**Routine Post Transplant Bloods - Patient Survey and Reaudit Findings**

**Introduction**

The recommendations of the Post Transplant Routine Bloods Working Group were accepted by all centres. To assess adherence / implementation of the findings the centres were asked to complete an audit proforma and a patient survey was undertaken.

Unfortunately, audit proformas have only been returned from 6 of the 9 transplant follow up services, Newcastle (adults), Manchester, Birmingham, Glasgow, Harefield and Papworth. Audit proformas were not returned from Newcastle Paeds, GOSH and Sheffield. The patient survey received 212 returns of which 210 related to the 6 services who returned their proformas.

This paper will only review the implementation of the recommendations for these 6 services.

**Patient Safety Recommendations**

1) **A shared monitoring document / agreement must be initiated for all new patients and where a patient changes GP Practice or transplant centre (England centres only)**

To date, no transplant centre has a NHSE / GMC compliant shared monitoring agreement in operation. Two centres (Harefield & Papworth) have been developing an agreement, but the CTPG Chair has yet to see a final operational version.

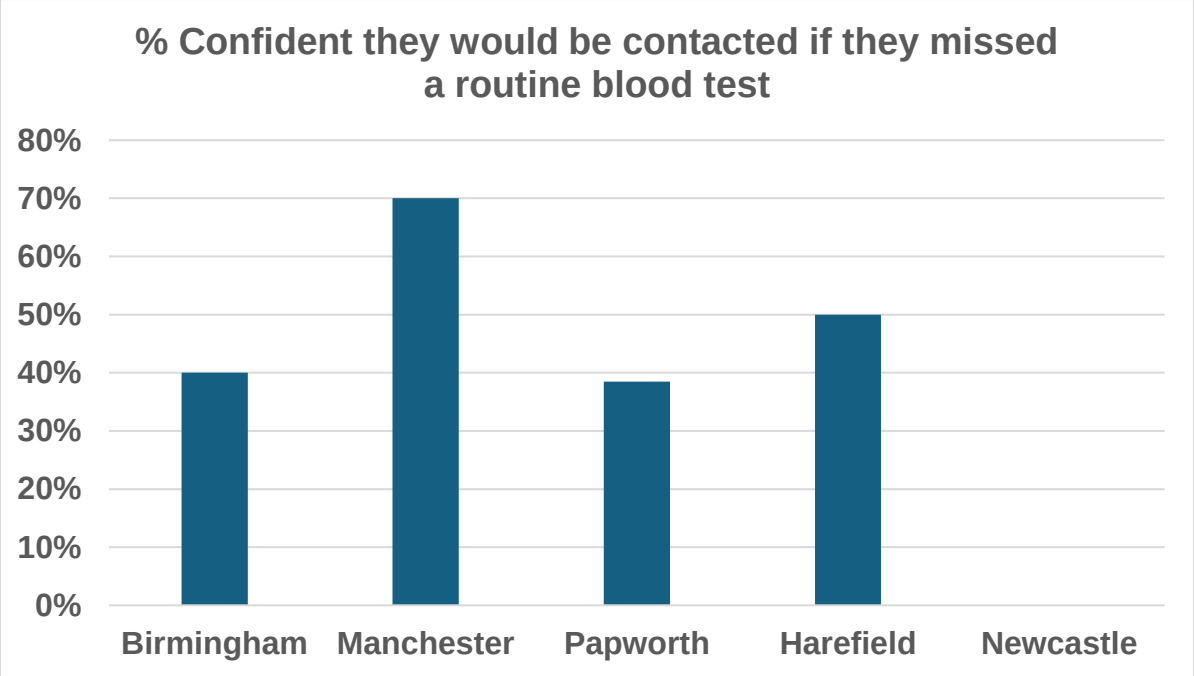
**Action Required**

All centres urgently need to implement a shared monitoring document / agreement.

2) **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**

Whilst all centres have a process in place to ensure patients have routine blood tests in line with clinical need, no centre audits their process.

Most patients (66%) always adhere to routine blood test requests and thus have not tested their centre's safety nets. However, of the 33% of patients who have missed at least one test, only 41% are confident their transplant centre would contact them. This varies considerably by centre, as shown below,




Note: Glasgow patient survey returns were too small to be meaningful

These results are worrying and demonstrate an overall lack of confidence in the robustness of transplant centre processes. Especially concerning are the results from Newcastle, where not one patient (n=13) expressed confidence in the routine blood test safety netting. Numerous patients at Newcastle expressed concerns about the ability to contact and communicate with the centre in a timely manner. Below are a sample of comments from the adult Newcastle service.

“Increasingly difficult to get blood results over telephone due to staff shortages”

“I get the sense there is not complete consistency in how things are done, which creates confusion. There is nowhere stating clearly what we should expect/do in terms of receiving results. It is also getting more and more difficult to get hold of clinic when needed.”

“The team are hopelessly disorganised and really difficult to get hold of”

“It is becoming increasingly more difficult to get through to clinic to get blood results. It took me 6 weeks to get through following local bloods had been sent. I am aware that they now phone following a clinic appointment. I am not sure what happens now following local bloods”

“I feel the lack of staffing at my transplant centre, Freeman , Newcastle is putting patients safety at risk .I was toxic for 3 weeks snd they didn't tell me. It has been the same system for 25 years snd is unsafe , ineffective and dated”

**Action Required**

All centres must undertake an audit of their processes for ensuring patients have blood tests in line with clinical need.

3) **All transplant centres must ensure all blood samples posted by patients are compliant with UN3373**

Patients reported a high level of compliance with this standard. All transplant centres are providing appropriate packaging, although Newcastle stated they were not sure whether they were compliant.

**Patient Equality Recommendations**

4) **All transplant centres must ensure all patients are supplied with pre-paid postage for the transit of blood samples**

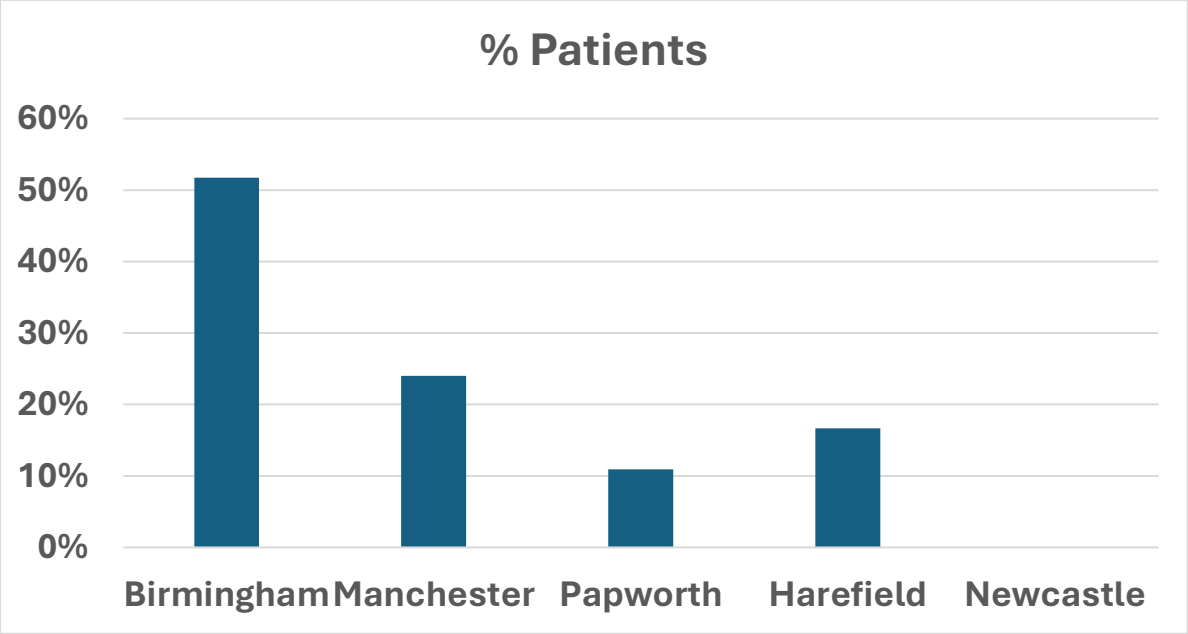
It appears two transplant centres (Papworth & Glasgow) are not providing patients with pre-paid postage for the transit of blood samples, although it is understood Papworth are close to implementation.

**Action Required**

Papworth & Glasgow should provide patients with pre-paid postage for the transit of their blood samples.

5) **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.**

Some patients from all centres (except Newcastle) have reporting they travel to their transplant centre for routine blood tests. The chart below shows the percentage of patients by centre who are required to travel to their transplant centre for routine blood tests and consider it to be neither local nor convenient. All these patients are travelling unacceptable distances for a blood test with many travelling extreme distances (hundreds of miles).




Note: Glasgow patient survey returns were too small to be meaningful

This approach appears to be particularly prevalent at Birmingham where over 50% of patients report travelling long and inconvenient distances to their transplant centre for a blood test. Patients are reporting varied and misinformed reasons why they are required to travel to their transplant centre, such as local tests being incompatible and only the transplant centre can undertake them, Birmingham do not appear to ask patients to send samples which is done by all other centres for immunosuppressant levels.

**Action Required**

Most centres, but especially Birmingham, must urgently address this recommendation. It is unacceptable to require patients to travel to their transplant centre for a blood test unless it is local to them.

“Think this is a good survey I have spent 9 yrs travelling every 3 months pre transplant and now monthly post-transplant it's a lot of money on petrol and hotel non of which I ever seem to be able to get refunded.” (Birmingham patient who reports travelling 4/5 hours to transplant centre)

**Patient Experience Recommendations**

6) **All transplant centres should explore the potential to implement finger prick testing of immunosuppressant levels for appropriate patients**

The patient survey results, and centre audit returns both indicate that Manchester and Harefield are the only centres to offer this service to appropriate patients. This method is extremely popular with patients and has a good evidence base.

**Action Required**

Papworth, Glasgow, Birmingham and Newcastle should explore the potential to implement finger prick tests of immunosuppressant levels for appropriate patients.

7) **All transplant centres should feedback results to patients regardless of whether any changes are required**

Based on the patient survey results and centre audit returns, Birmingham and Newcastle inform patients of their results regardless of whether any changes are required. Results at Harefield and Manchester can be accessed via the patient portal of the electronic record. This method receives positive feedback from patients. Papworth and Glasgow do not feedback results to patients unless changes are required.

The patient survey specifically asked if patients would like to see their results regardless of whether any changes were required. Most patients (77%) would like to know their results regardless of whether any changes were required.

**Action Required**

Papworth and Glasgow should implement positive results feedback processes, this could be in the form of an electronic patient record.

**Summary**

The table below shows the implementation of the recommendations in a red, amber, green matrix for the 6 centres.

As can be seen all centres have several recommendations to fully implement. Progress since the production of the recommendations has been disappointing.

| Recommendation | Birmingham | Manchester | Papworth | Harefield | Newcastle | Glasgow |
|---|---|---|---|---|---|---|
| A shared monitoring document / agreement must be initiated for all new patients and where a patient changes GP Practice or transplant centre | | | | | | NA |
| 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 | | | | | | |
| All transplant centres must ensure all blood samples posted by patients are compliant with UN3373 | | | | | | |
| All transplant centres must ensure all patients are supplied with pre-paid postage for the transit of blood samples | | | | | | |

| Recommendation | Birmingham | Manchester | Papworth | Harefield | Newcastle | Glasgow |
|---|---|---|---|---|---|---|
| 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. | | | | | | |
| All transplant centres should explore the potential to implement finger prick testing of immunosuppressant levels for appropriate patients | | | | | | |
| All transplant centres should feedback results to patients regardless of whether any changes are required | | | | | | |