Audit of neonatal screening programme for phenylketonuria and congenital hypothyroidism

Neil Simpson, Robina Randall, Simon Lenton, Sue Walker

Abstract

The performance of the neonatal screening programme was audited against clinical standards in the Bath clinical area from 1 April 1994 to 31 March 1996. The standards and policy were agreed by local service provider representatives of the screening and were audited, using laboratory and child health computer systems and medical records. Two annual reports were produced with recommendations for improvement communicated to representatives of the service. Thus the first audit loop has been completed.

The audit shows that the coverage of the service is excellent, with all eligible babies being offered screening; those with congenital hypothyroidism or phenylketonuria receive appropriate treatment by the 28 day standard. The process works extremely well, although areas for improvement have been identified, to increase the efficiency of the service.

It is concluded that an effective and efficient audit cycle can be established, to monitor and improve the performance of the neonatal screening service.

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In the UK all parents are offered testing for their babies shortly after birth for two conditions— phenylketonuria and congenital hypothyroidism. About 1 in 3000 babies will have congenital hypothyroidism and about 1 in 13 000 will have phenylketonuria. Without timely diagnosis and treatment these lead to irreversible severe learning difficulties.[1–3]

Screening for phenylketonuria using heel prick blood specimens was introduced following the recommendations of the Medical Research Council Working Party set up in 1965.[4] Screening for congenital hypothyroidism was added to the service throughout the United Kingdom in 1981.[5] Some regions are currently screening for other conditions, such as cystic fibrosis and other metabolic conditions.[6]

Both tests are carried out in centralised laboratories on blood collected by heel prick. The screening programme should ensure that all infants are offered testing, and that any infant with phenylketonuria or congenital hypothyroidism starts appropriate treatment as soon as possible after birth. This neonatal screening programme has proved effective,[7] is accepted, and although expensive, is thought to be cost effective.

The neonatal screening service involves the close cooperation of families, health professionals, and administrative staff in a range of locations. Because the screened conditions are rare and the consequences of missing them so serious, it is important to have clear quality assurance measures to ensure that the service is running in the most effective, efficient, equitable and humanitarian way possible. Community paediatricians are increasingly responsible for neonatal screening programmes.

An audit of screening for congenital hypothyroidism in Liverpool from 1983 to 1989 concluded that administrative deficiencies were predominantly responsible for the inefficiencies identified in the screening programme.[8] A further study looked at the variation in screening coverage by ethnic group and found that it was incomplete in African infants and in families mobile at the time of birth. It identified problems in recording results, follow up of infants not tested, and monitoring of the programme.[9] Both studies recommend that explicit process measures should be introduced to address these problems and monitor the screening programme through audit.

The third edition of *Health for All Children* emphasises the importance of careful monitoring and clear accountability to avoid disasters and says litigation costs for "missed" cases are already considerable and will rise. It also emphasises the importance of ensuring that parents are informed about the screening tests.[10]

Therefore, this audit was set up to evaluate the neonatal screening service in the Bath clinical area using explicit process and output standards. The audit aimed to inform people of the performance of the neonatal screening service in relation to the clinical standards, highlight areas of shortfall, recommend improvements to address these, and to establish an ongoing monitoring system. This is a detailed audit from a well defined clinical area. We are not aware of any similar local audits, although a national audit has been conducted and is due to be published.

This audit reports on the process and output standards of the service. It does not look at outcomes of the service in terms of parent and baby satisfaction and the positive benefits of identifying children with congenital hypothyroidism and phenylketonuria as soon after birth as possible. The benefits of early detection and treatment of these two conditions have been shown elsewhere and conclusions cannot be drawn

Child Health Department, Newbridge Hill, Bath, BA1 3QE
N Simpson
R Randall
S Lenton

Salisbury District General Hospital, Salisbury, Wilts
S Walker

Correspondence to:
Dr Neil Simpson.

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Table 1 Clinical standards

Standard	*Monitored by*
1. 100% of all eligible resident babies to be screened	Child health department
2. 100% of parents to receive adequate verbal and written information about the screening programme and tests	Maternity department
3. 100% of tests should be taken between 6 and 10 days (excluding cases with difficult access, repeat samples and babies who move into district)	Screening laboratory
4. 95% of screening card samples to be received by the laboratory within 6 days of being taken, 100% within 13 days	Screening laboratory
5. 100% of samples should be of adequate quality for testing, repeats should be requested on no more than 2% of babies	Screening laboratory
6. 90% of results will be available within 2 working days of sample receipt, 100% within 4 working days	Screening laboratory
7. 90% of results should be received by the child health department within 4 working days of completion of analysis, 100% within 7 working days	Child health department
8. 100% of all appropriate results to be entered on the child health computer within 3 working days	Child health department
9. 100% of eligible resident babies should have results or recall for repeat testing generated by 28 days of age	Child health department
10. 100% of neonates diagnosed as having congenital hypothyroidism should commence appropriate treatment by 28 days of age	Community paediatrician
11. 100% of neonates diagnosed as having phenylketonuria should start appropriate treatment by 28 days of age	Community paediatrician

about outcomes from the small numbers involved in this audit.[1–3]

Description of the neonatal screening service

The neonatal screening service comprises: an input of "at risk" babies, a process or series of changes which are described below; and an output (or changed input)—either babies no longer "at risk" or babies "at higher risk" who require investigation and treatment. Because there are so many stages, it is important to have clear time standards for each part of the process as delays in one or more stages will rapidly lead to unacceptable delays in treatment of affected babies.

The process of the neonatal screening service involves five stages. Stage 1—sample collection; stage 2—sample analysis; stage 3—data entry and dissemination of the results; stage 4—follow up; stage 5—management of positive results, when these occur.

STAGE 1

The midwife or neonatal nurse discusses the screening test with the parents and takes heel prick blood samples from the baby according to the district policy. The fully completed screening card is sent to the laboratory in the prepaid envelope without delay, after the top blue sheet has been detached and stored in the clinical notes.

STAGE 2

The blood spots are analysed in a screening laboratory. Two result labels are produced for each baby and sent immediately to the child health computing department. Requests for retests are initiated if necessary.

STAGE 3

Data are input on the child health computer. One result label for each child is sent out to the appropriate health visitor to discuss the result with the family and enter it into the personal child health record. The remaining result label is attached to the birth notification card.

STAGE 4

There are three follow up systems in place to ensure that all eligible babies are screened.

1. Once a week a computer printout is generated of all children between the ages of 21 days and 6 months (this includes babies who have moved into the district after birth) who do not have a result. Each of these children is followed up individually with requests for repeat tests or phone calls/letters to previous districts as appropriate. A code, typed description of follow up, and date of initiation is entered on the child health computer. They continue to appear on the weekly printout until a result is entered.
2. The birth notification cards are not filed until a screening result label has been attached.
3. Each health visitor is responsible for ensuring that every child on their case load has a result for neonatal screening by 28 days, and if not, to inform the community child health department to initiate further follow up.

STAGE 5

Should the results be positive, these are communicated directly from the screening laboratory to the on-call paediatric consultant by phone and letter. Guidelines have been agreed to ensure that the diagnosis is confirmed and treatment started without any unnecessary delay.

Methods

In December 1994 a policy and set of 11 clinical standards (table 1) were agreed by local provider representatives of the neonatal screening service. The service was first audited in August 1995 (for the period 1 April 1994 to 31 March 1995) and reaudited in July 1996 (for the period 1 April 1995 to 31 March 1996). The methods used for each standard are described below.

Standard 1: A child health computer enquiry was set up to determine the number of babies born in the district and the number of babies under 6 months, and therefore eligible for screening, who move into the district. Early neonatal deaths were subtracted to give the total number of eligible for screening. The number of babies without a result was then determined to give the percentage of eligible babies screened.

Table 2 Summary of results

Standard	*Achieved?*
1. 100% of all eligible resident babies to be screened	Yes
2. 100% of parents to receive adequate verbal and written information about the screening programme and tests	Not done
3. 100% of tests should be taken between 6 and 10 days (excluding cases with difficult access, repeat samples and babies who move into district)	No (97.9%)
4. 95% of screening card samples to be received by the laboratory within 6 days of being taken, 100% within 13 days	Part 1 - yes, part 2 - no (99.8%)
5. 100% of samples should be of adequate quality for testing, repeats should be requested on no more than 2% of babies	Part 1 - no (98.1%) part 2 - no (2.9%)
6. 90% of results will be available within 2 working days of sample receipt, 100% within 4 working days	Yes
7. 90% of results should be received by the child health department within 4 working days of completion of analysis, 100% within 7 working days	Yes
8. 100% of all appropriate results to be entered on the child health computer within 3 working days	No (85.3%)
9. 100% of eligible resident babies should have results or recall for repeat testing generated by 28 days of age	Yes
10. 100% of neonates diagnosed as having congenital hypothyroidism should commence appropriate treatment by 28 days of age	Yes
11. 100% of neonates diagnosed as having phenylketonuria should start appropriate treatment by 28 days of age	Yes

Standard 2: This standard has not yet been audited due to a delay in the production of an information sheet. "Adequate" information is defined to mean that all parents should receive an information sheet and the midwife, nurse, or health visitor should explain the test at the time and give parents the opportunity to ask questions.

At present the personal child health records are distributed by the health visitor on day 10 when they take over from midwife care. In the future it has been proposed that the personal child health records will be given out by midwives before or soon after birth. When this happens the parent information sheet will be adapted to be included with the personal child health record. The maternity department will be responsible for auditing this standard by a survey of parents twice a year.

Standards 3–6: Information is generated by the screening laboratory computer system for these standards and disseminated in their internal audit report published annually. The results relate to the Bath clinical area except standard 6 which includes all districts served by the screening laboratory.

Standards 7 and 8: The date of arrival of batches of results from the laboratory and the date they are input is recorded. The number of working days can be calculated between completion of analysis (from date on the reports) and arrival of results at the child health department. The number of working days taken to enter the results is calculated from the recorded date of arrival and the date they are input. The results usually arrive in the morning. Therefore, if the date of arrival was the same as for entry on the child health computer this was counted as one working day.

Standard 9: From April 1995 a new code was entered on the child health computer when follow up was initiated. It includes the date and a typed description of the follow up action. Therefore, it is possible to establish how many babies have a result or follow up initiated at 28 days of age by computer inquiry.

Standards 10 and 11: The medical notes of children with positive results were examined to determine the age at which babies started appropriate treatment. Each case was broken down to show the time intervals between each stage of the process.

Results

The full results are presented for the second audit (1 April 1995 to 31 March 1996) with the percentages achieved for the first audit (1 April 1994 to 31 March 1995) for comparison. The percentages do not add up precisely due to rounding errors. Table 2 summarises the results.

STANDARD 1

All eligible babies were screened if parental refusals are excluded (table 3). Assessing the number of eligible babies relies entirely on the integrity of the child health database. Every effort is made to ensure this is as complete as possible and that it is updated every day. Birth notifications from the Bath clinical area and copies of births in other areas but resident in the Bath clinical area are sent to the child health department. Information about children moving in and out of the area relies on health-care professional contact with the family and communication with the child health department. Information about pre-school children is felt to be very good because the organisation of the immunisation and pre-school surveillance is coordinated by the child health computing department.

Five families refused screening in 1996. The laboratory was aware of all of these, an improvement on the previous audit. The reason for refusal is not always recorded. One

Table 3 Standard 1: 100% of all eligible resident babies to be screened

Results	*1996*	*1995*
Number of resident newborn babies	5443	5330
Number of deaths	34	21
Number of newborn babies resident outside district (included)	418	382
Therefore total number of eligible newborn babies	5827	5691
Total number of "move ins" less than 6 months old	159	171
Total number of eligible babies	5986	5862
Total number without result entered or follow up initiated	5	7
Number of parental refusals	5	7
Percentage of eligible babies screened	99.9%	99.9%

Table 4 Standard 3: 100% of tests should be taken between 6 and 10 days (excluding cases with difficult access and repeat samples)

Results	*1996*	*1995*
Total number of neonates screened	5017*	
(Total number of samples screened)	5169	
Number taken at or sooner than 5 days	36 (0.7%)	0.3%
Number taken at 11-21 days	39 (0.8%)	1.1%
Number taken at 22-35 days	18 (0.4%)	0.25%
Number taken after 35 days (range 36-79)	10 (0.2%)	0.1%
Total number not taken between 6-10 days	2.1%	1.8%
Percentage of tests at 6-10 days	97.9%	98.2%

* This figure is less than before because the number of eligible births does not include some babies born in, but screened in another, district as a result of banding anomalies. These births therefore appear on the other districts' databases at the screening laboratory.

of these refusals was subsequently tested at 10 weeks of age. Families who refuse neonatal screening for their baby must be given adequate verbal and written information to ensure their decision is as informed as possible. A clear record of discussions with the parents must be kept in the clinical records, dated and signed. A fully completed screening card including the reason for refusal should be sent to the laboratory who offer a follow up service for the primary health care teams with extra information for these families.

Some of the reasons given for refusal of screening include families who had had a home delivery with minimal or no medical input and a family who believed the screening test was a barbaric procedure based on the experience of an acquaintance.

STANDARD 3

Thirty six (0.7%) of samples were taken before 6 days (table 4). Therefore, about 1 in 140 samples were repeated simply because they were taken too early. Unfortunately, this is worse than the results for 1995. Most of the early samples were taken on day 5 and it depends whether the date of birth is included as day 0 or 1. It can be argued that testing on the 5th day of life in a fully enterally fed infant is acceptable without decreasing the sensitivity of the test.

Sixty seven (1.3%) were taken after 10 days, thus introducing unnecessary delay in identifying and treating positive cases. The reason for delay in initial testing is still not consistently recorded. The commonest reasons were non-receipt by the screening laboratory of the first sample and missed initial screening.

The internal audit report from the screening laboratory highlights the problem of delayed testing of sick neonates on neonatal intensive care units and surgical wards in several districts. It strongly recommends that all babies on neonatal intensive care units are tested at 6–10 days (as defined in standard 3) with sufficient clinical information, including feeding, birthweight, and gestation to help interpretation of results and generation of repeat test(s) as appropriate.

Tests for congenital hypothyroidism can be performed if babies are being fed parentally. Babies fed in this way should have a further test taken when the baby is on full milk feeds, to screen for phenylketonuria. This is monitored by the screening laboratory until a further test is sent.

STANDARD 4

Part 1 of standard 4 was achieved, but part 2 was not. Ten (0.2%) screening cards were received more than 13 days after being taken and so needed repeating (table 5). The screening laboratory looked at the reasons for this across the region by limited survey and found a considerable number were due to a delay in posting rather than a delay in the post.

It is not clear why there should be a delay in posting. Prepaid first class envelopes are provided with each screening card which should make it straight forward to put it in the post immediately after collecting the sample. The envelopes are given priority by the post office and this continued during recent industrial action so that there were no delays as a result.

STANDARD 5

Standard 5 was not achieved. A significant number of samples were of inadequate quality. 1.9% or 1 in 53 samples had to be repeated because they had not been taken and sent appropriately (table 6). The best way to collect the blood and the information required on the

Table 5 Standard 4: 95% of screening card samples to be received by the laboratory within 6 days of being taken and 100% within 13 days of being taken

Results	*1996*	*1995*
Total number of neonates screened	5017	
Total number of samples screened	5169	
Number received at 7-13 days	131 (2.5%)	2.8%
Number received at 13 days or more (range 9 between 15-27 days and 1 at 119 days)	10 (0.2%)	0.2%
Percentage of samples received within 6 days	97.2%	97%
Percentage of samples received within 13 days	99.8%	99.8%

Table 6 Standard 5: 100% of samples should be of adequate quality; repeats should be requested on no more than 2% of neonates (including all reasons)

Results	*1996*	*1995*
Total number of neonates screened	5017	
Total number of samples screened	5169	
Insufficient sample to complete both tests	42 (0.8%)	0.8%
Sample contaminated (no results)	7 (0.1%)	0.1%
Sample unsuitable (delayed receipt)	9 (0.2%)	0.2%
Sample unsuitable (taken too early)	36 (0.7%)	0.3%
Unlabelled anonymous sample	2	
Total number of inadequate/unsuitable samples	96 (1.9%)	1.3%
Percentage of samples of adequate quality	98.1%	98.7%
Repeat samples requested by the laboratory	70 (1.4%)	1.1%
Total repeat samples received for all reasons	152* (2.9%)	2.8%

* The discrepancy in this figure is because it includes several repeat samples sent while a neonate received total parenteral nutrition, transfers in/out of the district of sick inpatients. Other reasons for repeats included, for example, laboratory technical problems, mildly abnormal results and some received in the next financial year.

Table 7 Standard 7: 90% of results should be received by the child health department within 4 working days of completion of analysis; 100% within 7 working days (includes 112 batches of results)

Results	*1996*	*1995*
Total number of results	4966	
No of results received within 4 working days	4834 (97.3%)	97.2%
No of results received within 7 working days	4966* (100%)	100%

* This number is less than total number of eligible babies and number of samples screened by the laboratory because it does not include results obtained from other districts for "move ins," and at least one batch of results which arrived after 31 March 1996 but had been analysed before.

Table 8 Standard 8: 100% of all appropriate results to be entered on the child health computer within 3 working days (includes 112 batches of results)

Results	*1996*	*1995*
Total number of results	4966	
No of results with incorrect details	141 (2.8%)	3.6%
No entered on child health computer within 3 working days	4236 (85.3%)	83.1%

Table 9 Standard 9: 100% of eligible babies should have results or recall for repeat testing generated by 28 days of age

Results	*1996*
Total number of births	5443
Number of deaths	34
Therefore total number of eligible births	5409
Total number with result or follow up initiated by 28 days of age	5409 (100%)

form is outlined in the policy. Unnecessary repeat tests affect the baby and parents and have resource implications.

Two samples were sent anonymously without any details completed at all. Fortunately, the samples were negative on analysis and it was safe to wait until the child was identified later by the follow up system. If the initial sample had been positive an unnecessary delay in treatment would have resulted.

Over the past seven years anonymous samples have only been sent from districts which do not routinely detach the top blue sheet from the screening card and add it to the clinical notes. This process increases the chance of noticing that details have not been completed and acts as a record that a sample was taken. This is in the policy and was a recommendation in last year's annual report. Implementation was delayed because it was thought that a new screening card was going to be introduced nationally. However, two more anonymous samples were sent at the beginning of this year and it was decided to introduce this practice in March 1996. About two thirds are now being sent with the top sheet detached.

STANDARD 6

Standard 6 was easily achieved, with all results (n = 21089) available to telephone and written enquiries within 4 working days and most (97.5% in 1996 compared with 98.6% in 1995) within 2 working days. The laboratory uses regular internal and external quality control systems to monitor the analytical service. Consideration should be given to increasing this standard.

STANDARD 7

Standard 7 was achieved, and the results confirm that the delays experienced by the laboratory in receiving the screening cards from the community are most likely to have been due to delays in posting the envelopes rather than the postal service itself (table 7).

An E-mail link from the laboratory to the child health department is being piloted. This will speed up the identification and follow up of unscreened infants. The aim is to set up a direct computer to computer link to cut out keyboard entry of the results in the child health department but at the same time ensure the results are verified and acted on appropriately. Hard copies will continue to be sent on sticky labels for the personal child health records and the birth notification cards for the time being.

STANDARD 8

Standard 8 was not achieved. Eighty five per cent of results were entered on the child health computer within 3 working days (table 8). This represents an improvement on last year's results. The priority when results arrive in the department is to forward the health visitors copies (for the personal child health records) and enter and follow up abnormal results; the negative results are then input. The results arrive twice weekly and there are an average of 46 results in each batch. Difficulties occur when members of staff are on holiday or on sick leave, but this does not account for all the delays in data entry.

One hundred and forty one (2.8% of results) had incorrect details that required follow up and confirmation. This mostly relates to names, dates of birth, and sex of children. If the details were filled in accurately, completely and clearly, significant time could be saved and efficiency enhanced. This has improved since last year's annual report, but needs further audit.

Table 10 Standard 10: 100% of neonates diagnosed as having congential hypothyroidism should start appropriate treatment by 28 days

Positive cases for congenital hypothyroidism (TSH > 39.9 mU/l)	*1996*	*1995*
Number of positive cases on screening	1	4
Percentage of cases receiving appropriate treatment by 28 days	100%	100%
Breakdown of each case:		
Case 1 Day of birth→7 days→heel prick→3 days→telephone→6 days→treatment		16 days
Case 2 Day of birth→16 days→heel prick→7 days→telephone→1 day→treatment		24 days
Case 3 Day of birth→7 days→heel prick→5 days→telephone→same day→treatment		12 days
Case 4 Day of birth→7 days→heel prick→6 days→telephone→1 day→treatment		14 days
Case 5 Day of birth→7 days→heel prick→3 days→telephone→1 day→treatment		11 days

Telephone means positive result communicated to paediatrician.

Table 11 Standard 11: 100% of neonates diagnosed as having phenylketonuria should start appropriate treatment by 28 days of age

Positive cases for phenylketonuria (phenylalanine > 600 μmol/l)	*1996*
Number of positive cases on screening	1
Percentage of cases receiving appropriate treatment by 28 days	100%
Breakdown of each case:	
Day of birth→7 days→heel prick→4 days→telephone→3 days→treatment	14 days

Telephone means positive result communicated to paediatrician.

STANDARD 9

Standard 9 was achieved and shows that babies who have not been screened are being identified within the 28 day standard to allow prompt follow up. Babies without results are actually being identified from 21 days of age (table 9).

STANDARD 10

Standard 10 was achieved. There were four positive cases of raised thyroid stimulating hormone in 1995. Case 1 shows that a delay was introduced by withholding treatment after venous blood was taken on the ward (to confirm the diagnosis) until the child was seen in outpatients five days later (table 10). This is not appropriate. Case 2 shows the effect of delay in initial testing.

The baby identified in 1996 was admitted to the neonatal intensive care unit from the postnatal ward at 6 days of age with jaundice and paronychia. The baby also had an umbilical hernia and macroglossia. Neonatal screening was taken on day 7 and showed a thyroid stimulating hormone value of 140 mU/l. This was confirmed by venous sampling with result of 100 mU/l. Treatment with thyroxine was started at 25 mcg a day at 11 days of age.

The mean age at which appropriate treatment was given was 15.4 days (range 11–24 days), well within the four week standard.

No laboratory test can be completely reliable and the diagnosis of phenylketonuria and congenital hypothyroidism should always be considered in appropriate clinical circumstances and repeat tests taken where there is any doubt.

STANDARD 11

There were no positive cases identified in 1995 (table 11). The case shown demonstrates the effectiveness of the service, with the baby receiving appropriate treatment by 14 days of age. The phenylalanine concentration was >1000 μmol/l on the blood spot with the same value confirmed on venous sampling. Biopterin concentrations were normal. Another child had a slightly raised phenylalanine concentration of 300 μmol/l with normal biopterin values. This was followed up and a diagnosis of benign hyperphenylalininaemia made.

Actions taken as a result of the audit

The annual reports are sent to all line managers encouraging them to discuss it with their staff and try to identify areas for further improvement. This year a summary of the audit has been sent to all staff involved in the screening programme to inform them of the effectiveness of the service. In view of the continued significant number of results falling outside the recommended time and quality standards, a confidential questionnaire has been sent to all practitioners collecting screening samples to try to gain a better understanding of why this is happening and to ask for further ideas to improve the service.

The audit has provided the impetus to produce a parent information sheet. The maternity department will be responsible for auditing standard 2 relating to parent information twice a year. The data entry and follow up process have been reviewed and cross cover arrangements put in place. The E-mail pilot is underway and will be further developed.

The standard for starting appropriate treatment of children with congenital hypothyroidism and phenylketonuria has been reduced to 21 days. As a final output measure a twelfth standard has been introduced: "100% of babies will have the result for neonatal screening entered into the personal child health record by the 6 week surveillance check." The surveillance form will be adapted to include these data and allow the standard to be audited by computer enquiry.

Conclusions

The neonatal screening service is a complex process requiring the close cooperation of a wide range of people, including midwives, health visitors, nurses, child health computing staff, central laboratory staff, GPs, paediatricians and parents. They must all work together to provide an efficient, effective, and equitable service while trying to minimise the anxiety and discomfort caused to families and babies by the process.

The audit of the neonatal screening service shows that all eligible babies are being screened (excluding parental refusals) and that positive cases are being seen and treated well within the first 4 weeks of life (Standards 1 and 10/11). Thus the output of the service can be considered as very satisfactory.

The audit shows that the process is working efficiently but that there are still areas not reaching the agreed standards (Standards 2, 3, 4, 5 and 8). Overall, there has been some improvement towards the standards with the exception that more samples are being taken too early.

A significant number of samples have to be repeated because they are not taken and sent according to the standards and policy. This reduces the efficiency of the service and results in discomfort for babies and increased anxiety for families who need unnecessary repeat tests. It is important to continue to address these areas and we have shown that the audit cycle will facilitate this process.

Careful monitoring and clear accountability must continue to ensure that children with congenital hypothyroidism and phenylketonuria are not missed by the screening service and suffer as a result. The appropriate use of information technology makes this achievable.

The Bath clinical area in conjunction with Salisbury screening laboratory now has a well established audit cycle which shows the neonatal screening service is working extremely well, is improving, and hopefully will continue to do so. We believe that this audit will be of interest

nationally as a model of good practice for providers and purchasers to aid development of efficient and effective monitoring and quality assurance systems for neonatal screening services.

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