

Results of Molecular Genetics Laboratory User Satisfaction Survey Report 2009

Noonan syndrome

18/25 responses were received, higher than for any previous user survey. Questionnaires were sent to 25 random referring clinicians to enable a broader "picture" of the disease service to be assessed.

1) Reporting times

Reporting times rating - average 4.4/5

The laboratory is monitoring reporting times on a routine basis and is aiming to improve turnaround in light of proposed reporting time targets which are due for implementation in April 2010.

2) Reporting practice

All respondents thought the wording was "about right" and positive comments were received from 4 users commenting on clarity of reports. Therefore, no changes to the report format will be made at this time.

3) Screening stages

We asked users whether they would prefer the Noonan 3 stage screening to remain separate or as an all in one screen (bearing in mind cost implications of such a change). Additionally there continues to be considerable development work in adding further genes in to the mutation screening protocol as more are discovered and reported in the literature. In summary:

- 9 users (50%) preferred the service to remain as separate stages.
- 8 users (45%) would prefer an all-in-one approach and one commented that perhaps a combined stage 2&3 screen would be preferable, for those cases with a less defined phenotype would not have to have an all-in-one screen.
- 1 user did not state a preference but commented that we would be in a better position to judge how based on results obtained in the past.

It has therefore been decided that no changes to the service will be made at this time. A review of Noonan syndrome will take place in June 2010 to discuss progress in integrating new genes and mutation analyses. At that time, any changes to the screening service which will be disseminated to users as appropriate.

4) Information

Most users were aware of the departmental website and none had any comments regarding it. The information regarding sample sending was rated at an average of 4.2/5 and the advice from staff rated as 4.5/5.

5) Overall quality of service

Users rated the service an average of 4.3/5 overall.

Conclusions

The Noonan service is expanding rapidly due to the ongoing discovery of related genes and mutations. As discussed above, no decision has been taken as of March 2010 regarding the separated screening stages but this will be decided in June 2010.

The Laboratory is grateful for the input of it's users in this survey and would like to thank all respondents.