cancer over the next 15 years is 1.2%, 259 women need to be screened to prevent one death. **The UK government is a strong supporter of breast cancer** 

<sup>&</sup>lt;sup>xiv</sup> McPherson K (2010) *Screening for breast cancer - balancing the debate*, British Medical Journal, 340:c3106

### screening, but it is important that women who take part in the programme understand the limitations of screening and what such programmes can – and can't – offer.

Around 95% of women are reported as having normal results following the first mammogram and will be invited again in three years. Of those who undergo further investigation, around one in six will be found to have cancer.<sup>43</sup>

### Figure 9: What happens at a breast screening unit.



Source: NHS Cancer Screening Programmes

The NHS Breast Screening Programme has screened over 19 million women in the UK, detecting over 117,000 cancers. During 2007/08 alone, over 16,000 cases of breast cancer were detected in the UK and an estimated 1,000 lives per year are saved as a result of the programme.<sup>43</sup>

Estimates suggest that if 70% of eligible women attend screening, a 25% reduction in breast cancer mortality rates in women invited for screening would occur.<sup>44</sup> In 1992, the *Health of the Nation*<sup>45</sup> strategy included the uptake target of 70%, which remains the minimum standard for the NHS Breast Screening Programme.

As mentioned earlier, the NHS Breast Screening Programme is being extended to cover women aged 43 to 73 years. In the extended age areas, women aged 50-70 years are invited for screening as normal, whilst around half of those aged 47-49 years and 71-73 years are randomly selected to receive screening invitations (this will allow for evaluation of the effectiveness of the age extension).<sup>46</sup>

Another future development is digital mammography, which was introduced in 2005. While regular mammography uses x-ray files, digital mammography uses computer imaging. Every breast screening unit should have at least one digital set by 2010.<sup>46</sup>

### Organisation of breast cancer screening in Cumbria

In Cumbria, two breast screening programmes operate - the North Cumbria programme, provided by North Cumbria University Hospitals NHS Trust and the North Lancashire and South Cumbria programme, provided by University Hospitals of Morecambe Bay NHS Foundation Trust. The North Cumbria programme is one of the smallest in the North West, covering less than half the number of women covered by the North Lancashire and South Cumbria programme.<sup>47</sup>

### **Programme performance**

According to the most recent data (March 2009),<sup>42</sup> the breast screening coverage rate is higher in Cumbria than both the national and North West averages. Coverage has increased slightly across all areas compared to March 2008 figures (Table 11).

### Table 11: Breast screening national (coverage) targets

	As	at 31 <sup>st</sup> March 2	2008
	Cumbria Primary Care Trust	North West	England
70% coverage (less than three years since last test) among women aged 53-70 years	78.5%	74.7%	75.9%
70% coverage	As at	31 <sup>st</sup> March 20	09
(less than three years since last test) among women aged 53-70 years	82.1%	75.8%	76.5%

Source: NHS Information Centre and NHS Breast Screening Programme

In 2008/09 North Cumbria had a higher percentage uptake (79%) than the national

average (74%), while North Lancashire had an equal uptake (Table 12). Between 2007/08 and 2009/10 both North Cumbria and North Lancashire saw a 1% fall. A larger decline (4%) is evident in North Lancashire when compared with uptake figures for 2002/03.

### Table 12: Breast screening national (uptake) targets

	2002/03 to 2008/09 by Breast Screening Unit					
	North Cumbria	North Lancs.	North West	England		
Uptake by	Gumbha	Lancs.	West			
women aged						
50-70 years						
(minimum						
should be						
70%)	0.00/	====	===0/	====(		
2002-03	80%	78%	75%	75%		
2003-04	80%	77%	75%	75%		
2004-05	81%	77%	74%	74%		
2005-06	80%	76%	74%	75%		
2006-07	80%	75%	73%	74%		
2007-08	80%	75%	72%	73%		
2008-09	79%	74%	73%	74%		

Source: NHS Information Centre and NHS Breast Screening Programme

Performance in general is above the national average and targets are being met.

However, in June 2010 the North Cumbria breast screening service received a quality assurance visit. The visit found that not enough women were receiving a needle biopsy after being recalled for further examination following their routine three-yearly mammogram.

The Director of Public Health, acting on national and regional advice, suspended the screening programme while a review was carried out.<sup>47</sup>

In December 2010 a new service for North Cumbrian women was introduced. The service is still delivered locally but is now delivered by Newcastle-upon-Tyne Hospitals NHS Foundation Trust.

### Planned/future developments

### Cumbria Primary Care Trust has agreed that by December 2012 it will:

- 1) expand the breast screening programme to all women aged 47-73 years; and
- 2) fully implement the shift from analogue to digital mammography.<sup>24</sup>

In addition, the 2010/11 Operating Framework has stated that by March 2011, all breast screening programmes must

all breast screening programmes must expand by at least 8% of the population. Such changes bring with them financial challenges and these are currently being addressed by the Primary Care Trust commissioners and University Hospitals of Morecambe Bay NHS Foundation Trust.<sup>24</sup>

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#### **Bowel cancer screening**



Introduced in July 2006, the *NHS Bowel Cancer Screening Programme* aims to detect bowel cancer as early as possible, to allow treatment to be most effective. Screening can also detect polyps which are non-cancerous but can develop into cancer over time. They are easy to remove, therefore reducing the risk of bowel cancer developing.<sup>50</sup>

The bowel is part of the digestive system and is made up of two sections, the small bowel (small intestine) and the large bowel (colon and rectum). Cancer of the small bowel is rare so the term bowel cancer almost always refers to cancer of the large bowel (therefore often referred to as colon, rectal or colorectal cancer).<sup>48</sup>

The lining of the bowel is made of cells that are constantly being renewed. Sometimes these cells grow too quickly, forming a clump known as a bowel polyp or an adenoma. Polyps are usually non-cancerous (benign); however, if left untreated they may change over time to become cancerous (malignant).

Bowel cancer is the third most common cancer in the UK,<sup>49</sup> affecting approximately one in twenty people during their lifetime.<sup>50</sup> Over 16,000 people die from bowel cancer each year, making it the UK's second leading cause of cancer deaths.<sup>49</sup> Research has shown that regular bowel cancer screening can reduce the risk of dying from bowel cancer by 16 per cent.<sup>49</sup> Factors that increase the risk of developing bowel cancer include:  Age - bowel cancer is more common in those over the age of 50 years;

2011

- Diet a diet high in animal fat and protein and low in fibre (such as fruit and vegetables);
- Alcohol intake heavy drinkers may be at higher risk;
- Family history having one or more family members with bowel cancer;
- Bowel diseases people who have suffered with bowel diseases such as Crohn's disease or ulcerative colitis for long periods may have an increased risk of developing bowel cancer;
- Obesity;
- Lack of exercise; and
- Smoking.<sup>51</sup>

There are a number of 'programme hubs' that work with local screening centres to coordinate the programme in their area. Each hub distributes faecal occult blood test kits,<sup>xv</sup> analyses samples and dispatches the results. Those people who receive abnormal results are referred to screening centres which can provide endoscopy services and specialist screening nurse clinics. These screening centres also refer those who need further treatment to their local hospital multidisciplinary team.

Polyps and bowel cancers sometimes bleed, and the faecal occult blood test works by detecting tiny amounts of blood which cannot normally be seen in bowel motions. The test does not diagnose bowel cancer, but the results will indicate whether further investigation (usually a colonoscopy) is needed. A colonoscopy involves looking directly at the lining of the large bowel by passing a flexible tube with a tiny camera attached into the back passage.<sup>50</sup>

All men and women aged 60-74<sup>xvi</sup> years who are registered with a GP are offered bowel cancer screening every two years. People over the age of 75 years can request a testing kit by contacting a free phone helpline number.<sup>xvii</sup> Those eligible for screening are sent an invitation letter along with an information leaflet about the screening programme. About a week later, the faecal occult blood test kit and details on how to complete the test and return it to the hub laboratory are sent to the person's home. Once

<sup>&</sup>lt;sup>xv</sup> 'Occult' means hidden

<sup>&</sup>lt;sup>xid</sup> The programme was initially offered to those aged 60-69, however from April 2010 the age range was extended to include men and women up to their 75th birthday (60-74 year olds)

<sup>&</sup>lt;sup>xvii</sup> Free phone helpline number: 0800 7076060

received, the test will be processed and results sent by letter to the individuals home within two weeks. Figure 11: Predicted outcomes of bowel cancer screening.



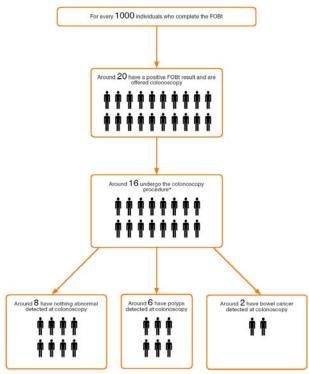


Source: NHS Bowel Cancer Screening Programme (www.cancerscreening.nhs.uk/bowel)

The majority of people (approximately 98 in 100) will receive a normal result and will not require any further treatment. They will continue to be invited for screening every two years assuming they are still within the eligible age range. For those who receive abnormal results (around 2 in 100), further investigation is required, usually in the form of a colonoscopy. In some cases (around 4 in 100) initial results may be unclear i.e. there may have been a slight suggestion of blood in the test sample. It is possible that this may be due to a condition other than cancer such as haemorrhoids (also known as piles), however the test will be repeated to clarify. Figure 11 shows the predicted outcome of bowel cancer screening.

As part of the *Cancer Reform Strategy*, from April 2010 the age range for the NHS Bowel Cancer Screening Programme was extended to invite men and women up to their 75<sup>th</sup> birthday.<sup>39</sup>

There were around 38,610 new cases of bowel cancer diagnosed in the UK during 2007, 21,000 males and 17,600 females. In the UK during 2008, around 16,260 people died of bowel cancer.<sup>49</sup> Survival rates for bowel cancer are improving; people diagnosed with bowel cancer today are twice as likely to survive for at least ten years as those diagnosed in the 1970s.



Source: NHS Bowel Cancer Screening Programme (www.cancerscreening.nhs.uk/bowel/about-bowel-cancerscreening.html)

### Organisation of bowel cancer screening in Cumbria

In Cumbria, bowel cancer is the third greatest cause of cancer deaths in men after lung and prostate cancer, and the third most common in women after lung and breast cancer.<sup>52</sup> There were 172 deaths from colorectal cancer in Cumbria Primary Care Trust during 2008.<sup>53</sup>

Nationally the five year survival rate is 52.1%. In Cumbria the position is similar, at 52.9%. Premature mortality rates for colorectal cancer are significantly higher in Cumbria as compared to the national average.<sup>52</sup>

The Cumbria and Morecambe Bay Bowel Cancer Screening Programme was set up in 2008. In April 2010 responsibility for commissioning the programme was passed to NHS Cumbria. The hub for Cumbria is the Midland and North West Bowel Cancer Screening Programme hub, based in Rugby.

NHS Cumbria is working to improve uptake of bowel cancer screening through the delivery of an effective health promotion programme.<sup>54</sup> A health promotion strategy for 2010-2013 is currently in production. As part of NHS Cumbria's 2010-2013 service specification, the bowel cancer screening programme will use health promotion activities to help meet four aims set out by NHS North West:

- Increased participation in the screening programme, particularly in areas of low uptake;
- 2. Improved access to bowel screening and bowel cancer information;
- 3. Improved awareness and understanding of the screening programme; and
- 4. Improved awareness of the causes and symptoms of bowel cancer.

As part of Cumbria's 2010 Cancer

*Commissioning Strategy*, colorectal cancer was identified as high priority for review due to its high incidence, mortality rates (compared to other tumour types) and because of variation in outcomes across localities.<sup>55</sup>

### Programme performance

The target for uptake of bowel cancer screening was set at 60% following the national pilot that ran in 2006. Since the programme commenced in Cumbria and Morecambe Bay in March 2008 there has been a steady improvement.

For example, in their *Screening Programmes: A Stock Take* review, NHS North Lancashire note that in January 2010, cumulative uptake of bowel cancer screening was 57.7% across North Lancashire. The target has been achieved by 10 out of the 39 practices.<sup>24</sup>

Overall, the uptake rate in Cumbria is higher than the national target of 60% (63% in 2009/10).

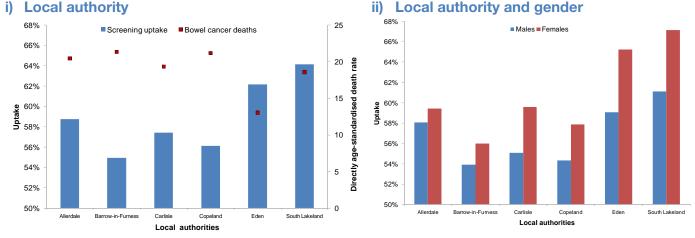
However, there is some variation in uptake between localities and amongst different population groups. Such variation has the potential to contribute to health inequalities and presents an opportunity to improve performance overall.

2011

For example, the uptake rates across the six local authorities in Cumbria during 2009 range from 55% in Barrow-in-Furness to 64% in South Lakeland (Figure 12). Just two of the six local authorities have uptake rates that meet the target of 60% (Eden: 62% and South Lakeland: 64%). However, early indications are that this is improving in 2010 with only two localities below the 60% target (Figure 13).

### Areas with the lowest uptake rates in 2009 also had the highest deaths rates from

**bowel cancer** (the most recent year of deaths data available from the UK Cancer Information Service is for 2008, as shown alongside uptake data in Figure 12).



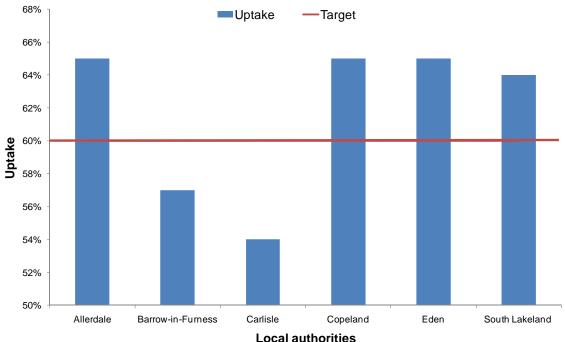
#### Figure 12: Uptake of bowel cancer screening. Cumbria, January - December 2009. i) Local authority ii) Local authority and gender

Source: NHS Cumbria Public Health Intelligence Team and UK Cancer Information Service

Uptake across the localities also varies by gender (Figure 12). Men have lower uptake than women, which reflects national trends. Men, however, have a higher incidence of bowel cancer overall. This highlights the need to concentrate efforts to improve uptake amongst men. Examining bowel screening uptake by both age and gender (Figure 14) reveals that, within the age range of the initial program (60-70 years), men have lower uptake, particularly those at the younger end of the scale.

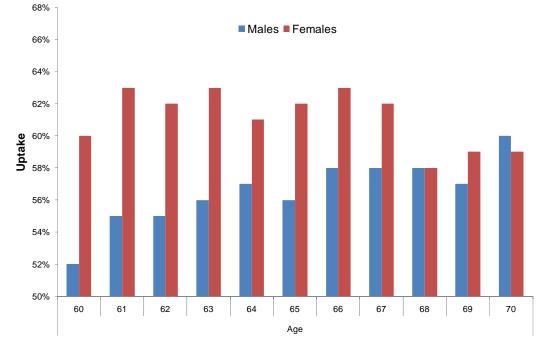
2011

Figure 13: Uptake of bowel cancer screening, by local authority. Cumbria, January - (part of) August 2010.



Source: NHS Cumbria Public Health Intelligence Team





Source: NHS Cumbria Public Health Intelligence Team

Table 13 shows the elapsed time between receiving a positive faecal occult blood test result and attending a specialist screening practitioner appointment for further diagnostic testing. The maximum number of days waited is higher in Cumbria than the target set nationally (17 days and 14 days respectively), but four days lower than regionally (21 days in the North West).

### Table 13: Bowel screening national targets

Waiting time	October - December 2010				
between	Cumbria and				
suspected cancer	Morecambe				
and appointment	Bay Bowel				
with a specialist	Cancer				
screening	Screening	North	National		
practitioner	Centre	West	Target		
	(days)	(days)	(days)		
Minimum value	2	1			
Lower quartile	6	7			
Median value	8	9			
Upper quartile	11	12			
Maximum value	17	21	<14		
Standard deviation	3.37	3.36			
Mean value	8.55	9.01			
No. of patients	159	1,328			

Source: Open Exeter from the Hub

### Planned/future developments

The Department of Health is committed to funding Cumbria's bowel screening programme until 2012. Funding for expansion of the scheme beyond 2012 has not been agreed.<sup>24</sup>

In December 2010 the draft version on quality assurance arrangements in the NHS Bowel Cancer Screening Programme was developed. The guidance is aimed at quality assurance teams, programme hubs and screening centres and sets out arrangements for quality assurance visits to screening centres and programme hubs. This guidance will be reviewed and revised as work progresses.

### **Examples of local successes**

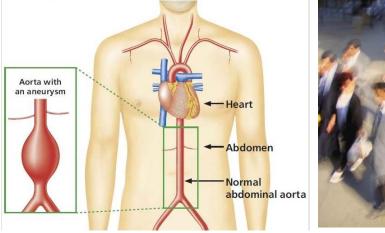
Positive developments include the increase in uptake in the early part of 2010 and the age extension to 75 years that commenced in June 2010 in the Cumbria and Morecambe Bay Bowel Cancer Screening Programme (previously only screened on a self referral basis).

As noted earlier, Cumbria has seen an improvement in uptake in the early part of 2010 and while between January 2008 and December 2009 only two out of the six localities were achieving the 60% uptake target, this has increased and by August 2010 only two localities (Barrow-in-Furness and Carlisle) are failing to achieve the 60% uptake (Figure 13).

2011

As the screening programme progresses, more information is becoming available including uptake rates by deprivation quintile from the North West Bowel Cancer Screening Quality Assurance Reference Centre, NHS Bolton. This will improve the targeting of health promotion activity to increase the uptake rate.

#### Abdominal aortic aneurysm screening





Source: NHS Abdominal Aortic Aneurysm Screening Programme (http://aaa.screening.nhs.uk/aaa)

The NHS Abdominal Aortic Aneurysm Screening Programme launched in March 2009 with the hope of reducing deaths from abdominal aortic aneurysms (AAAs, also called 'Triple As') through earlier detection of the condition.<sup>56</sup>

An abdominal aortic aneurysm is a symptomless, potentially life threatening condition which occurs when the wall of the aorta (the main supplier of blood to the entire body) weakens and bursts.<sup>56</sup> Large aneurysms are fairly uncommon but people will generally die from this. However, even where an aorta is only a little bigger than normal, it is important that this is detected and monitored because it could grow over time into something more serious.<sup>56</sup>

It is estimated that six times more men than women have an abdominal aortic aneurysm.<sup>56</sup> Men aged 65 years and over are most at most risk and around 4% of those aged between 65 and 74 years have the condition in England.<sup>56</sup>

The likelihood of an abdominal aortic aneurysm is greatest among smokers, individuals with high blood pressure or those who have a close family member with the condition.<sup>56</sup>

The screening programme is being rolled out slowly and currently covers six areas nationally, including south Manchester in the North West, but also West Sussex, Leicester, Gloucester, South Devon and Exeter, and South West London, with planning in place to ensure the programme is available throughout England by March 2013.<sup>57</sup> For a future screening programme to be viable, it must cover a population of at least 800,000 people and already have in place vascular services that are able to deliver the treatment that people with an abdominal aortic aneurysm need.<sup>58</sup>

The screening involves a very quick and painless ultrasound scan of the abdominal area with the result available immediately.<sup>56</sup>

The national screening programme is based on a variety of evidence about the potential benefits of screening. For example, a decade of results from the Multicentre Aneurysm Screening Study show that screening of men aged 65 years can potentially cut deaths from abdominal aortic aneurysm by 40%.<sup>57</sup> It is also shown that for every 10,000 men screened, a total of 65 abdominal aortic aneurysm ruptures will be prevented and 52 lives saved, although six men who are screened will die following surgery for the condition.

As noted in the programme's first annual report, the national programme has already achieved a number of its objectives, including the launch of a nationwide IT system in January 2010 (developed in partnership with Northgate Information Solutions) to support the existing local programmes and help performance monitoring.<sup>57</sup>

Further achievements include the publication of a factsheet for doctors, information about commissioning for commissioners and public health professionals as well as consultation with the public about the invitations and leaflets for abdominal aortic aneurysm screening.<sup>57</sup> A key challenge in 2009/10 included ensuring that local and national vascular services met the quality standards set out by the Vascular Society of Great Britain and Ireland.<sup>57</sup> Despite initial costs to establish a screening programme (such as for radiographers, equipment and premises) there is great potential for longer term cost savings if more individuals with an abdominal aortic aneurysm decide to have surgery at a chosen time rather than arriving at hospital as an emergency.<sup>24</sup>

The national targets are for 90% of men eligible for the NHS Abdominal Aortic Aneurysm Screening to be invited for an initial test. In addition, 90% of those with a known aneurysm whose condition is only being monitored (i.e. because the aneurysm only measures between 3.0 to 5.4 centimetres and is therefore not yet large enough to require treatment) should receive a conclusive test result. National standards also require no more than eight in 100 deaths (from any cause) 30 days post operation among those who choose to have their abdominal aortic aneurysm repaired.

### Organisation of abdominal aortic aneurysm screening in Cumbria

The abdominal aortic aneurysm screening lead is also the Associate Director of Public Health. An NHS North West board meeting in July 2010 noted the submission of a bid for a Cumbria and Lancashire Abdominal Aortic Aneurysm programme<sup>59</sup> and that screening should start in April 2011. **A business case has been prepared jointly by the Cumbrian and Lancashire primary care trusts and is still being considered by NHS North West.** Since the management of people picked up by the initial screen as having a significant aneurysm will create more demand for vascular surgery, **a review is also examining the number of centres providing vascular surgery across**  the North West. The review is internal to Cumbria and Lancashire and is being coordinated by a Vascular Clinical Advisory Group. Membership of this group includes vascular surgeons and other cardiovascular specialists, as well as local GPs. The review is still in progress and further discussions about the introduction of abdominal aortic aneurysm screening will take place as soon as the findings are published.

The Cumbria and Lancashire Abdominal Aortic Aneurysm Screening Programme once established will offer screening for people in the six primary care trusts covering a total population of 1,948,247 (including males and females) therefore the screening population will be above the 800,000 target set nationally (Table 14).

#### Table 14: Screening population. Cumbria and Lancashire, 2008.xviii

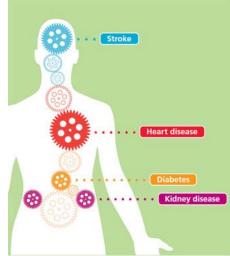
	Total population		
	(males and	Males aged	Males aged
Area	females, all ages)	65 years	over 65 years
Blackburn with Darwen	140,673	558	7,813
Blackpool	141,916	801	11,786
Cumbria	496,627	3,067	43,094
North Lancashire	331,095	1,943	29,209
Central Lancashire	453,436	2,466	32,650
East Lancashire	384,500	1,965	26,647
Cumbria and Lancashire	1,948,247	10,800	151,199

Source: Office for National Statistics

 $<sup>^{\</sup>rm xviii}$  Data are from mid-year 2008 single year population estimates

#### Section 3: Evolving screening programmes in Cumbria

#### NHS Health Checks (previously called Vascular Checks)





Source: Revised NHS Health Check Identity Guidelines (www.improvement.nhs.uk/NHSHealthCheck/GuidanceDocuments/tabid/57/Default.aspx)

The *NHS Health Check* programme was launched in April 2009<sup>60</sup> as part of a nationwide move towards more preventative healthcare outlined by the then Prime Minister in 2008.<sup>61</sup> The programme is expected to achieve full coverage nationally by 2012/13.<sup>60</sup> NHS Improvement, in partnership with the Department of Health have established an NHS 'Learning Network' to help share best practice, from areas with existing or new programmes, about measuring and managing vascular risk.<sup>60</sup>

Vascular disease (which includes coronary heart disease, stroke, diabetes and kidney disease) are the result of fatty lumps in the body which can harden and block blood vessels.<sup>62</sup> These diseases generally show relatively few symptoms in the early stages, however, they account for 36% of all deaths and one-fifth of all hospital admissions in England.<sup>63</sup> The likelihood of getting a vascular disease is higher among people living in more disadvantaged areas and among particular ethnic groups, such as South Asians.<sup>63</sup> Risk of vascular disease increases with age and is higher among people whose family members suffered from one of these diseases in late middle age.<sup>64</sup>

The programme targets every adult aged between 40 and 74 years, who has not already been diagnosed with a vascular disease.<sup>60</sup> The check includes asking basic questions about a person's lifestyle and family medical history, measuring their height and weight, and taking a blood sample to test cholesterol and, in some cases, glucose levels (Figure 15).<sup>60</sup> On the basis of the results it is recommended that all adults aged 40 years or over should have a vascular disease risk score calculated. This result shows how likely it is that he/she will develop one of the diseases in the next ten years, for example, those with a score of 20% or more have a two in ten chance.<sup>64</sup> Those at high risk should be offered ongoing advice, support or treatment to improve their health (such as help to stop smoking or to take up physical exercise, as well as advice about appropriate drugs).<sup>61</sup>

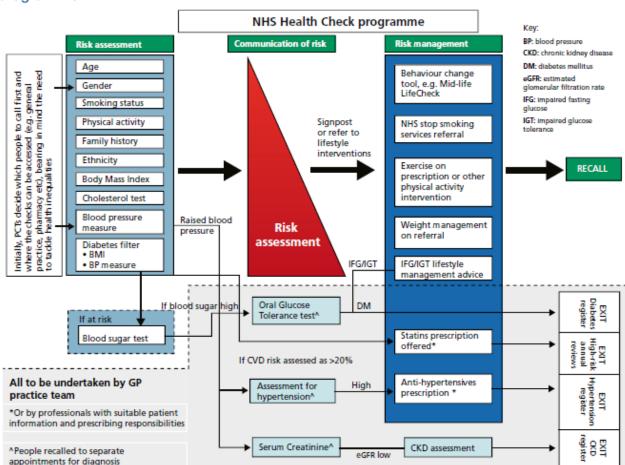


Figure 15: Diagrammatic overview of the vascular risk assessment and management programme.

Source: Putting Prevention First. NHS Health Check Vascular Risk Assessment and Management Best Practice Guidance (www.dh.gov.uk/prod\_consum\_dh/groups/dh\_digitalassets/documents/digitalasset/dh\_098410.pdf)

The national target is that by 2012/13 primary care trusts will be inviting at least one-fifth of their eligible population for a health check every year as part of a five year rolling programme. The programme is being gradually rolled out and, to date, 19 areas have acted as pilot sites for health checks,<sup>65</sup> one of which was Blackburn with Darwen Primary Care Trust.<sup>xix</sup>

A review to examine primary care trusts' progress towards the 2012/13 target recommended that each should have a plan (formally agreed by their board) about how they intend to implement the checks, details of which should also be included in their commissioning strategies and operational plans for 2010/11.<sup>66</sup> As part of the review, all primary care trusts were asked to provide information about how many NHS Health Checks would be offered between April 2009 to April 2010 for comparison with the predicted number of checks that could be carried out in the primary care trust, that year, as calculated using the Vascular Checks and Interventions Toolkit.<sup>66</sup>

The review also recommended that a variety of methods should be used to help identify and target a greater number of patients, however, to date many primary care trusts rely upon one or limited methods (mainly GP practice registers). The review team suggested this is perhaps due to a reluctance to discover a huge cohort of patients with considerable health problems as this could present a sudden burden on existing resources. For example, 49 primary care trusts said that they use a single method to recruit people into the programme (85% using GP records, 8% population based methods and 7% opportunistic screening), 44% of primary care trusts are already targeting patients using two or more methods, while some areas (including Central Lancashire Primary Care Trust) are using three or more methods of patient identification.<sup>66</sup> A total of 42% of primary care trusts have profiled the inequalities in health in their

<sup>&</sup>lt;sup>xix</sup> See

www.lsccardiacnetwork.nhs.uk/uploads/files/cardiac/events/internal/2009\_prevent \_and\_detection/Jayne\_Swarbrick\_Paula\_Black\_NHS\_Health\_Checks\_for\_Cardiova scular\_Disease.pdf

catchment area to help decide how to target their NHS Health Checks service.<sup>66</sup> The NHS Health Check is not covered in the Quality Outcomes Framework. However, a number of the indicators are related to it, such as the number of patients with high blood pressure who have had their blood pressure tested in the previous nine months.<sup>67</sup>

# Organisation of NHS Health Check in Cumbria

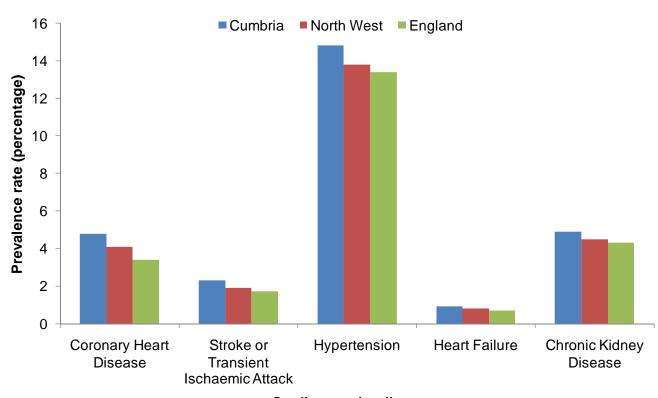
NHS Cumbria has not yet launched its full population based NHS Health Check programme. However, a local enhanced service has been available across the county since 2009 providing incentives to GP practices to develop cardiovascular disease risk registers identifying patients at high risk of the disease using existing data on practice systems and opportunistic screening as appropriate. Payment is currently based on the number of patients on high risk registers, rather than the number provided with health checks.

### **Programme performance**

According to the most recent Quality Outcomes Framework prevalence data, from April 2009 -March 2010, of all patients registered with a doctor in Cumbria Primary Care Trust (Figure 16):

2011

- 4.8% have coronary heart disease the third highest of any primary care trust regionally and higher than the regional and national averages;
- 2.3% have stroke or transient ischaemic attacks - slightly higher than regionally and nationally;
- 14.8% have hypertension higher than regionally and nationally;
- 0.9% have heart failure similar to in the North West and England; and
- 4.9% have chronic kidney disease (among those aged 18 years and over) slightly higher than regionally and nationally.



# Figure 16: Prevalence of cardiovascular diseases. Cumbria, North West and England. April 2009 - March 2010.

Cardiovascular diseases

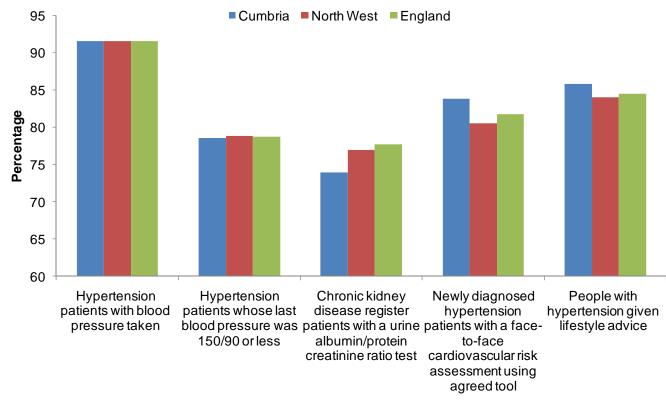
Source: Quality Outcomes Framework

- 91.5% of patients with hypertension have a record of their blood pressure in the previous nine months - the same as in the North West and England (Indicator BP4);
- 78.5% of patients with hypertension who had their last blood pressure measured in the previous nine months had a reading of 150/90 or less - similar to across the North West and England (Indicator BP5);
- 73.9% of patients on the chronic kidney disease register had a record of a urine albumin/protein creatinine ratio test in the previous fifteen months - slightly below the North West and England (Indicator CKD6);

 83.8% of patients with a new diagnosis of hypertension had a face-to-face cardiovascular risk assessment at the outset of diagnosis (within three months of the initial diagnosis) using an agreed risk assessment tool - slightly above the North West and England averages (Indicator PP1); and

2011

 85.8% of people diagnosed with hypertension were given lifestyle advice in the last 15 months (for increasing physical activity, smoking cessation, safe alcohol consumption and healthy diet) - slightly above the England and North West values (Indicator PP2).



## Figure 17: Indicators relevant to the NHS Health Check. Cumbria, North West and England. April 2009 - March 2010.

**Quality Outcomes Framework Indicators** 

Source: Quality Outcomes Framework

2011

Over the last 12 months, 93% of local GP practices in Cumbria have committed to delivering the NHS Health Checks Local Enhanced Service and to date 1,500 patients are identified as having more than a 20% risk of developing vascular disease.<sup>68</sup>

#### **Planned/future developments**

Options for implementing a population based approach are currently being explored and Copeland, one of six district council/GP commissioning consortia localities, is currently piloting a population based programme, targeting men and women in hard to reach groups.

A population based health check programme will be launched from April 2011, probably in a targeted form.

Data from the current cardiovascular disease high risk register suggests that uptake is higher in GP practices serving more affluent areas. To address issues of health inequality, NHS Cumbria are exploring the potential impact of either a targeted GP programme or a GP programme supplemented with community based activity.

#### Chlamydia screening



Source: Best to Know Campaign (www.best2know.co.uk)

Launched in 2003, the *National Chlamydia Screening Programme* already covers all 152 primary care trusts in England and targets young people aged under 25 years at times when they are already attending health venues or other settings for another purpose (so called 'opportunistic' screening).<sup>69</sup>

Chlamydia affects both sexes, especially sexually active young adults, and is currently the most frequently diagnosed bacterial sexually transmitted infection (STI) across the UK.<sup>69</sup> The case for a screening programme is strong because not only is the infection symptomless, if left untreated it can significantly damage a person's future reproductive and long term physical health; yet the condition can be detected relatively easily through a simple urine test.<sup>69</sup>

The aim of the programme is to make regular screening the norm, especially when changing sexual partners, to help prevent further spread of infection and ensure more people who are already infected get the necessary treatment to reduce the likelihood of further complications.<sup>69</sup> In early 2010, a 'Chlamydia Worth Talking About' campaign was launched nationally to encourage more young people to take the test when offered it.<sup>70</sup>

It is increasingly recognised that delivering screening through the major primary care services (such as pharmacies, dentists and especially GPs) is critical to getting greater numbers of people tested and meeting national targets; for example, GPs see an estimated 60-75% of young people at least once a year.<sup>70</sup> Evidence suggests that greater working with GPs is not only the most cost effective way of



testing, it also provides an opportunity to help signpost young people to further relevant advice or support (for example, about contraception or safe sex).<sup>71</sup> A total of 30 GPs currently act as national champions promoting the benefits of providing screening in surgeries rather than sending patients to Genitourinary Urinary Medicine clinics.<sup>72</sup>

The National Chlamydia Screening Programme recommends that a minimum of 60% of screening each year should be through the major primary care services.<sup>70</sup> The national target (Chlamydia Vital Signs Indicator 2010/11) is that 35% of the population aged 15-24 years should be tested by end of quarter four in 2010/11.<sup>72</sup> Plans are in place to continue funding the programme after April 2011, but probably with some changes built in.<sup>69</sup>

An independent review of chlamydia screening programmes nationally was conducted in 2008 and made a number of recommendations including that primary care trusts need to ensure better cost effectiveness.<sup>73</sup>

# Organisation of chlamydia screening in Cumbria

Cumbria's Chlamydia Screening Programme is located in the contraceptive services; it was launched in October 2006, targeted at those aged under 19 years and is available from a variety of locations around the county such as schools, workplaces, GP surgeries and in community venues.<sup>74</sup>

The programme operates across all of Cumbria and is commissioned centrally. Responsibility for performance rests with children's services, primary care, young people's providers and pharmacies.

Cumbria and Lancashire's Best to Know<sup>xx</sup> campaign, launched on Valentine's Day 2008, targets young people aged 16 to 24 years and provides free, confidential chlamydia testing along with information about the risks of STIs and the value of being regularly tested.<sup>71</sup> It currently covers four of the six primary care trusts and funding is in place to continue with a website and text messaging service into 2011.<sup>71</sup>

#### Programme performance

Information (about numbers of young people screened, by sex and age, etc.) is sent weekly to NHS informatics teams and commissioners by staff groupings (to inform them about progress towards targets) and a notional target has been set in Cumbria for each group. For example, school nurses (4,000 screens) or contraceptive services (3,000 screens). Each of these services has a monthly trajectory.

The most recent data available (April to September 2010) for measuring progress towards the Vital Signs Indicator target for March 2011 shows that the proportion of young people tested in Cumbria was below that both regionally and nationally (Table 15); the proportion tested is joint lowest in the North West alongside Bury Primary Care Trust (also 8.2%), compared with 17.7% in Halton and St Helens Primary Care Trust (the area with the highest rate).

A total of 7.0% of young people tested positive for the infection in Cumbria compared with 7.1% in the North West and 5.6% across England. A total of 4,764 tests were carried out in Cumbria: 2,550 among those aged 15-19 years and 2,214 among those aged 20-24 years. These tests included 3,424 reported to the National Chlamydia Screening Programme and 1,340 outside of Genitourinary Urinary Medicine not reported to the National Chlamydia Screening Programme directly.

## Table 15: Chlamydia screening nationaltargets

	April - September 2010		
	Cumbria	North West	England
35% of young people aged 15-25 years should be tested <sup>xxi</sup>	8.2%	11.5%	11.4%

Source: NHS National Chlamydia Screening Programmexxii

As noted in NHS Cumbria's *Vital Signs* 2009/10<sup>75</sup> report, the percentage of the population aged 15 - 24 years tested for chlamydia in the county was below that both regionally and nationally, however, Cumbria's rate of improvement was one of the best in England.

In NHS Cumbria, all practices have also been offered training in this element of the Local Enhanced Service. However, the uptake has varied greatly from locality to locality.

Some big hits for the service, such as street events and at club nights or by targeting workplaces has not led to big numbers of screens and was therefore not cost effective. Feedback from young people showed that although these events were good for awareness raising, they would go elsewhere for a screen.

### Planned/future developments

Given the importance of GPs in helping to meet national screening targets, in January 2010, Cumbria Primary Care Trust agreed plans to pay GPs in Cumbria £2.50 per screen if the practice reached the national target level and it was hoped that all services would be commissioned like this in future.<sup>76</sup> The use of text messaging was also being examined.<sup>76</sup> The Local Enhanced Service was updated in October 2010 in line with the 30% target for 2010/11 to include partner notification for positive patients and an increased payment of £5.

Training will be ongoing and a support network developed to support future activities. In addition, in clinical services, Cumbria has integrated the screen into

xxii See the data tables at

\*\* See www.best2know.co.uk

 $<sup>^{\</sup>rm xxi}$  Based on Office for National Statistics mid-year 2006 population estimates (57,900 people aged 15-24 years)

www.chlamydiascreening.nhs.uk/ps/assets/pdfs/data/VSI\_PCT/VSI\_PCTQ1-Q2\_Apr10-Sept10.pdf and

 $www.chlamydiascreening.nhs.uk/ps/assets/pdfs/data/PCT_Detailed_Tables-Apr10-Sept10.pdf$ 

2011

## usual practice instead of being a standalone programme.

#### **Examples of local successes**

Examples of success include the chlamydia opportunistic screening in the Copeland Public Health Quality Outcomes Framework that was developed in one of the locality GP areas. This highlighted the importance of young people's health as a primary care public health measure and introduced discussions about lifestyles and risk taking behaviour as well as discussions on chlamydia screening.

The programme has found that using national publicity and advertising materials instead of those with a local identity helped to raise the profile of the programme and cut costs.

Further success included using general laboratory forms in primary care and taking a urine sample while the patient was already in the GP practice (as postal packs were not always returned). This approach also facilitated discussion about general lifestyle behaviours.

Further innovative methods to raise awareness and uptake of screening occurred in August 2010. NHS Cumbria successfully screened one in 10 (765) young people at the Kendal Calling Music Festival using the offer of a better toilet facility to attract attention and increase participation in testing.<sup>77</sup>

The National Support Team held its first ever Chlamydia Screening Stakeholder Event in Cumbria during February 2010 which was followed by tailored local support to deliver the screening programme.<sup>71</sup> **Two main recommendations came out of the event,** first to mainstream the programme through all services that see or work with young people, allowing consistency of message and approach. Second, to develop a more targeted approach to delivery and monitoring. Both these recommendations have been implemented. There are a number of screening opportunities which might become available nationally and across Cumbria in the future.

### **Alcohol screening**



Alcohol poses an increasingly serious threat to people's physical and psychological health, for example, mouth cancer is over three times as common among men who frequently drink more than two pints of strong lager a day. Over 9,000 people die every year across the UK due to alcohol<sup>78</sup> and in parts of Cumbria, incapacity benefit claimant rates due to alcohol are higher than the national average.<sup>74</sup> There is also a national indicator (NI39) against which local areas are assessed and this measures progress towards reducing the number of hospital admissions due to alcohol-related harm across England.<sup>79</sup>

It is suggested that Accident and Emergency (A&E) departments are one potential venue for providing screening to people at risk from misuse of alcohol<sup>80</sup> and there are already a number of screening tools available.<sup>81</sup> For example, Cumbria Alcohol and Drugs Advisory Service, who provide advice and support across the county to those affected by alcohol or drugs misuse, xxiii use the Alcohol Use Disorders Identification Test and Fast Alcohol Screening Tool<sup>xxiv</sup> screening tools.<sup>82</sup> The Alcohol Use Disorders Identification Test tool is a set of ten questions developed by the World Health Organization to help identify signs that an individual is at risk of hazardous or harmful drinking and mild dependence upon alcohol. Questions in the test include asking how often a

person consumes six or more drinks on one occasion or how often during the last year he/she has failed to do what was normally expected from them because of drinking. Staff from Cumbria Alcohol and Drugs Advisory Service have also provided training for GPs, A&E staff and workers at Haverigg Prison on behalf of the former North Cumbria Primary Care Trust to help raise general awareness about sensible drinking, alcohol misuse and earlier identification.<sup>83</sup> For example, an average GP sees around 354 hazardous or harmful drinkers in a year and problem drinkers go to the doctor around twice as many times as an average patient.<sup>84</sup> Cumbria's alcohol strategy outlines plans for more staff and agencies in the county to be trained in alcohol interventions and in recognising the signs of alcohol misuse with the aim of helping to reduce harmful and dangerous drinking, particularly among young people living in the area.<sup>85</sup>

## Prostate cancer risk management programme



Another potential screening opportunity in future could be to assess someone's risk from prostate cancer. Found only in men, the prostate is a walnut sized gland located below the bladder, surrounding the tube that carries urine from the bladder.<sup>86</sup> It produces some of the fluid in semen and is therefore important for a man's sex life. Prostate cancer occurs when a single cell in the prostate multiplies out of control to form a tumour. In some cases, cells may break away and travel to other sites in the body causing further tumours to develop. Prostate cancer is a treatable and in many cases, curable, disease. It is more common in older men, particularly those over the age of 50 years. Men of black-African and black-Caribbean origin and those with a family history of prostate cancer are also at greater risk.

xxiii See www.cadas.co.uk

x<sup>dv</sup> The Fast Alcohol Screening Tool uses four questions from the Alcohol Use Disorders Identification Test to screen for alcohol misuse

2011

Prostate cancer is the most common cancer among men in the UK, with 36,100 diagnoses in 2007 alone.<sup>87</sup> Survival rates have improved and more than three-quarters of men diagnosed with prostate cancer will now survive their disease for more than five years. In the UK, much of this improvement is due to the rise in use of Prostate Specific Antigen<sup>xxv</sup> tests.<sup>87</sup>

Whilst there is currently no prostate cancer screening programme in place, an informed choice programme, Prostate Cancer Risk Management Programme has been introduced nationally.<sup>86</sup> The aim of this programme is to ensure that men who are worried about the risk of prostate cancer receive clear and balanced information about the pros and cons of the Prostate Specific Antigen test and prostate cancer treatment. This will allow men to make an informed decision as to whether they want to take the test. The UK National Screening Committee recommends that a prostate cancer screening programme should not be introduced in England at the moment. This is because of the natural history of the disease; in many cases prostate cancer takes many years to progress and it is in fact found to have been present in older men who have died from completely unrelated conditions. For this reason prostate cancer does not meet the Wilson and Jungner criteria for a screening programme (see technical note on the back cover). The UK National Screening Committee will however continue to keep the situation under review.<sup>86</sup>

xxv A protein produced by the cells of the prostate gland

#### Section 5: Conclusions



In summary, systematically delivered and high quality screening services are recognised as important public health interventions which have the potential not only to reduce people's risk from particular diseases or conditions, but to also help save lives.

As noted in *Cumbria 2010*, the annual report from the Director of Public Health, screening programmes are generally performing well across the county. However, there are a number of potential areas for improvement and greater assurance of quality across each of the screening programmes, as evidenced in the recent service failure of breast screening in North Cumbria.

This report identifies a number of key findings in relation to each of the screening programmes. Please note that the findings which are shaded blue below are for initial action, while those without shading will require further consideration and identification of additional funding.

#### Antenatal and newborn screening

- There are many examples where screening programmes achieve or surpass the expected national expected standards. However, there are likely to be some inconsistencies and limitations in the collation and reporting of data due to time and resource constraints (such as the lack of a comprehensive IT support system), particularly for the sickle cell and thalassaemia and newborn and infant physical examination programmes.
- There is a marked variation in uptake of screening for Down's syndrome risk across



Cumbria (and nationally), the causes of which requires further investigation.

- Additional resources are required to roll out the combined test for Down's syndrome (such as ultrasound and maternity care support workers).
- Cumbria needs to respond to the outcomes of a national mapping of newborn and infant physical examination screening which will identify gaps and share best practice nationally.

### **Diabetic retinopathy screening**

The national target for all people with diabetes to be offered screening each year is not currently being achieved across Cumbria; while some GP practices have tested 100% of their diabetic patients in the last 15 months, for others it is 66.0%.

#### **Cervical cancer screening**

While cervical screening coverage in Cumbria is consistently above regional and national averages, there is a way to go before the county achieves the target of all women receiving their results within two weeks.

#### **Breast cancer screening**

NHS Cumbria is committed to extending the breast cancer screening programme (from women aged 50-64 years to those aged 47-73 years) and to fully introduce digital mammography testing by December 2012. However, women undergoing screening should be aware of the limitations of this intervention.

- Despite improvements, greater uptake of bowel cancer screening is needed across some localities, particularly in the younger age groups. Low screening uptake is also associated with higher rates of death from bowel cancer.
- Greater health promotion will be key to increasing uptake. The increasing availability of more detailed programme performance data (including data by deprivation) will help targeting.

#### **NHS Health Checks**

- Data from the current cardiovascular disease high risk register suggests that uptake is higher in GP practices serving more affluent areas.
- To help reduce health inequalities, a greater variety of methods should be used to identify participants, not just from GP registers.

### Abdominal aortic aneurysm screening

Cumbria is awaiting the outcomes of a submitted business plan along with a review of vascular surgery providers in the North West.

#### **Chlamydia screening**

- Despite improvements, uptake in Cumbria is below nationally and regionally.
- GPs see large numbers of the target group and are therefore, along with other primary care services, key partners in helping to boost uptake rates among young people in the county.

#### **Emerging screening programmes**

- It is suggested that A&E departments are one venue where alcohol screening could be undertaken to reduce risk from alcohol misuse. A variety of tools already exist to support this.
- In the absence of a national prostate cancer screening programme, men who are worried about their risk from the disease should receive clear and balanced information about

the relevant tests and treatments which can be made available on request.

#### Recommendations

The following are the initial recommendations which can be drawn from this *Health Screening in Cumbria* review. It is suggested that NHS Cumbria should:

- Review its entire screening pathway annually and produce an annual screening report.
- Develop a screening toolkit to allow a more uniform approach to screening across the county and throughout screening programmes.
- Develop an annual/bi-annual screening forum for practitioners across the screening pathway and for all partners involved in screening to share good practice.
- Increase opportunities for health promotion and social marketing across the screening pathway as well as in each individual screening programme.
- Ensure consistent and up-to-date use of IT across the county for the purposes of call and recall and for monitoring screening programmes.
- Develop a quality assurance framework across the screening pathway (in addition to quality assurance within each screening programme).
- Identify localities and population groups that have low uptake in order to target efforts to increase uptake.
- Increase opportunities for updates and training for staff from all sectors involved in screening.

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#### **Acknowledgements**

The authors of this report would like to thank all the screening leads and related staff across NHS Cumbria, the University Hospitals of Morecambe Bay NHS Foundation Trust and North Cumbria University Hospitals NHS Trust who provided data and further details about the local screening programmes. Thanks also to Dr Nigel Calvert (Associate Director of Public Health, Health Protection), Lyn Murphy (Senior Health Protection Nurse Lead) and Donald Read (Public Health Trainee) of NHS Cumbria for their help and support in shaping the content and structure of the report.

Further thanks also to staff at the North West Public Health Observatory for their help with editing and proofreading the report including Steven Knuckey, Caroline Hilliard and Lynn Deacon, and Lee Tisdall for the cover design and images.

#### **Technical notes**

#### Wilson and Jungner criteria for screening

Knowledge of disease:	The condition should be important. There must be a recognisable latent or early symptomatic stage. Natural course of condition, including development from latent to declared disease, should be adequately understood.
Knowledge of test:	Suitable test or examination. Test acceptable to population. Case-finding should be continuous (not just a "once and for all" project).
Treatment for disease:	Accepted treatment for patients with recognised disease. Facilities for diagnosis and treatment available. Agreed policy concerning whom to treat as patients.
Cost considerations:	Costs of case-finding (including diagnosis and treatment of patients diagnosed) economically balanced in relation to possible expenditures on medical care as a whole.

(see www.patient.co.uk/doctor/Screening.htm#ref2#ref2)

#### **NHS Cumbria**

This is the title of the organisation known previously as Cumbria Primary Care Trust or PCT. Like other primary care trusts across the country who have undergone the name change, they are now the lead organisation for health in their own area.





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January 2011

ISBN: 978-1-908029-16-4 (web version)

A report commissioned by:

