

Newborn Screening User Survey 2019-2020



Summary

Nineteen responses were received from a range of healthcare professionals (5 midwives, 5 screening coordinators, 4 clinicians, 2 CHIS members of staff, 1 CF specialist nurse, 1 nurse and 1 screening and immunisation manager).

Overall the responses received were very positive with the majority (>10/19) of participants stating strongly agree with the following:

- Prompt referral of positive screens
- Lab visits are useful
- Staff are friendly and helpful
- Staff are sufficiently knowledgeable

Positive screens are communicated promptly and effectively.

All responses were positive, the majority of these being 'strongly agree'

Newborn screening results are promptly and effectively communicated with the clinical team

Management of repeat newborn screens is satisfactory

Only one participant (midwife) stated 'disagree' with any of the questions i.e. 'management of repeat newborn screens is satisfactory'. This is an outlier as, of the 15 remaining respondents, 6 indicates strongly agree and 9 agree. There was no free text comment to support this score or contact details provided to enable us to 'drill down' into this response further. The management of avoidable repeats and review of KPI performance is a standing agenda item at the regular SW Newborn Screening Governance meetings where feedback from regional midwifery teams is regularly discussed.



Advice is readily available

Fifteen users were in agreement. Two selected “N/A”, one failed to comment and one midwife chose to disagree but, unfortunately, did not add a comment.



Prompt accurate advice
when needed.

Lab visits are useful

There was good agreement here with the majority of respondents selecting “strongly agree”

Educational meetings are helpful

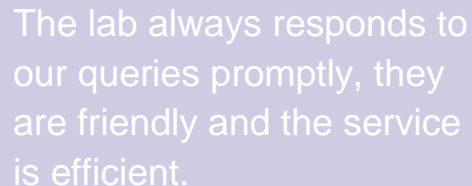
We feel that the educational meetings we provide are useful, but it is good to have this confirmed by our users.

Staff are friendly and helpful


Our staff are a credit to our service, so it is great to see that they are also appreciated by our users with the majority selecting “strongly agree” and no negative comments.



Very helpful, willing to help



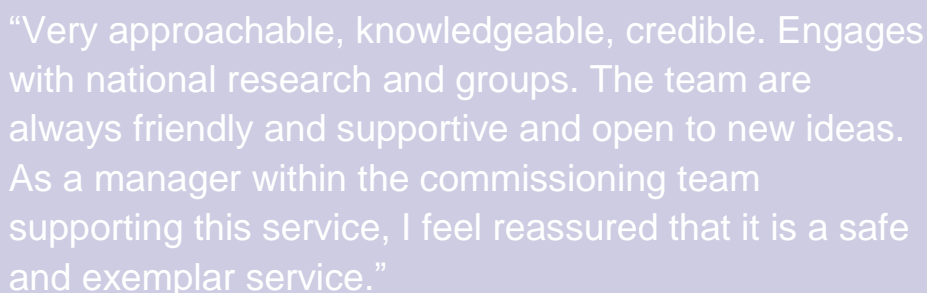
The lab always responds to
our queries promptly, they
are friendly and the service
is efficient.



I have always found the lab
staff very helpful

Staff are sufficiently knowledgeable

Lots of agreement here. One of the best comments comes from the manager within the commissioning team:



“Very approachable, knowledgeable, credible. Engages with national research and groups. The team are always friendly and supportive and open to new ideas. As a manager within the commissioning team supporting this service, I feel reassured that it is a safe and exemplar service.”

Have you accessed our Severn Pathology Website (Newborn Screening section) for information?

We try very hard to ensure that our website is kept up to date with the latest and most useful information for our services. The majority of responses indicated that users were not familiar with the Newborn Screening section on the website.

Are there any improvements we could make to our website?

In line with the question before it, as users had not accessed our website there were no comments about improvements we can make.

The following observations were also made which require action:

‘It would be helpful if repeats for clinical reasons could be e-mailed to the screening midwife as well as to the midwifery team directly.’

It is not clear what this comment refers to as repeats for clinical reasons i.e. inconclusive CF, borderline CHT are requested via the screening midwives and written requests e-mailed to the e-mail address provided which is usually a generic e-mail

Action: This will be followed up with Regional PHE Screening & Immunisation and QA teams along with the screening midwives to identify the underlying issue.

‘Not informing us about CF positive patients. The information is usually passed to the wrong regional network centre.’

Again it is not clear what this statement refers to. The respondent was a SCBU clinician. Notification of SCBU clinicians is not part of the referral pathway for CF, all referrals are managed through the Specialist CF Clinicians. On occasion babies may be on NICU in a different area to the relevant regional network and we would consider it the responsibility of the specialist teams to liaise accordingly.

It is good practice, as we usually do for CF and other positive screens, to notify NICU/SCBU of the positive screen, and to copy the referral letter to the relevant NICU clinician. There is scope to standardise practice in this area.

Action: a NICU specific template letter will be generated to include a copy to go to the NICU consultant. A change request has been added to the relevant SOPs

