Cardiothoracic Transplant Routine Bloods Working Group

Final Report and Recommendations

1. Recommendations

1.1 All recommendations are included in the main body of the report at the point with which they derive from the evidence presented. However, for ease of reference they are summarised in this section.

1.2 The recommendations have been distinguished between those which should be delivered at a national / CTAG level (prefixed with a C) and those which need to be delivered by the individual transplant services (prefixed with a L). For reading ease each recommendation also includes the "report reference", this is the location within the document where each recommendation appears.

1.3 Each recommendation also has an indication of the timescale in which delivery should be achieved.

1.4 The following recommendation is a key strategic aim which neither the CTAGs or transplant service providers have the authority or ability to implement. This authority lies with each nation's commissioners of health services.

Recommendation (Report Reference 4.14)	
C1	**The CTAGs write to Commissioners outlining the long-term need for a national pathology requesting and reporting system.**
Long	**Full delivery is likely to take more than one year**

1.5 The following recommendations are critical safety issues. Without full implementation the safety of patients cannot be assured. These are key issues that could get audited by regulatory bodies such as the Care Quality Commission.

Recommendation (Report Reference 4.14)	
C2	**The CTAGs develop a generic shared monitoring document / agreement between prescribing transplant centres and GPs with the ability to amend depending on the clinical needs of individual patients. Dr Courtenay has drafted a version (See Appendix 16)**
Medium	**Should be able to be delivered within 6 months**

Recommendation (Report Reference 4.14)	
L5	**When developed this shared monitoring document / agreement must be initiated for all new patients and where a patient changes GP Practice or transplant centre**
Medium	**Should be able to be delivered within 6 months**

Recommendation (Report Reference 5.8)	
L10	**All transplant centres must have processes in place to ensure patients are having routine blood tests in line with clinical need. The**

	processes must be subject to regular audit and refinement to ensure effectiveness.
Medium	**Should be able to be delivered within 6 months**
Recommendation (Report Reference 3.6)	
L2	**All transplant centres must ensure all blood samples posted by patients are compliant with UN3373**
Short	**Should be delivered within 1 month**

1.6 The following recommendations are essential to eradicate avoidable patient discrimination.

Recommendation (Report Reference 3.7)	
L3	**All transplant centres must ensure all patients are supplied with pre-paid postage for the transit of blood samples**
Short	**Should be delivered within 1 month**

Recommendation (Report Reference 4.4)	
L4	**All transplant centres must ensure appropriate arrangements / agreements are in place to enable patients to undertake their routine blood tests close to home. All transplant centres must organise an alternative local pathology requesting and phlebotomy service if the patient's GP practice decline to take on the role. This could mean the commissioning of a private service.**
Medium	**Should be able to be delivered within 6 months**

1.7 The following recommendations are all aimed at improving either the efficiency of the current processes or the patient experience.

Recommendation (Report Reference 3.5)	
L1	**All transplant centres should explore the potential to implement finger prick testing of immunosuppressant levels for appropriate patients (contact Brain Keevil, Consultant Biochemist, Manchester (brian.keevil@mft.nhs.uk))**
Medium	**Should be able to be delivered within 6 months**

Recommendation (Report Reference 4.22)	
L6	**All transplant centres who do not have GP Connect contact their IT Depts and request they commence discussions with their patient record systems provider to enable the GP Connect application to be added (central GP Connect Contact (gpconnect@nhs.net). Transplant centres should utilise GP Connect when the service is available**
Medium	**Should be able to be delivered within 6 months**

Recommendation (Report Reference 4.22)	
L7	**All transplant centres should actively use their local Shared Care Record**
Short	**Should be delivered within 1 month**

Recommendation (Report Reference 4.22)

C3	**CTAGs should receive an assessment of the potential benefits of remote Shared Care Record access from Birmingham and Papworth on completion of their pilot**
Medium	**Should be able to be delivered within 6 months**

Recommendation (Report Reference 4.22)	
L8	**All transplant centres should disseminate to all relevant staff information on NHS Service Finder (NHS Service Finder - NHS Digital)**
Short	**Should be delivered within 1 month**

Recommendation (Report Reference 4.22)	
L9	**All transplant centres should feedback results to patients regardless of whether any changes are required**
Medium	**Should be able to be delivered within 6 months**

1.8 Recommendations L10, L2, L3 and L9 are the only ones applicable to patients who reside in Scotland and are under the care of Glasgow. This is due to Scotland having different GP contracts and arrangements for immunosuppressant prescribing. Scottish patients, commissioners, and the transplant centre all report satisfaction with their current arrangements.

1.9 If CTAGs or transplant centres require advice or support with implementing the recommendations then please contact either Robbie Burns (robertwburns@tiscali.co.uk), CTPG Chair or Dr Tamsin Courtenay (tcourtenay@doctors.org.uk) Retired GP and GP Federation Medical Director.

2. Background

2.1 Following concerns widely raised by the cardiothoracic transplant patient community the June 2022 Cardiothoracic Transplant Patient Group (CTPG) agreed to establish a working group to review current practices, share best practice, and scope potential improvements.

2.2 The working group would have wide ranging membership and be led by the CTPG Chair. The final report and recommendations would be presented to the Cardiothoracic Transplant Advisory Groups for both Heart and Lung Transplant (CTAGs). The agreed Terms of Reference and membership is shown in Appendix 1.

2.3 To assist the thinking of the working group an information gathering exercise was conducted which consisted of a patient survey and each centre completing a stocktake of their current processes. These are shown in Appendices 2-10

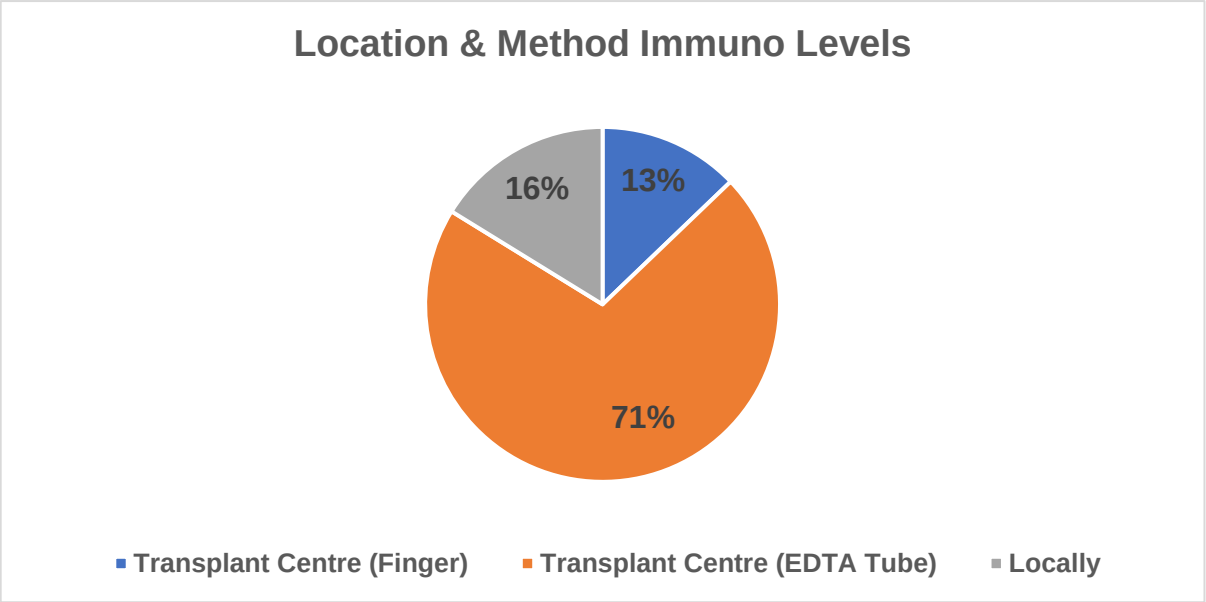
2.4 The working group held four meetings, with the first three meetings covering specific elements of the clinical pathway and the final meeting agreeing the recommendations. The minutes of each meeting are shown in Appendices 11-14

2.5 Relevant feedback from both the patient survey and process stocktakes were considered alongside the appropriate element of the clinical pathway.

2.6 This report will be a summary, split by the stages of the clinical pathway and outline the key evidence considered and recommendations made.

3. Tests for Immunosuppressant Levels

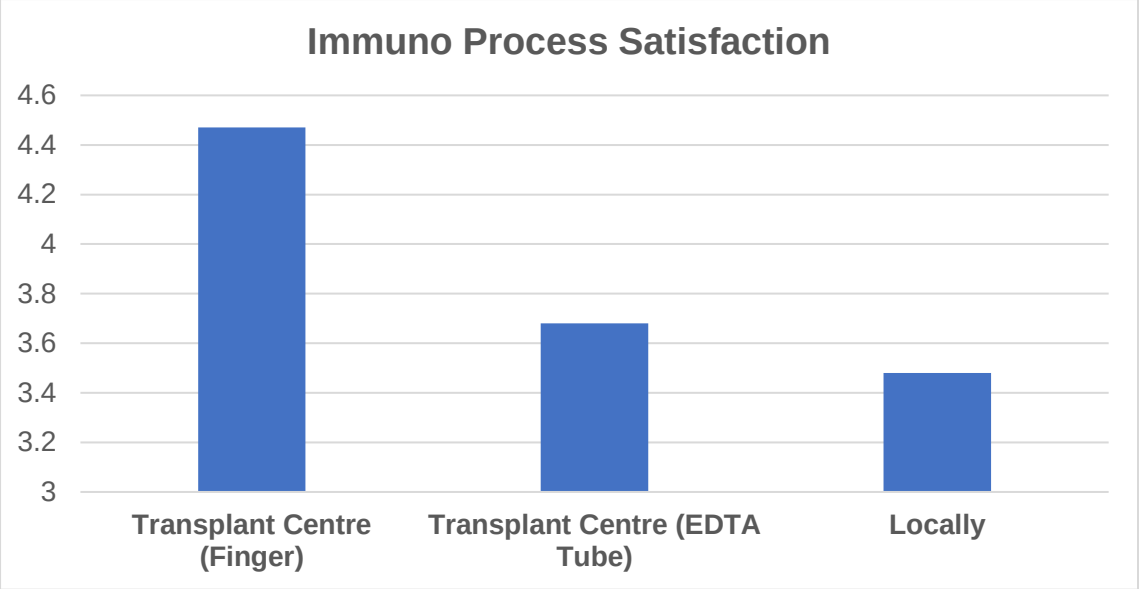
3.1 The results from the patient survey highlighted that most (84%) patients send a blood sample to their transplant centre for testing of immunosuppressant levels.



3.2 Dr Brian Keevil, Consultant Biochemist from Manchester, gave a presentation on the development and utilisation of fingerprick capillary samples for testing immunosuppressant levels. The presentation can be seen in Appendix 15

3.3 Dr Keevil demonstrated that the tests were reliable and received high levels of patient satisfaction.

3.4 Very high satisfaction with this methodology was also reported in the patient survey



3.5 The finger prick methodology is currently used by some patients at Harefield and Manchester

Recommendation	
L1	**All transplant centres should explore the potential to implement finger prick testing of immunosuppressant levels for appropriate patients (contact Brain Keevil, Consultant Biochemist, Manchester (brian.keevil@mft.nhs.uk))**
Medium	**Should be able to be delivered within 6 months**

3.6 It was noted that not all centres were currently compliant with regulation UN3373 (Transporting infectious substances - GOV.UK (www.gov.uk)) regarding the posting of blood samples.

Recommendation	
L2	**All transplant centres must ensure all blood samples posted by patients are compliant with UN3373**
Short	**Should be delivered within 1 month**

3.7 In the survey many patients expressed concern and dissatisfaction where they are expected to pay for the sample transit. Postage is prepaid by many centres but not all, this is an area of inequity that could lead to widening health inequalities.

"The cost of sending the bloods to the transplant hospital is extremely expensive, £6.60 for signed for delivery. It would be nice if this was supplemented in some way. Occasionally I have had to have bloods sent 2-3 times a month and financially this is difficult."

"I don't mind posting my bloods through to the transplant clinic, but it does cost me quite a lot in postage"

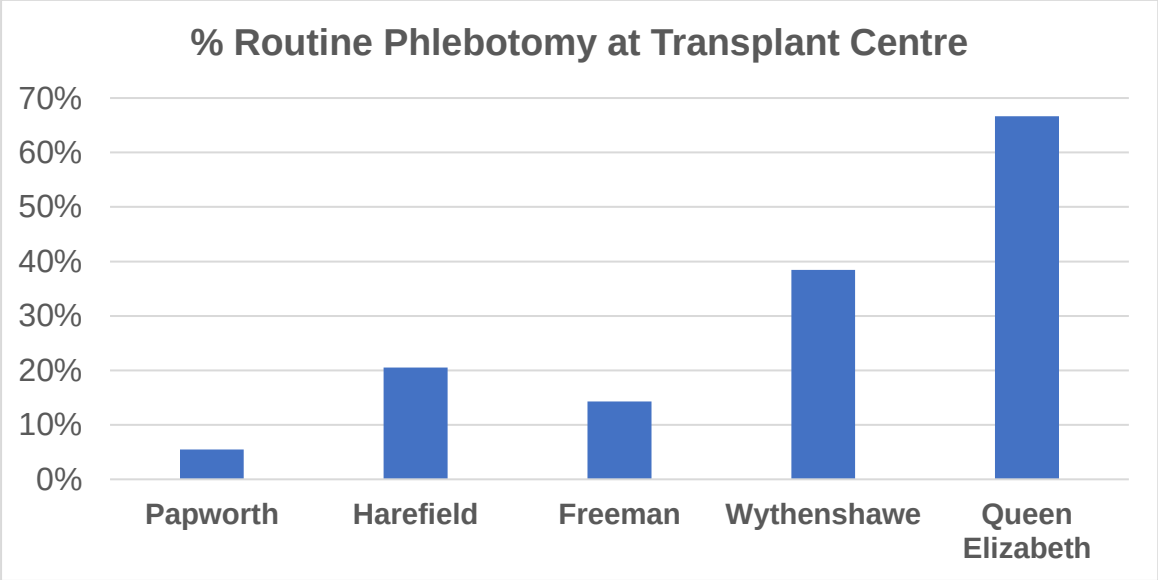
"Then getting to post office can be difficult, especially when I was shielding! and costs me £7-8 each time which isn't refunded, more if it's a weekend"

Recommendation	
L3	**All transplant centres must ensure all patients are supplied with pre-paid postage for the transit of blood samples**
Short	**Should be delivered within 1 month**

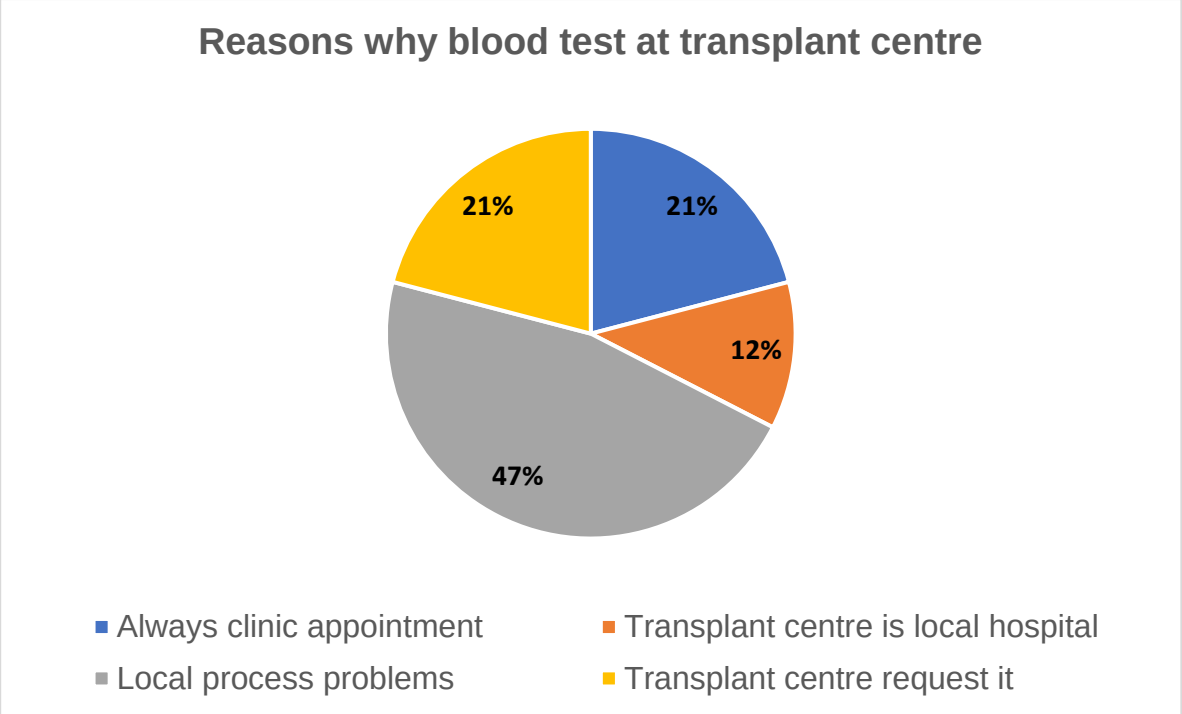
4. Other Bloods Tests (e.g. FBC and U & Es)

4.1 In the patient survey most patients (77%) reported that they had their routine blood tests taken locally. However, 23% of patients reported that they always had all their blood tests at the transplant centre.

4.2 The proportion of patients having their routine phlebotomy at their transplant centre varied considerably across the centres.



4.3 This specific group of patients were asked why they had their blood taken at the transplant centre. As can be seen below 1/3 of patients reported that either the transplant centre is their local hospital, or the phlebotomy is always associated with a clinic appointment.



4.4 However, in 2/3 of the cases, these blood tests are not being undertaken in a location that is most convenient for the patient. Many patients are reporting regular long trips for bloods tests, sometimes over 200 miles. This group of patients express dissatisfaction with this arrangement.

"I would really like to be able to have my blood taken locally and avoid a 4-hour return journey (in good traffic) for a 10-minute blood test appointment"

"Would be easier to go to local hospital as it is a long drive and time off work for such a small procedure "

"It would be much easier if any blood tests required outside of clinic appointments could be done at a local hospital. This would mean me not having to make a 3 hour round trip on the M6 for a 10-minute visit"

Recommendation(s)	
L4	**All transplant centres must ensure appropriate arrangements / agreements are in place to enable patients to undertake their routine blood tests close to home. All transplant centres must organise an alternative local pathology requesting and phlebotomy service if the patient's GP practice decline to take on the role. This could mean the commissioning of a private service.**
Medium	**Should be able to be delivered within 6 months**

4.5 The clinical process of other routine blood tests has three key stages, raising the blood test request, booking the blood test in line with clinical requirements and the transmission of results back to the transplant clinician.

4.6 Patients report extensive challenges with all stages of the pathway

“My GP decided they would no longer do 'hospital bloods' and directed me to a local NHS medical centre, and that centre then decided they would only do bloods for local hospitals, so it was back to the GP for me”

“I am constantly having to ask for a blood test form, explaining what I want everytime. Sometimes it's difficult to get through to GP surgery”

“Getting an appointment for bloods at GP surgery becomes more difficult. Often several weeks ahead”

“The process of taking bloods and returning bloods to the transplant centre relies to heavily on the good will of the GP staff”

“I do a lot of chasing of bloods and also take full responsibility for making sure bloods are done and chased up quickly. I feel like I have to be really on the ball”

“I have been told by my GP,s practice Manager, that if I ask them nicely they will pass on my results to the transplant centre!”

“Our hospital never shares results with Papworth despite being requested to on the blood request form every time. Not only do they not share the results they have never bothered to alert us to the fact that they will not share them”

4.7 All transplant centres also report similar challenges with the process – see Appendices 3-10 Section 9.

4.8 NHS England Primary Care Team and The General Practice Committees of England and Wales confirmed that GPs are under no contractual obligation to raise blood test requests for secondary care requirements.

4.9 Phlebotomy services are not part of the core GP contract in England or Wales. Phlebotomy is commissioned differently throughout the country and the associated Integrated Care Systems need to be contacted for local arrangements.

4.10 Other highly specialist (HSS) and specialist services report similar challenges, with a known example of one HSS provider considering establishing contractual arrangements with a private provider.

4.11 The working group agreed that the ideal solution is for transplant centres to have the capability to raise the blood test request, the patient to be able to receive phlebotomy at a convenient provider and for the analysing laboratory to send the results electronically back to the clinician who raised the request.

4.12 The working group acknowledged this solution would be difficult to achieve due to organisational and IT fragmentation in the NHS. Notwithstanding this, the need to deliver a national pathology requesting and results reporting service is essential to ensure patient safety and compliance with the statuary requirement to deliver integrated services under the NHS Act 2006 (HSCA, s13N and s23).

4.13 The Working Group Chair has liaised with NHS Digital who are aware of the clinical need but do not believe it is a current active workstream.

4.14 The working group discussed a fictional clinical scenario presented by Dr Courtenay (wife of patient, retired GP and GP Federation Medical Director). The working group agreed that clinical responsibility (in the eyes of the General Medical Council) will lay with the clinician who raised the pathology request. This view differed to that outlined by some of the transplant centres in Question 3 of the stocktake of their current processes (See Appendix 3-10).

4.15 All members of the working group agreed that production of a shared monitoring document / agreement was essential to clarify this issue and ensure patient safety. It should be noted for paediatric patients the shared monitoring may be with a local paediatrician rather than GP.

Recommendation	
C1	**The CTAGs write to Commissioners outlining the long-term need for a national pathology requesting and reporting system.**
Long	**Full delivery is likely to take more than one year**

Recommendation	
C2	**The CTAGs develop a generic shared monitoring document / agreement between prescribing transplant centres and GPs with the ability to amend depending on the clinical needs of individual patients. Dr Courtenay has drafted a version (See Appendix 16)**
Medium	**Should be able to be delivered within 6 months**

Recommendation	
L5	**When developed this shared monitoring document / agreement must be initiated for all new patients and where a patient changes GP Practice or transplant centre**
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4.16 Patients and transplant centres both reported extensive challenges with obtaining blood test results from tests conducted local to the patient.

4.17 The Working Group Chair investigated in detail the potential different tools to assist in the retrieval of local blood results (See Appendix 17)

4.18 Monika Krupa, Senior transplant nurse, Papworth, presented the Trust's use of GP Connect and the significant time benefits it is providing their teams with the retrieval of results. (See Appendix 18). Sheffield also reported similar benefits. GP Connect is an England wide tool that enables access to sections of the patient's primary care record including blood test results requested by the GP.

4.19 Very few transplant centres were utilising their local Shared Care Record Systems (ShCR) to access the results of blood tests requested locally. The Newcastle Paediatric Team were doing so and finding benefits.

4.20 The working group discussed the potential benefits from obtaining access to remote ShCRs and agreed two pilots, Papworth to access CHIE (Hampshire, Dorset and IOW) ShCR and Birmingham to access the Welsh Clinical Portal.

4.21 A patient held electronic record was not currently considered to be an effective tool for retrieving local blood test results. This was because only one provider currently has the requisite untethered technology. This provider would require contractual agreements at both ends which would be unrealistic and expensive.

4.22 NHS Service finder is a useful free tool available to all NHS Staff in England. It will be beneficial to all staff who regularly call GP practices as it provides the "bypass" numbers (telephone numbers which are not accessible to the public) and may therefore reduce time in a GP practice telephone queue.

Recommendation	
L6	**All transplant centres who do not have GP Connect contact their IT Depts and request they commence discussions with their patient record systems provider to enable the GP Connect application to be added (central GP Connect Contact (gpconnect@nhs.net). Transplant centres should utilise GP Connect when the service is available**
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Recommendation	
L7	**All transplant centres should actively use their local Shared Care Record**
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Recommendation	
L8	**All transplant centres should disseminate to all relevant staff information on NHS Service Finder (NHS Service Finder - NHS Digital)**
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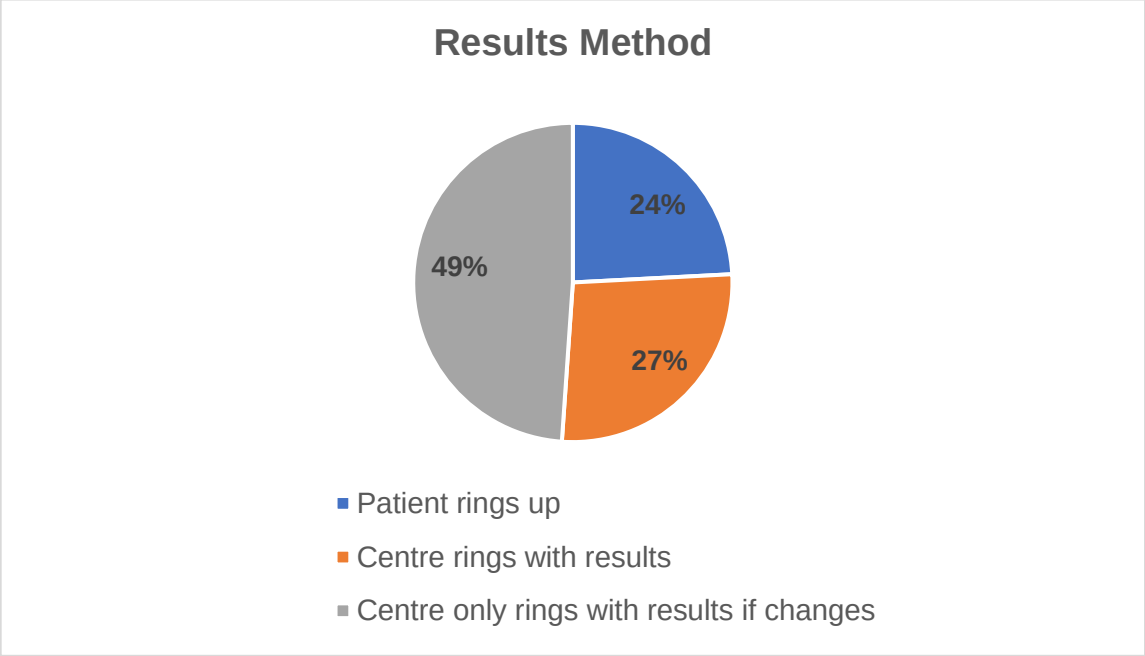
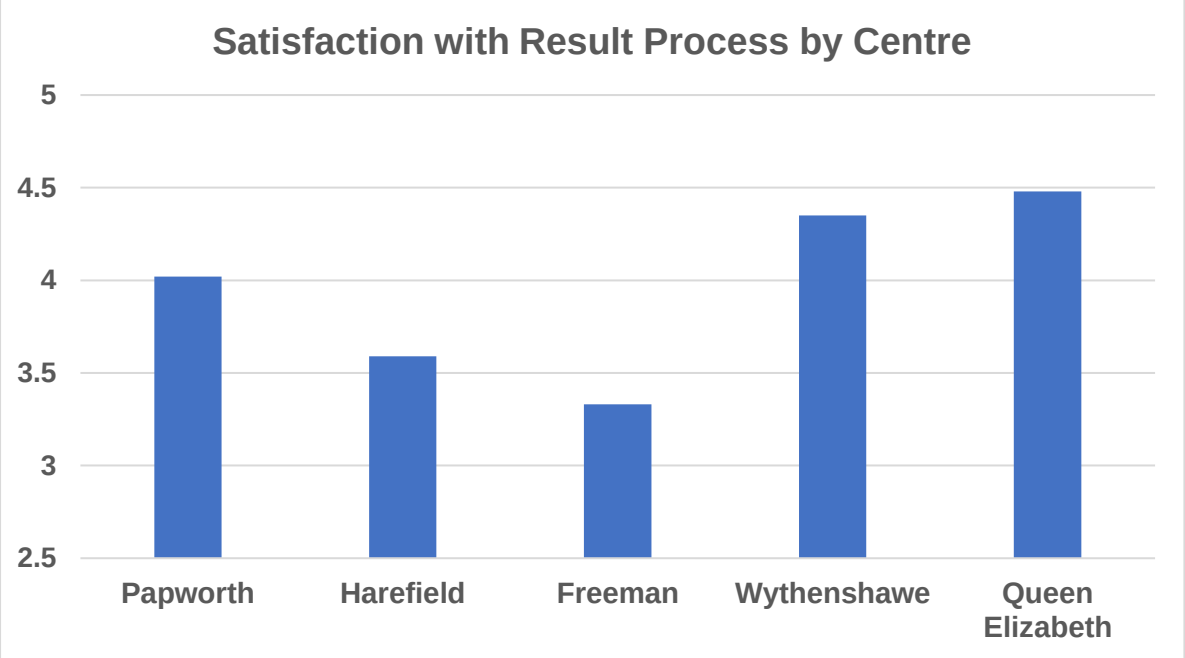
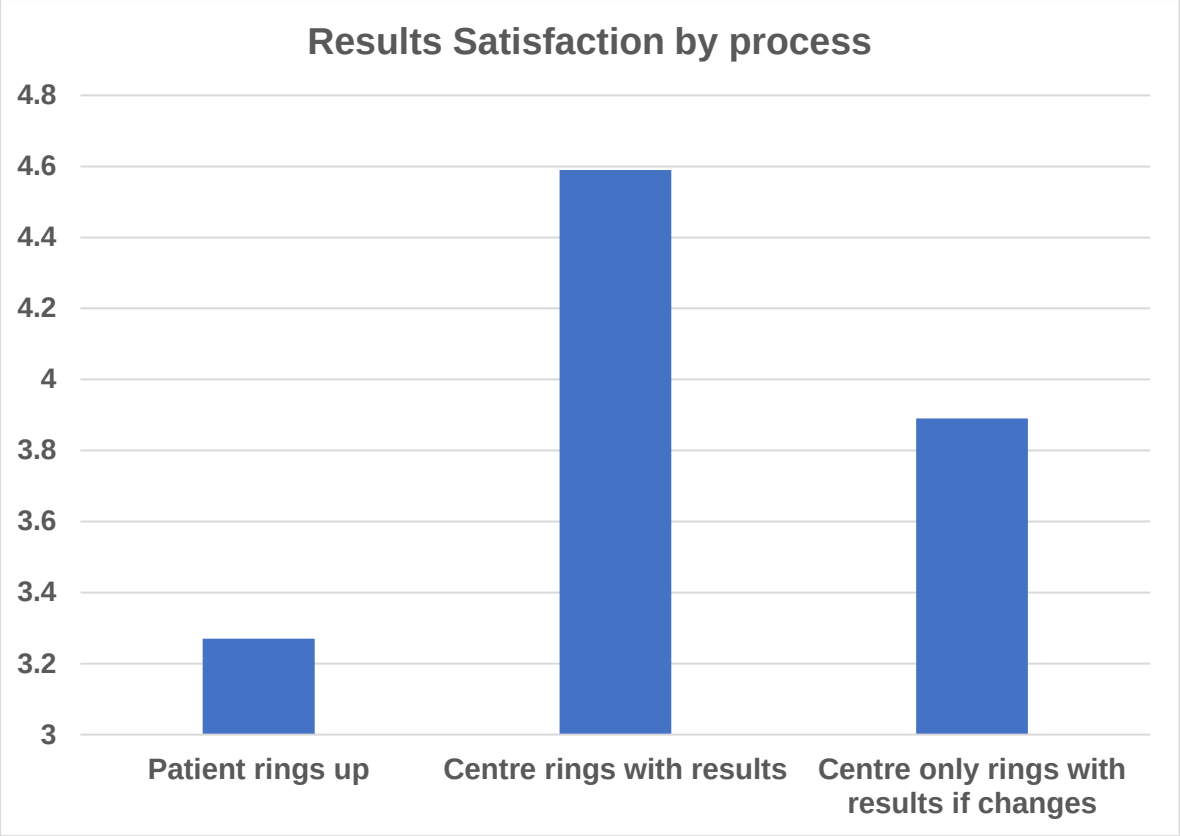
5 Results Reporting and Monitoring

5.5 The patient survey asked how patients were informed of the results of their routine bloods tests and their satisfaction with this process. The pie chart below shows the split of results reporting methodologies.



5.6 The following two charts show the patient satisfaction split by centre and by methodology





5.7 This highlights that positive feedback of results, even if no changes are required, has very high patient satisfaction rates. Conversely the patients ringing up for results report much lower levels of satisfaction. This experience is reflected extensively in the free text feedback.

"Patients should be informed of the results whether or not any changes are required. This is an important safety net to close the loop"

"I have never been informed of my results until I attend F2F clinic now being once a year"

"would be nice to be called with blood results, as we still want to know our levels even when medication isn't changed."

"To phone patient irrespective of results. In the past assumptions have been made about my bloods, that they are ok. When they were not. The ranges were wrong. For example my Kidney Function was getting worse. But not told"

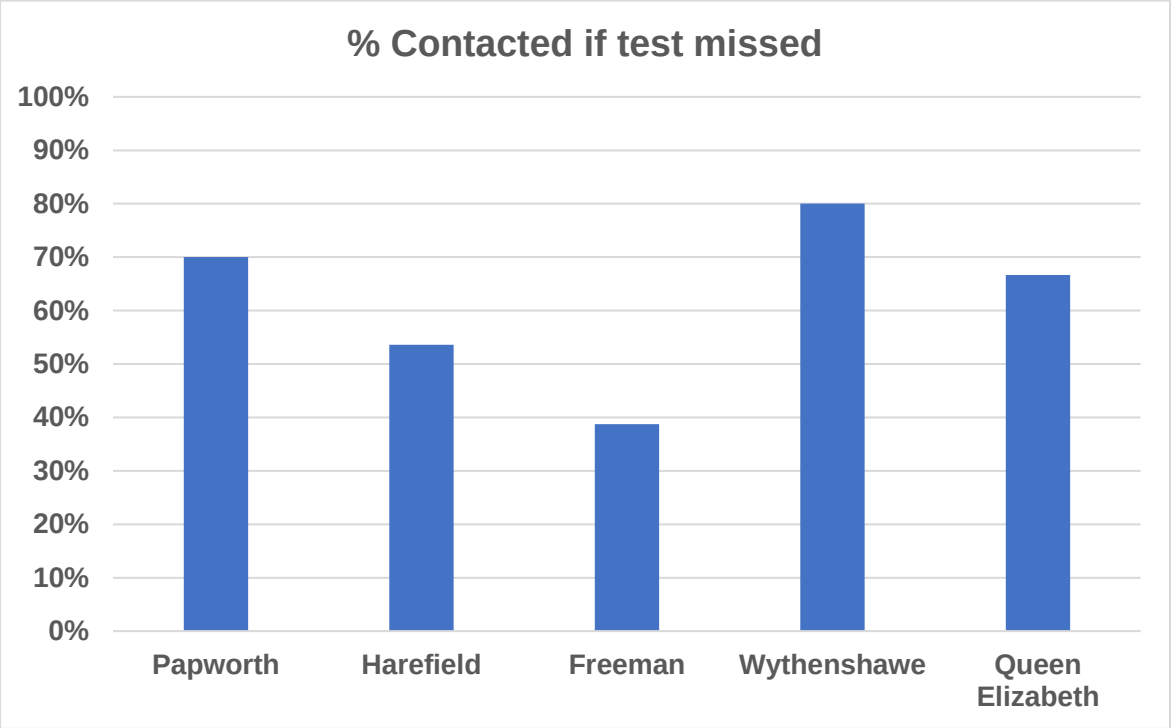
"A call regardless of change would be appreciated"

5.8 The working group agreed that from a safety, experience and engagement perspective results should be reported to patients even if no changes were required. The group recognised that this does not always mean a telephone call and other methods such as text, patient held electronic records and email could be just as effective.

Recommendation(s)	
L9	**All transplant centres should feedback results to patients regardless of whether any changes are required**
Medium	**Should be able to be delivered within 6 months**

5.9 A review of each centre's answer to Question 7 on the process stocktake returns revealed that each centre was employing a different system to ensure patients were undertaking blood tests in appropriate clinical timescales. Many centres also expressed concern over the effectiveness of their processes.

5.10 Patients were also asked what happens if they do not take a blood test in the time frame advised by the transplant centre. Approximately 60% of patients reported that they are contacted by their transplant centre, with the other 40% reporting that nothing happens. There is significant variation in this response by centre, as shown below



5.11 Terry Hewitt, Transplant Nurse, at the Paediatric Service in Newcastle, gave a presentation showing their processes undertaken to ensure patients have blood tests in line with clinical needs. Regular audit and continuous process improvements based on audit findings were demonstrated. The presentation is shown in Appendix 19.

5.12 The working group applauded the work and considered that all services must have similarly robust systems.

Recommendation(s)	
L10	**All transplant centres must have processes in place to ensure patients are having routine blood tests in line with clinical need. The processes must be subject to regular audit and refinement to ensure effectiveness.**
Medium	**Should be able to be delivered within 6 months**

6 Summary

6.5 The investigations undertaken by the working group have revealed inconsistent provision of services for routine blood tests post-transplant.

6.6 Overall patient satisfaction is moderate to poor with a significant proportion of patients finding processes complex, challenging and stressful.

6.7 Many patients take on personal responsibility and inequity based on education level / deprivation is inevitable.

6.8 Clinical risk has been observed at all stages of the process.

6.9 It should be noted many of the issues are significantly impacted by organisational and IT fragmentation within the NHS. Transplant centres, patients and local care providers are all trying to develop work arounds to combat these challenges. The vast majority of the recommendations would not be required if there was a national pathology requesting and reporting service.

6.10 The recommendations include many highly effective work arounds and sharing good practice between centres would bring immediate benefits both to patients and transplant centres (including cost efficiencies).

6.11 CTAGs are advised to approve all recommendations, and either include implementation within their workplans or devolve implementation to transplant centres.

Table of Appendices