Title: Newborn Screening User Survey 2017	Q Pulse Identifier: CB-REP-REP-16
Version: 1	Copy No: electronic Q-pulse
Date of Issue: 09/03/17	Author: C. Manfredonia
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Manchester Newborn Screening Laboratory - User Survey 2017

1. Introduction

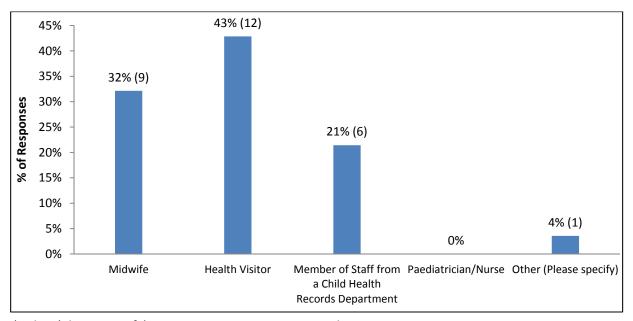
In order to receive feedback from the users of the Manchester Newborn Screening Laboratory a survey was distributed to all users via the Senior Quality Assurance Advisor for our region, Pam Tarn. The survey consisted of 5 questions (see Appendix 1) and was distributed in electronic format using Survey Monkey.

The survey was available for completion between the 14/12/16 and 20/01/17.

2. Results

Question 1

We received 28 responses to the survey from a variety of staff groups.



^{*}Other (please specify) – Service Manager MSCTC Newborn Screening

Question 2

Users were asked to state whether they agreed or disagreed with a variety of statements which focused on different aspects of the laboratory (see below). Overall ≥50% of responders selected 'Strongly Agree' for all statements with the exception of statement 6: 'The Newborn Screening Laboratory effectively communicates any changes to guidelines & policies' to which 46% of responders selected 'Strongly Agree'.

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In total ≥85% of users selected 'Agree' or 'Strongly Agree' to all statements with the exception of statement 6 where it was 64%, with 32% of users selecting 'Neither Agree nor Disagree'.

1 user (Health Visitor) selected 'Strongly Disagree' to all statements. This is difficult to interpret as this user rated the service as 'Excellent' overall. No additional comments were left to explain this selection so we assume the user misinterpreted the key.

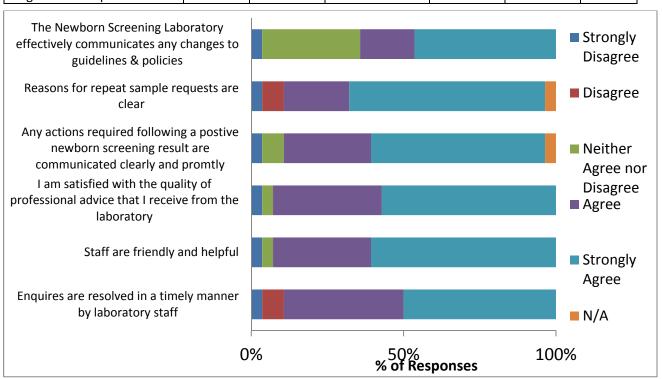
2 users selected 'Disagree' to the statement 'Enquires are resolved in a timely manner by laboratory staff'. This will be discussed at the next laboratory staff meeting. Users are encouraged to leave messages on the departmental answer phone whenever our admin team are not available and we endeavour to respond to these queries as soon as possible.

2 users selected 'Disagree' to the statement 'Reasons for repeat sample requests are clear'. The laboratory issues a letter alongside every repeat request which details the patient information, who took the sample and the reason why the repeat is required. This letter is sent to the Child Health Record Departments (CHRD) to be forward to the relevant midwifery team. We would be grateful if any users asked to collect a repeat sample for an unknown reason contact the laboratory so we can liaise with the relevant CHRD to ensure the our letter is forwarded to you. The reason for repeat requests is also available on the failsafe system.

9 users selected 'Neither Agree nor Disagree' to statement 5 'The Newborn Screening Laboratory effectively communicates any changes to guidelines & policies'. Any changes to local laboratory policies are communicated to users in a memo via the Quality Assurance team, but it is difficult to assess how well this information is cascaded down to all users of the service. In future, in addition to sending out a memo, changes to lab policies/procedures will be uploaded to the Manchester Newborn Screening Laboratory website which will be available for all users to access.

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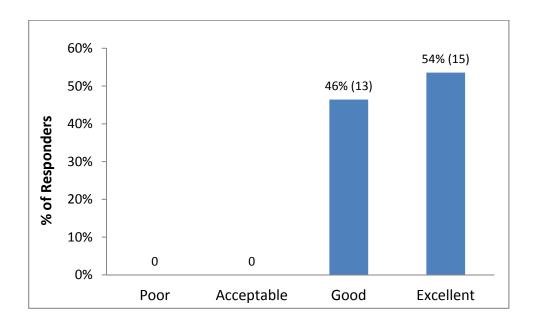
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	N/A
Enquires are resolved in a timely manner by laboratory staff	4% (1)	7% (2)	0%	39% (11)	50% (14)	0%
Staff are friendly and helpful	4% (1)	0%	4% (1)	32% (9)	61% (17)	0%
I am satisfied with the quality of professional advice that I receive from the laboratory	4% (1)	0%	4% (1)	36% (10)	57% (16)	0%
Any actions required following a positive Newborn Screening result are communicated clearly and promptly	4% (1)	0%	7% (2)	29% (8)	57% (16)	4% (1)
Reasons for repeat sample requests are clear	4% (1)	7% (2)	0%	21% (6)	64% (18)	4% (1)
The Newborn Screening Laboratory effectively communicates any changes to guidelines & policies	4% (1)	0%	32% (9)	18% (5)	46% (13)	0%



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Question 3

Users were asked to rate the service provided by the Newborn Screening Laboratory. 100% of users rated the service as 'Good' or 'Excellent'.



Question 4

The Manchester Newborn Screening Laboratory has launched its website in 2017. http://www.cmft.nhs.uk/info-for-health-professionals/laboratory-medicine/newborn-screening

Users were asked what information they would like to see included on the site. 20 users responded to this question. The responses have been grouped into themes below. For the full list of comments see Appendix 2.

- 1) Contact names and numbers, template of correspondence
 - This is now available on the site
- 2) Information about tests done at the lab/screening pathways for each disorder and actions required for positive results
 - Information regarding each of the conditions screened for and links to the national website are available
- 3) Time scale for screening results/how long it takes to process a test
 - This will be added by April 2017
- 4) Sample requirements/criteria for an acceptable sample & examples of good practice
 - The site contains links to the Continuing Professional Development for Screening website which contains videos & tips for collecting good quality blood spot samples
- 5) A list of result codes with definitions

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- This will be added by April 2017
- 6) Results received and pending by area
 - This information is available on the national Failsafe System.
- 7) Information about delays in uploading to failsafe system
 - This information is communicated to CHRD via email. If there are significant delays of >2 working days then a memo is issued to CHRD & the QA team. Unfortunately delays in reporting cannot be communicated via the website as we do not have direct access to the site to allow changes on a daily basis.
- 8) Quarterly figures/Avoidable repeat rates/Key Performance Indicators
 - These are now included on the site
- 9) Any new information/changes to screening guidelines, links to relevant leaflets for parents Links to the national screening website and to patient leaflets can be found under 'Tests
 - and technology'.
- 10) Frequently asked questions
 - This is not yet available but will hopefully be developed in the future
- 11) Available training programmes/lab visits/links to e-learning for screening conditions
 - As mentioned above the website contains links to the training videos on how to collect a good quality blood spot sample. Information will be added to the site on how to go about organising lab visits.

Question 5

Users were also provided with an opportunity to leave any additional comments. These were as follows:

Do you have any other comments, questions or concerns?

- 1. I have a full time case load and am happy to do repeat blood sampling and give results when needed (as directed by Manchester labs or child health with removal in clients under one year in the area). I do not want to be responsible for searching out new clients with the fail safe system.
 - The Failsafe System is not run by the laboratory, and the laboratory will only ask for repeat samples via letter. Any concerns regarding the failsafe are best forwarded to the QA team
- 2. Overall no problems or concerns regarding communication with the lab. Only thing I have to mention is that I am being asked to complete avoidable repeat samples where this should be directed towards midwives not screening link Health Visitors. Thanks
 - Currently Health Visitors are asked to collect repeat samples for cystic fibrosis following an initial contaminated card which is classed as an avoidable repeat. A meeting has been

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planned to discuss who should collect these repeat samples and any changes to the policy will be communicated to users.

- 3. The service provided by the team is excellent. Professional, friendly, efficient with superb communication channels. The quarterly quality assurance multidisciplinary meetings are good governance.
- 4. Staff answering the phones are not always knowledgeable and do not check information with seniors. Senior staff are excellent.
 - This feedback will be discussed at the next laboratory staff meeting. All of our admin team are currently undergoing competency assessments and are trained to pass all queries they are not confident in answering to a senior member of staff.

3. Conclusions

Overall the feedback from the User Survey was very positive, and although it would have been useful to receive feedback from more users, the feedback we did receive was across a variety of staff groups.

The new Manchester Newborn Screening Laboratory website is now available and will hopefully help to improve our communication with users and provide answers to many common queries.

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4. Appendix 1

. To which staff group						
	do vou belor	ng?				
/ WIGWIIC	,	.5.				
Health Visitor						
Member of staff from a	a Child Health Re	cords Departme	nt			
Paediatrician/Nurse						
Other (please specify)						
. Please tell us whethe	r vou agree oi	disagree with	the following sta	tements		
Please select N/A if the	_	_	_			
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	N/A
Enquiries are resolved in a timely manner by laboratory staff	0	0	0	0	0	0
Staff are friendly and helpful	0	0	0	0	0	0
I am satisfied with the quality of professional advice that I receive from the laboratory	0	0	0	0	0	0
Any actions required following a positive newborn screening result are communicated clearly and promptly	0	0	0	0	0	0
Reasons for repeat sample requests are clear	0	0	0	0	0	0
The Newborn Screening Laboratory effectively communicates any changes to guidelines & policies	0	0	0	0	0	0
. Overall, how would y						
_		Acceptable	G	ood	Excell	ent
Poor						

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5. Appendix 2

Full list of answers to Question 3

The Manchester Newborn Screening Laboratory will be launching its website in 2017. What information would you like to see included on the site?

- Changes to guidelines Information about delays in uploading to failsafe system
- Current updates also a list of codes with definition
- Best practice maintained.
- data for each quarter and questions to be answered
- Time scale for screening results
- If I have any queries to have access to the one of the staff in the department during working hours.
- Any new information/changes to screening, links to relevant leaflets for parents
- Clear pathways re results and actions required
- not sure I only deal with results for entering into Electronic patient records
- frequently asked questions
- any current changes, contact names and numbers, template of correspondence
- Good practice. Frequently asked questions. Key performance indicators
- Positive result pathway Acceptable samples Recent reasons for avoidable repeats
- Straight to the point factual information, contact details, pathways
- Results received and pending by area.
- Who to contact directly with any queries. Information about tests done at the lab and how long it takes to process the tests.
- individual stats reports
- quarterly/annual reports training programmes/relevant events eg lab visit days
- Contact details Changes to practice Local statistics
- Full contact details, Links to e learning around conditions, links to leaflets on results at NHS.uk
- leaflets