

Patient Survey Summary

1. Background

1.1 A patient survey was undertaken as part of the preparation work for the Cardiothoracic Transplant Routine Bloods Working Group. A draft had been circulated to members of the group for comment and adjustments were made following these.

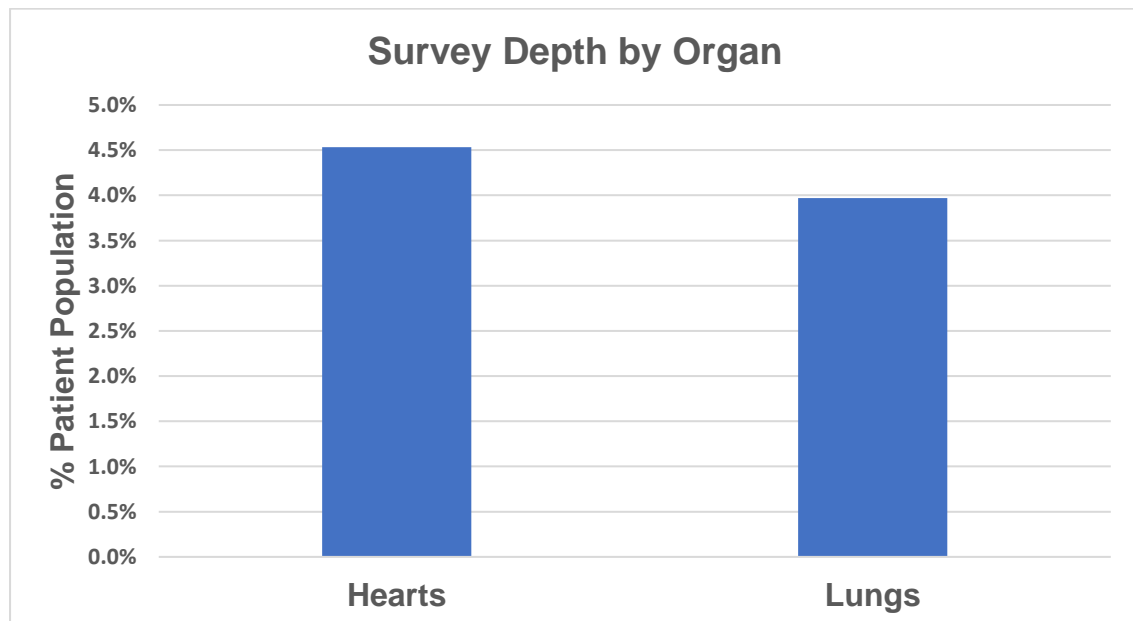
1.2 The survey was an online opportunist survey which was published through various cardiothoracic transplant support groups – professional, patient and charity led.

1.3 Patients were not asked for any personal identifiable details and the survey can be accessed online in the link below;

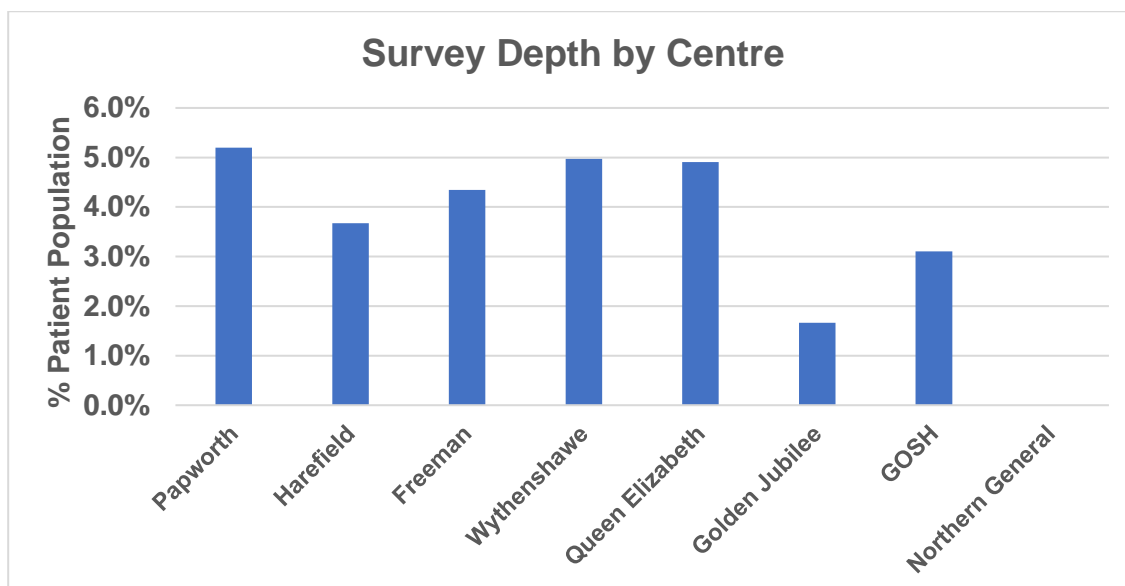
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1.4 191 patients completed the survey (by 10am 3 Sept 2022) which represents approx. 4.32% of the total UK post cardiothoracic transplant population. This is considered an excellent return.

1.5 A slightly higher proportion of the heart transplant community completed the survey, this is probably because heart transplant has a large patient led social media-based support group (Heart transplant families UK - Facebook). A similar one is not known to exist for lung transplant patients.



1.6 The representation of patients across the transplant centres was reasonably consistent for the 5 largest centres which care for over 90% of post cardiothoracic transplant patients. Due to the small numbers, centre specific metrics for GOSH and Golden Jubilee are not included in this analysis but are available. No patients cared for at Northern General (Sheffield) completed the survey.



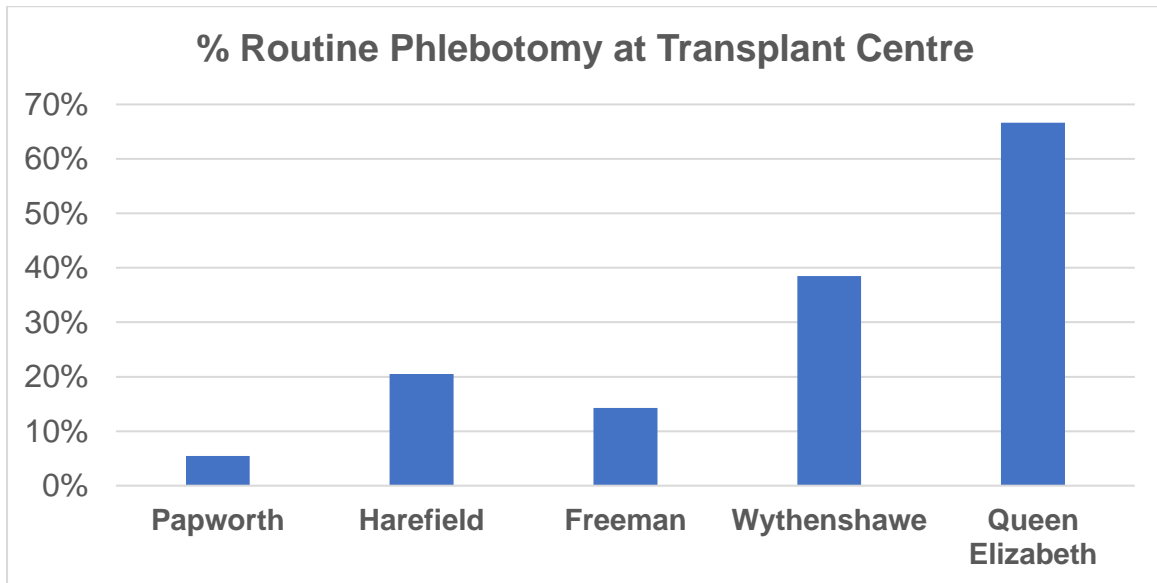
1.7 Of the 191 patients who completed the survey, 125 (65%), took the opportunity to add further free text when asked for comments about the current process and potential areas for improvement. These comments focused on a small number of themes which will be included in this analysis.

1.8 Where patient satisfaction has been sought, this has used the widely adopted one-to-five-star method. Any service, in any sector, should be seeking to score a minimum of 4.0, to be considered as providing customer / patient satisfaction.

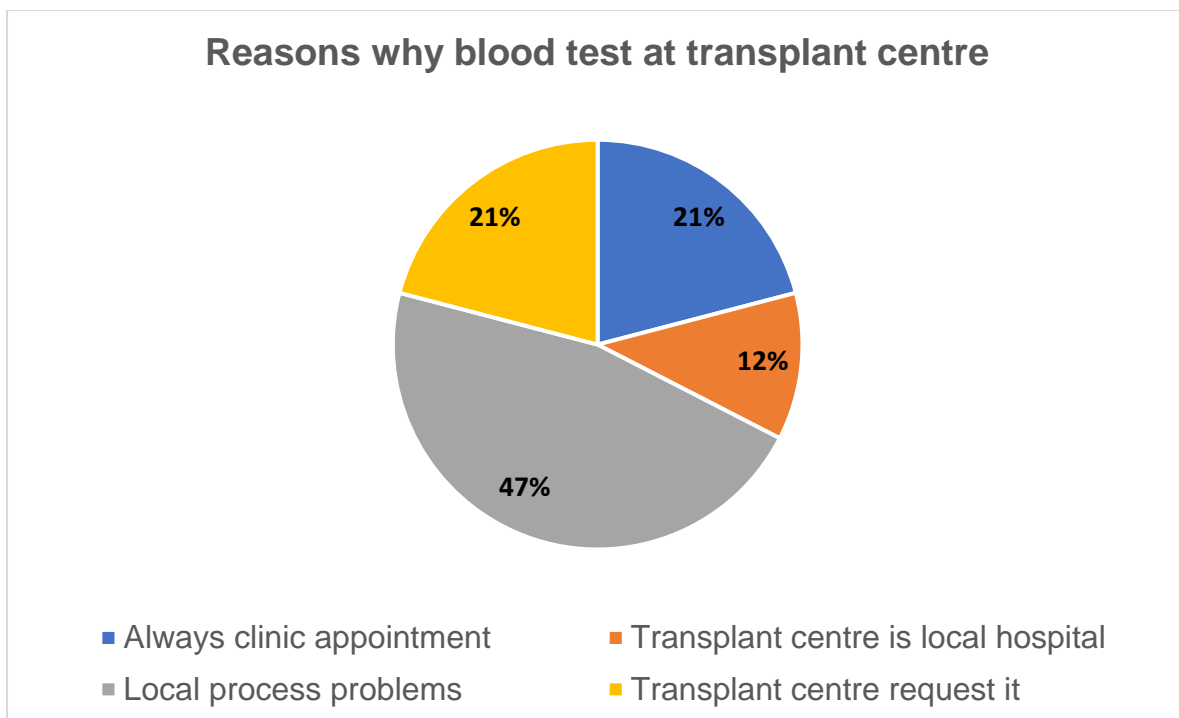
2 Phlebotomy Location

2.1 Patients were asked where they usually had a routine blood test for their transplant team when they do not have a transplant clinic appointment. 43/191 (23%) of patients reported that they had these blood tests at the transplant centre

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



2.3 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.



2.4 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”

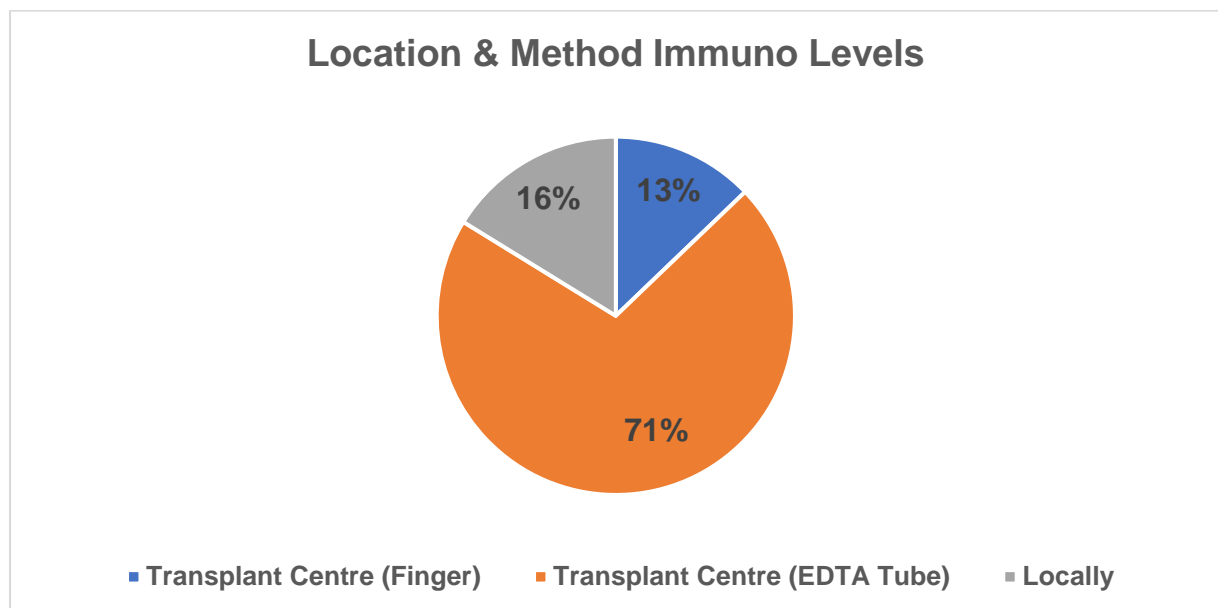
“Would be easier to go to local hospital as it is a long drive and time off work for such a small procedure “

“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”

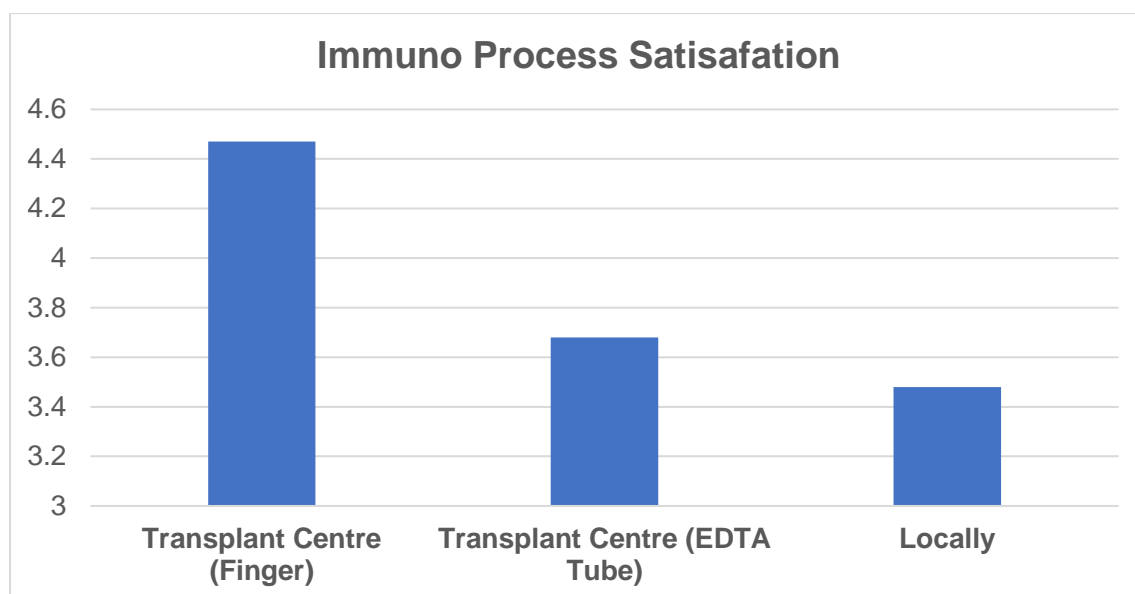
3. Immunosuppressant Levels

3.1 For the patients who had their blood samples taken locally, they were also asked what method was used to monitor their immunosuppressant levels. The pie chart below shows the split between transplant centre EDTA, transplant centre finger prick kit or locally processed sample.

3.2 The majority send blood samples to their transplant centre, with a small proportion using self-administered finger prick test kits. This method was reported by some patients at Wythenshawe, Harefield, GOSH and Freeman.



3.3 Splitting patient satisfaction by these three methods is quite revealing with via a finger prick test rating much higher than the other two methods.



3.4 It should be highlighted 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"

4. Other Blood Tests (e.g FBC)

4.1 Patients report extensive challenges with organising these tests locally. They are required to frequently and repeatedly explain their clinical background and the need for these tests

"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"

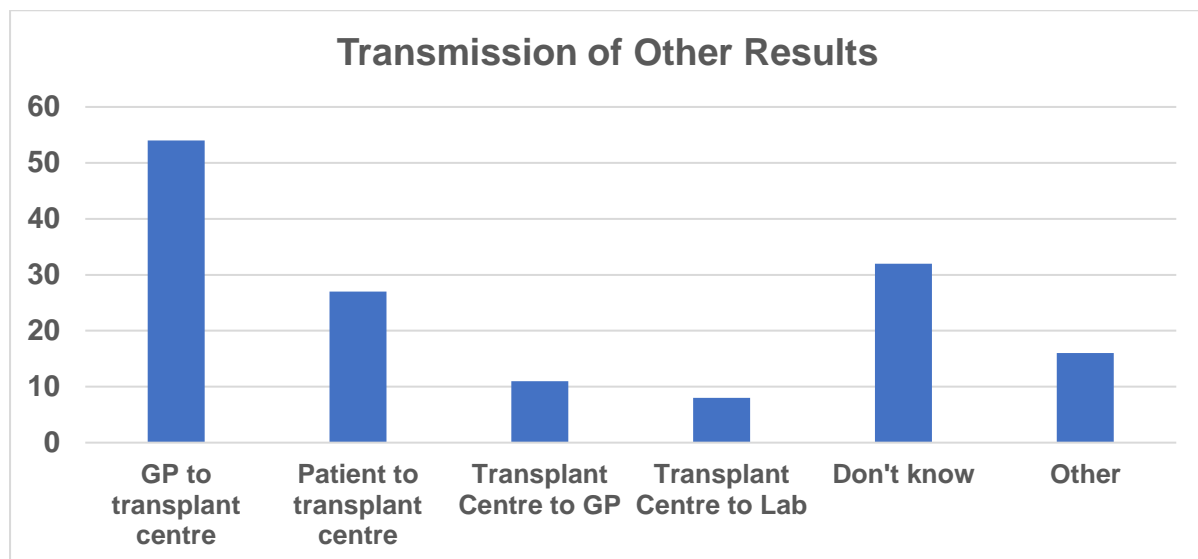
"The process of taking bloods and returning bloods to the transplant centre relies to heavily on the good will of the GP staff"

“My GP practise has been reluctant to undertake ‘follow up’ blood tests as requested by my transplant centre on occasions. This has required a call from my transplant centre to GP to resolve”

“I can sometimes get Tacrolimus blood tests carried out by my GP but often due to the timing they are not always able to accommodate me before 10 am. If that's the case I then go to my local hospital as early as possible but can sometimes encounter problems as I do not have a blood test form just a letter requesting blood be taken and the sample to be handed to me for me to post off to my transplant centre. It can take a while for the phlebotomists to get to grips with that process”

“Most times I have to go through same discussion when booking with my GP that this is routine but don't have form for LFTs etc as need to be done locally and reported to Harefield”

4.2 Patients outlined a wide range of different methods for the transmission of results from their GP / local hospital to the transplant centre, as can be seen in the chart below,



4.3 Many challenges and frustrations were expressed by patients regarding this. They feel as if they are required to act as a go between and if they don't follow things through then they won't happen.

“Get GP surgeries and Transplant Centres to be more joined up and to communicate better. My experience and that of other patients I know is appalling with both blaming the other and asking us the patients to act as a kind of middle man”

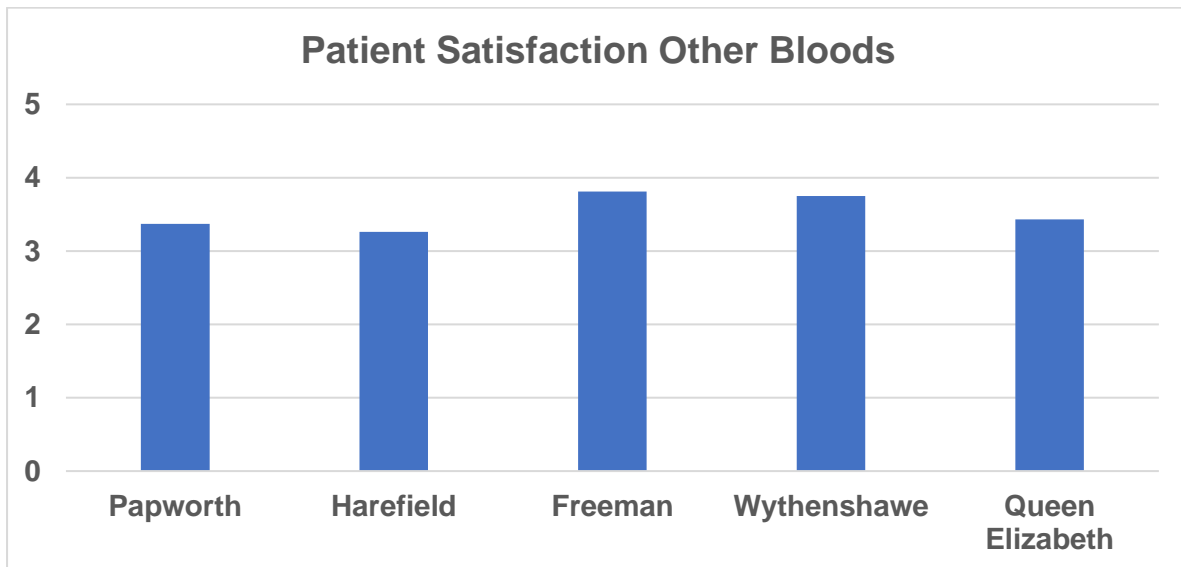
“Communication between transplant centres and GP's is dire, with us having to act as go a between. Ridiculous in this day and age that they can't pick up the phone and speak to one another or email without all the issues they claim”

“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!”

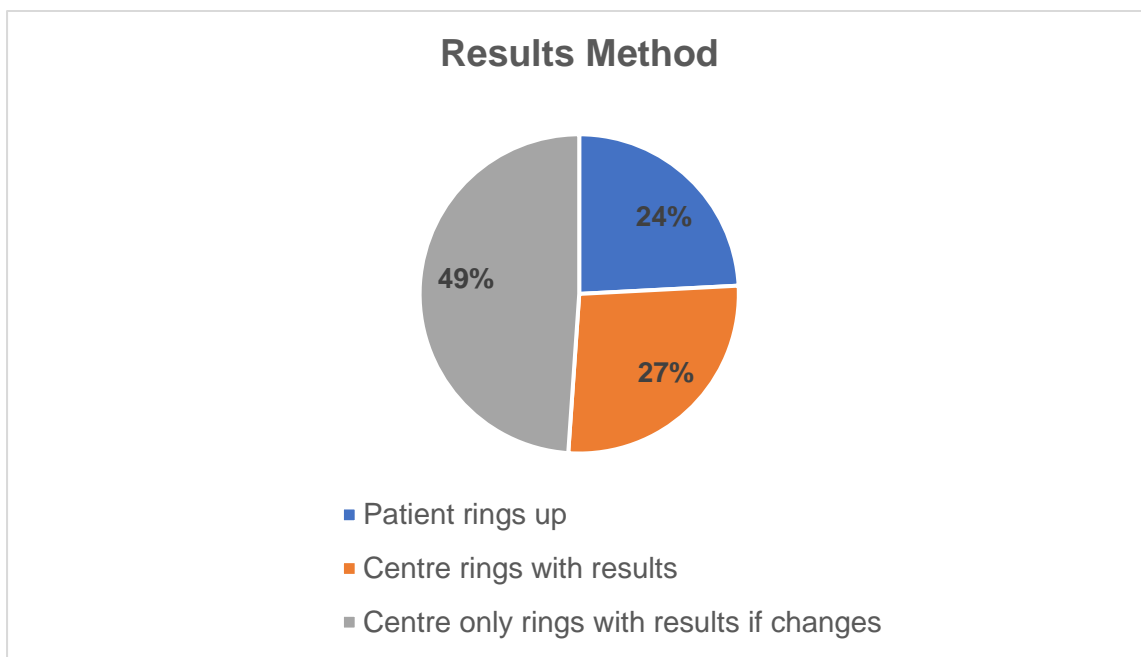
“Our hospital never shares results with Papworth despite being requested to on the blood request form every time. Not only do they not share the results they have never bothered to alert us to the fact that they will not share them”

4.4 These challenges are reflected across the whole country in the patient satisfaction scores, with no centre achieving a satisfaction of 4. This probably reflects the challenges of cross organisation communication, fragmentation of NHS services and poor IT integration.

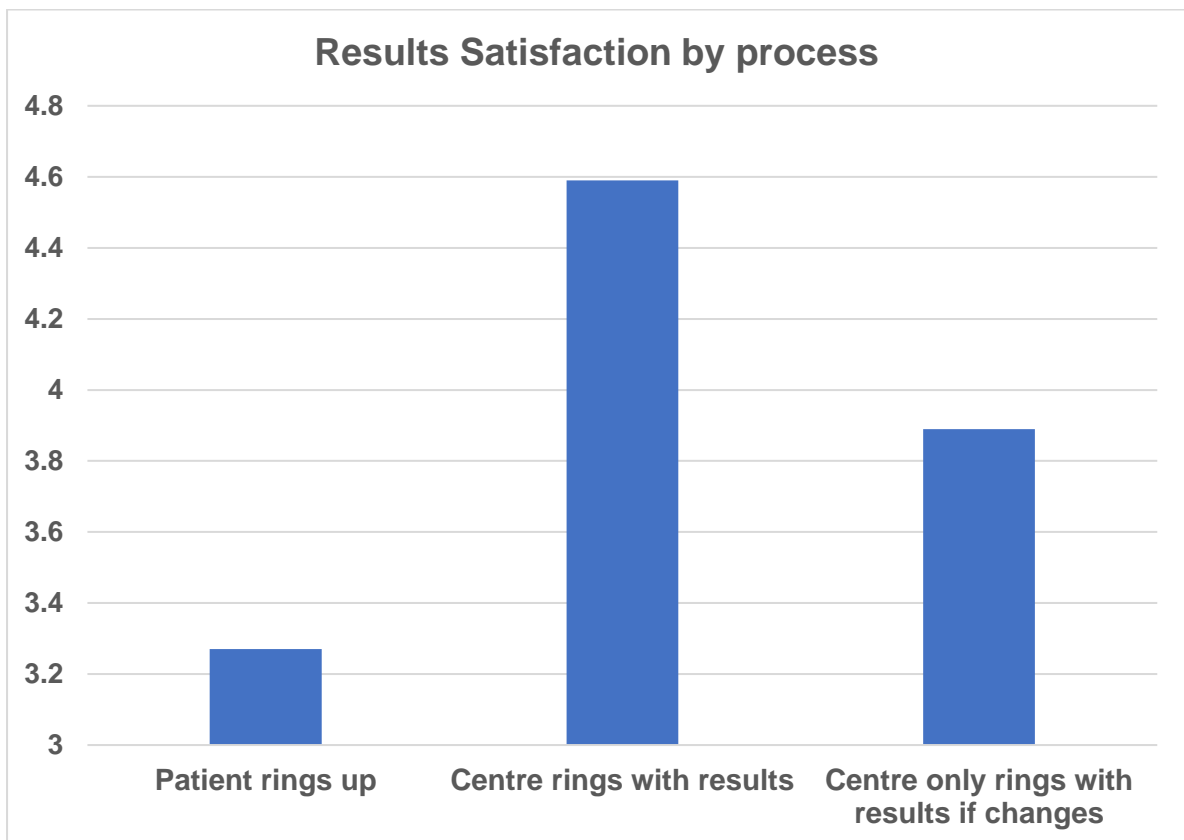
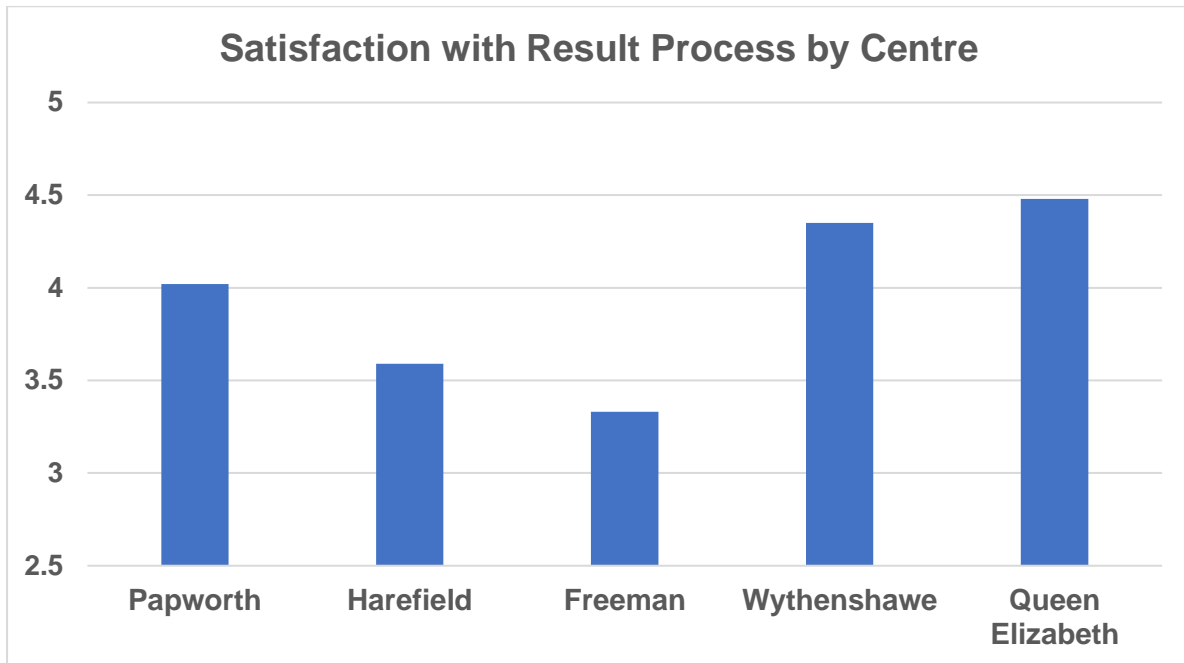


5. Results and Monitoring Processes

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



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



5.3 This highlights that positive feedback of results, even if no changes are required, has very high 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”

5.4 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

