Scottish Genetic Laboratory Consortium (SGLC) Major Review 2021 – Stakeholder Survey Results

2021-09

NSD conducted a survey to seek feedback from the clinical users of the SGLC in order to understand more clearly their experience of using the service that is currently provided. It is intended that the feedback will also help to influence the development of the delivery model strategy to address the future needs of users for the next five years.

The intention was for the user survey to reach a broad spectrum of clinical users. A link to the online survey was distributed to all the members of the groups comprising the consortium governance structure as set out below and the regional cancer networks, with an invitation to forward the link to others that may wish to add their feedback. NSD also specifically requested the heads of the consortium laboratories to distribute to their users.

Consortium Group's;

- Molecular Pathology Evaluation Panel
- Genetics Evaluation Panel
- Molecular Pathology Consortium Steering Group
- Genetics Consortium Steering Group
- Scottish Pharmacogenomics Working Group
- Genomics Laboratory Strategy Board

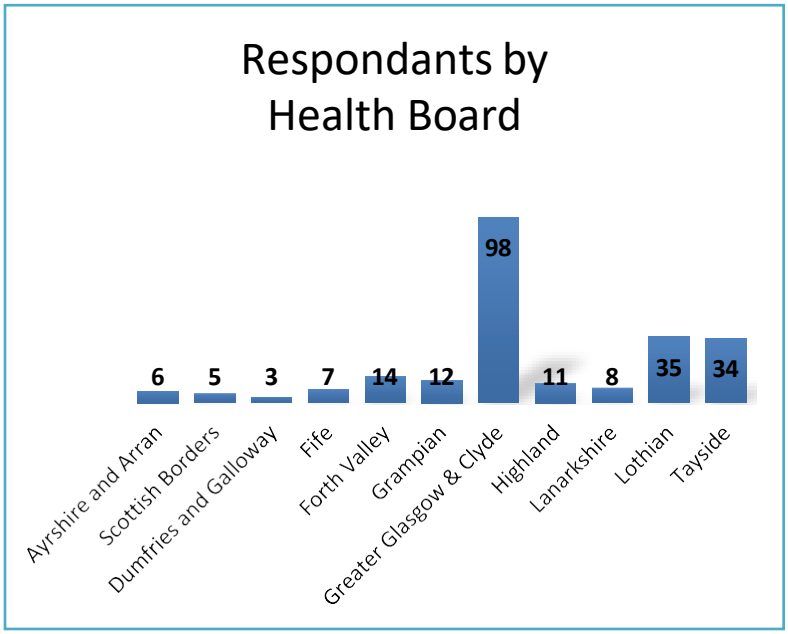
Survey Questions:

1. What is your clinical speciality?
2. Which Health Board do you work for?
3. In your opinion are you at present able to access an appropriate range of tests to support your clinical decision making and treatment planning?
4. Over the last year have you requested a test from a consortium laboratory (either rare disease / germline or cancer / somatic)? If so, approximately how many times?
5. Do you feel that the service that you are receiving is responsive? Are results available to you within the appropriate guideline specified reporting times?
6. Are laboratory reports clear and understandable?
7. Do you find that the laboratories are approachable and accessible where there is a need to seek technical guidance?
8. As a service user do you feel that you are involved in the decision making and able to influence changes within the laboratories that may affect the range of available tests or way in which the service is provided?
9. Are you aware of the Genetic Evaluation Panel / Molecular Pathology Evaluation Panel and their function?
10. Please provide any further comments or issues that you would wish the Review Group to consider.

The survey was live from 27th April 2021 to 28th May 2021. This report summarises user feedback acquired from the survey. It should be noted that not all respondents answered every question, consequently there is variance in the total number of answers for each question.

Questions 1. What is your clinical speciality?
Questions 2. Which Health Board do you work for?

The survey attracted 233 respondents from 38 clinical specialties and general practice from 11 of the 14 regional Health Boards. For the purposes of this report clinical / medical oncology and paediatric specialties have been grouped.

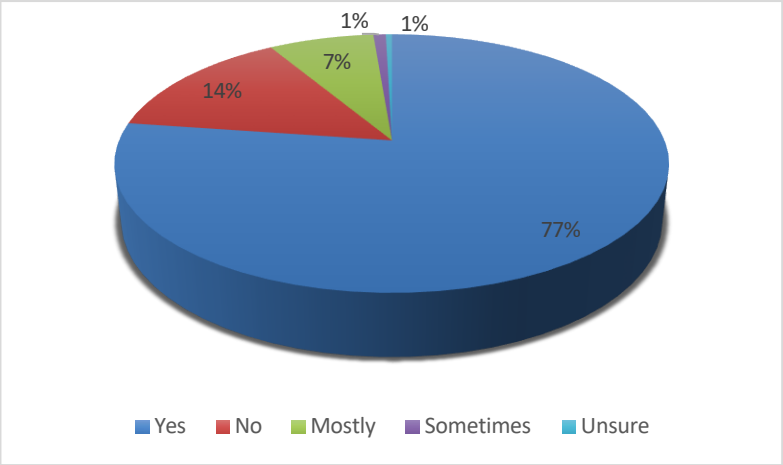


Most Frequent Respondents by Specialty	
Oncology (Clinical / Medical)	44
Paediatrics Specialties	26
Obstetrics and gynaecology	19
Pathology	19
Haematology	18
Clinical Genetics	10
General Practice	10

Question 3. In your opinion, are you at present able to access an appropriate range of tests to support your clinical decision making and treatment planning?

A large majority of respondents, 77% were of the opinion that they are currently able to access an appropriate range of tests to support clinical decision making and treatment selection

Responses	no.	%
Yes	180	77
No	33	14
Mostly	17	7
Sometimes	2	1
Unsure	1	0
Total	233	100

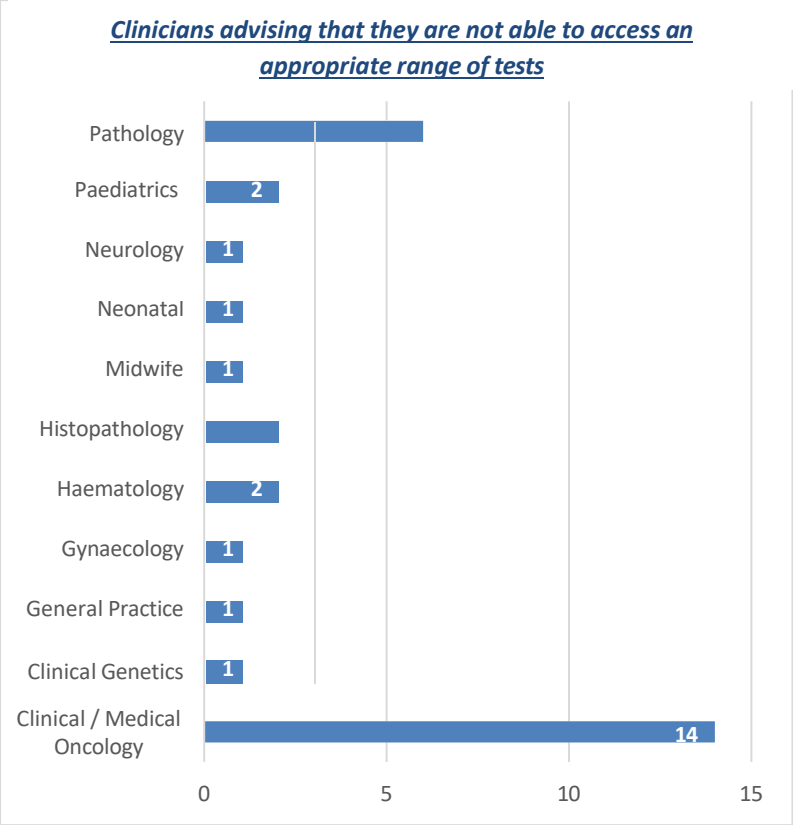


Although the majority of clinical users responded positively regarding the range of tests many were conscious of the need for further advancement;

☑ *Major advances in interpretation of whole genomes and in use of long-read sequencing and optical mapping are now making their way into clinical practice in other healthcare systems and it would be worthwhile thinking about these advances when planning lab genetics services in Scotland, since these will increase the usefulness of genetic/genomic testing for clinical decision making and treatment planning over and above clinical exomes.*

Of the 33 respondents who considered that they do not have access to a sufficient range of tests to support their clinical practice the most dissatisfied group of clinicians were Clinical / Medical Oncologists and Pathologists.

Clinical / Medical Oncology	14
Clinical Genetics	1
General Practice	1
Gynaecology	1
Haematology	2
Histopathology	3
Midwife	1
Neonatal	1
Neurology	1
Paediatrics	2
Pathology	6
Total	33



This feedback is mainly in relation to the range of tests available for somatic cancer and comparison is frequently drawn to testing that is available as standard care in other parts of the UK. Selected comments from clinical users who do not think that they have access to an appropriate range of tests from the SGLC;

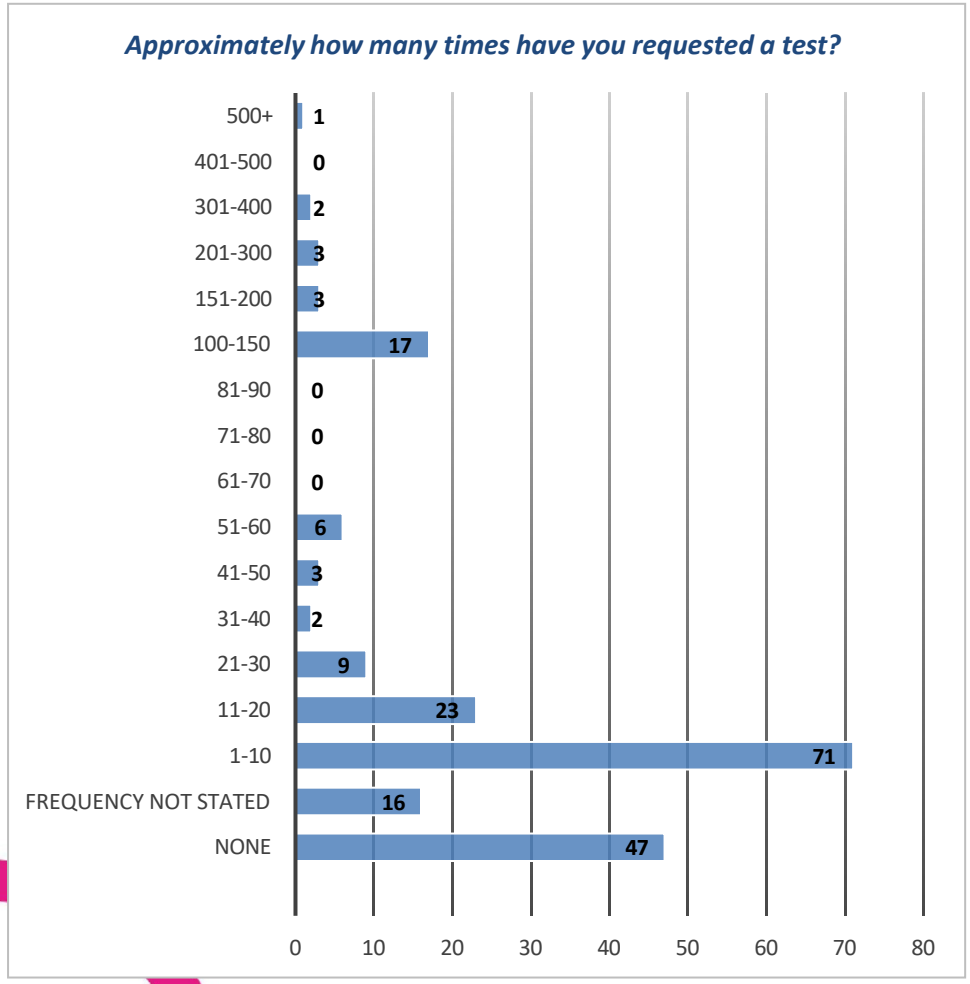
- ☒ *Insufficient access to a comprehensive range of results which might inform management compared to elsewhere in the UK.*

- ☒ *The genomic labs are extremely helpful, hardworking and are aspiring to provide the high quality genomics that Scotland needs but major investment and joined up strategy with engagement of the oncology community is required*.

- ☒ *Eventually - but it's like pulling teeth as we have to ask for MSI, DPD specifically and separately. The service is very disappointing; Scotland feels like we are in the dark ages compared to England*

- ☒ *No definitely not. we significantly lag behind England. HER2 still going to London for OG. MSI testing in colon is still not properly funded for all age groups…… In terms of excelling and pushing the boat out the GLHs are now doing DNA-RNA extractions and panel based testing and it feels we are miles off this. It's now effecting our ability to open clinical trials as the testing we offer is so basic.*

Question 4. Over the last year have you requested a test from a consortium laboratory (either rare disease / germline or cancer / somatic)? If so, approximately how many times?



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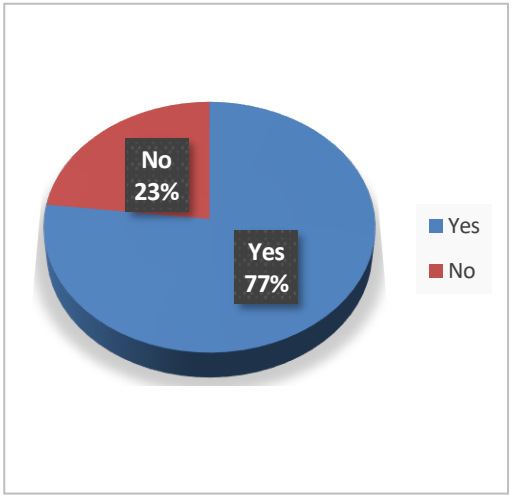
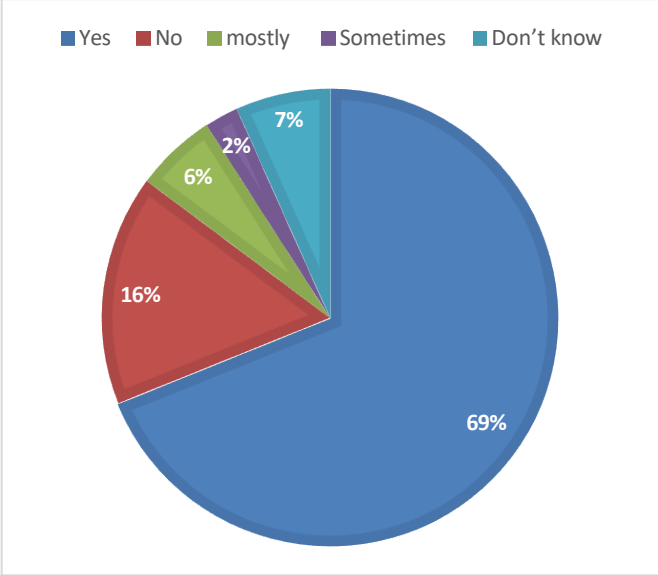


Yes	156
No	47
Total	203

Specialties requesting in excess of 100 tests p.a.
Clinical Genetics
Clinical / Medical Oncology
General Pathology
Haematology
Histopathology
Neuropathology
Paediatric and Perinatal Pathology
Pathology
Respiratory Medicine

Question 5. Do you feel that the service that you are receiving is responsive? Are results available to you within the appropriate guideline specified reporting times?

Yes	144	69
No	34	16
mostly	12	6
Sometimes	5	2
Don't know	14	7
Total	209	100



Clinical Specialists advising the service is not meeting guideline turnaround times*	
Breast Specialist /Surgery	2
Chemical Pathology	1
Clinical / Medical Oncology	12
Paediatrics Specialties	7
Gynaecology	1
Haematology	2
Hepatology	1
Histopathology	2
Neuopathology	1
Pathology	2
Respiratory Medicine	2
Surgeon	1
Total	34

**For reference SGLC Turnaround Times (TAT) data form across Laboratory sites for 2019/20 set out in Appendix 1*

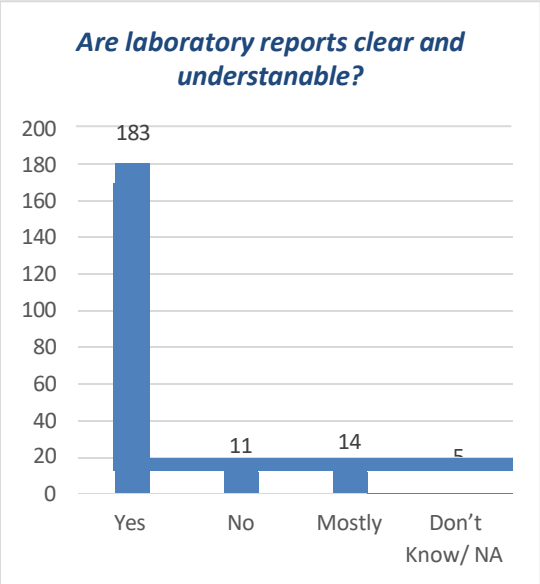
The Majority of those surveyed were satisfied with the responsiveness of the service and very complementary of the attentiveness of laboratory staff;

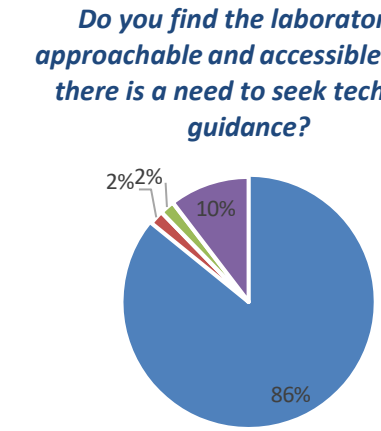
- ☑ *Advice is above and beyond what I could have hoped for…… They do a great job of explaining highly technical issues to clinicians and incorporating clinical question/discussion into interpretation of genetic results.*
- ☑ *Yes, without a doubt the service that we receive ……. is excellent and the staff are always very willing to answer questions, share information and help in any way that is required. I am never made to feel silly for asking questions ..... the staff are always very willing to educate myself and any members of staff working with me.*

Dissatisfaction with the responsiveness of the service was mainly related to turnaround times (TAT) with 20 respondents noting that results were slow or that reporting times were beyond those set out in clinical guideline.

8 references were made to incompatibility of electronic requesting / reporting software and inconvenience associated with this in accessing test results. Also, where results are emailed to individual requesting clinician there is no resilience during periods of staff absence, causing further delay in chasing patient results.

Question 6. Are laboratory reports clear and understandable?
Question 7. Do you find that the laboratories are approachable and accessible where there is a need to seek technical guidance?

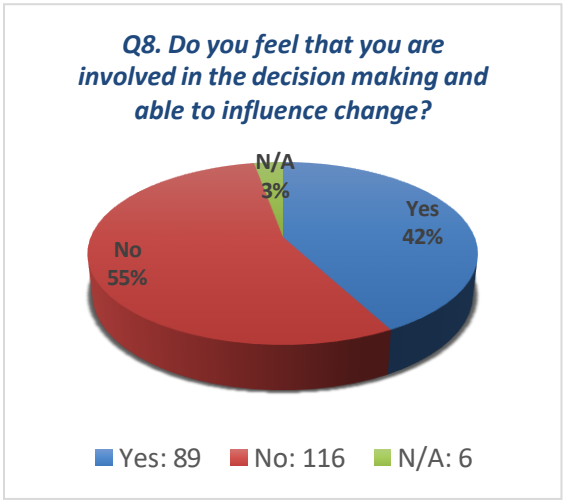




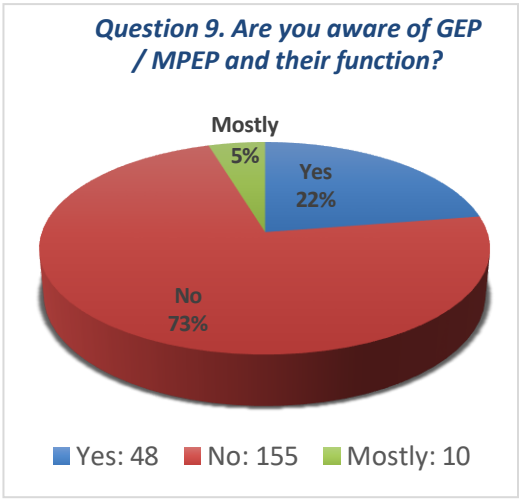
Yes	No	Mostly	Don't Know/ NA
182	4	4	22

11 of those surveyed found lab reports difficult to understand noting the use of complex, technical language and 'Jargon'. However, the majority went on to note that the labs were very responsive and helpful when assistance in interpretation was requested.

Question 8. As a service user do you feel that you are involved in the decision making and able to influence changes within the laboratories that may affect the range of available tests or way in which the service is provided?



Question 9. Are you aware of the Genetic Evaluation Panel Group (GEP) / Molecular Pathology Evaluation Panel (MPEP) and their function?



There was a correlation of results for survey questions 8 and 9. This is reflected in the comments, whereby clinicians felt more involved at a local level though engagement with the local lab but were unaware of the route to raise proposals for new services / service improvement at a national level through MPEP and GEP.

Question 10. Please provide any further comments or issues that you would wish the Review Group to consider.

There were 77 additional comments made, 22 of which were complementary of the service being provided. Key themes around suggestions for service improvement included;

- ☆ Electronic requesting / reporting and integration with local software systems / patient care record. Some highlighted concerns where results are emailed to a single clinician and delay caused in obtaining results associated with staff absence
- ☆ Calls for sustained investment in service improvement in particular NGS for personalised / precision care for cancer patients
- ☆ References negatively comparing inequity of services in Scotland to the standard testing available across the rest of the UK and the need to bridge the gap
- ☆ Greater integration with other laboratory services (e.g. histopathology, IHC, cellular pathology) and more collaborative working on testing pathways.
- ☆ Greater interaction with the clinical specialties including education events / information sessions user groups