

## Improving access to Therapeutic Apheresis Services in the North West of England & North Wales

### Results of a survey of current service provision and plans for a regional roadmap

#### Introduction

There is not a standardised referral pathway for the management of patients requiring therapeutic apheresis (TA) in the North West of England (NwoE) and North Wales. Current service provision and availability of services is variable. Some Trusts/Hospitals have access to a comprehensive 7 day service either “in-house” or outsourced to a tertiary provider using service level agreements or other formalised arrangements. For others however, access to services are fractured and unclear with the practice of “ringing around” or requesting staff to work beyond contracted hours. This practice is intensified in emergency situations.

There is reported evidence of service delivery failures and delay in patient treatments as a result of this situation. To help address the need for a more consistent and robust approach to the provision of apheresis services, NHS Blood and Transplant (NHSBT) and the Northwest Regional Transfusion Committee (NW RTC) have collaborated to better understand the demand for, and provision of, therapeutic apheresis services in the region.

#### Methods

A retrospective questionnaire (Survey Monkey™) was designed and circulated via email in February 2013 to named clinicians in haematology, renal medicine, dermatology, neurology, cardiology, rheumatology, immunology, endocrine (lipidology) and paediatrics at all hospitals in the North West, Merseyside and North Wales. The details of the named clinicians were obtained through local intelligence, consultation of hospital websites and direct contact with the designated departments at individual hospitals.

In March 2013, a letter outlining the rationale behind the project was sent to Chief Operating Officers of the organisations surveyed, inviting them to encourage completion of the electronic questionnaire by the relevant departments. At the same time a paper questionnaire (with a return envelope) was posted to all non-responders. Although this yielded an additional response, the overall response rate was still poor and as a result targeted phone questionnaires were conducted to achieve 100% from response from all haematologists in the region. Haematology was singled out as it was felt they were likely to have the most intelligence of the Trusts' use of therapeutic apheresis services.

Data was entered into an Excel© spreadsheet and analysed at NHSBT by an internal data analyst. Data was re-classified into numerical variables and the results reported proportionately (n, %). For the purposes of this report, the responses from adult services were analysed; paediatric services will be analysed in a separate report.

The data covers a 12 month period from January 2012 to December 2012. A copy of the questionnaire is provided in Appendix 1

#### Results

27 NHS Trusts were approached to provide details of apheresis service provision in the following specialities:

- Haematology
- Rheumatology / Immunology
- Renal
- Cardiology / lipidology
- Neurology
- Dermatology
- Paediatrics

Paediatrics has been excluded from these data, leaving a total of 26 Trusts

There was a response from at least one specialty from 23/26 Trusts (88%). In total there were 92 respondents, representing the specialities shown in Table 1. There was no response from 3 Trusts.

**Table 1: Number and Specialty of Respondents**

<b>Specialty</b>	<b>Number</b>
Paediatrics	21
Haematology	27
Renal	13
Rheumatology	8
Neurology	6
Dermatology	8
Cardiology	6
Lipidology	1
Immunology	2
<b>Total</b>	<b>92</b>

Responses to Q1 (below) are detailed in Table 2 and indicate the number of therapeutic apheresis procedures undertaken in 2012 by each Trust. The information is approximate and includes patients who were identified as requiring therapeutic apheresis but were referred elsewhere for treatment. There was no requirement to access therapeutic apheresis during this time period in 3 Trusts.

**Q1: Please indicate the approximate number of therapeutic apheresis procedures carried out in your department (hospital) in the last 12 months (table 2)**

**Table 2: Approximate Number of Procedures (by type)**

Hospital	Plasma exchange for renal conditions	Plasma exchange for haematological conditions e.g. TTP	Red cell exchange for sickle disease	Leucodepletion	Stem cell collection for transplant	Plasma exchange for neurological conditions	Plasma exchange for immunological / rheumatological conditions	Low Density Lipid removal
	<b>Estimated Number of Procedures Undertaken</b>							
Aintree University Hospitals NHS Foundation Trust		1-20						
Betsi Cadwaladr University Health Board		6-20		1-5	6-20			
Blackpool Fylde and Wyre Hospitals NHS Foundation Trust		1-5			>100			
Central Manchester University Hospitals NHS Foundation Trust	>100	>100	51-100		>100	6-20	6-20	51-100
Christie NHS Foundation Trust		6-20			>100			
Countess of Chester NHS Foundation Trust	1-5	6-20				1-5	1-5	
East Cheshire NHS Trust	None							
East Lancs NHS Trust - Royal Blackburn Hospital		21-50						
Lancashire Teaching Hospitals NHS Trust - Royal Preston Hospital	6-20	1-5				6-20		
Mid Cheshire NHS Trust	No response							
Noble's Hospital, Isle of Man					1-5			
North Cumbria University Hospitals NHS Trust	6-20	6-20					1-5	
Pennine Acute Hospitals NHS Trust		6-20					1-5	

Royal Bolton NHS Foundation Trust		1-5			6-20			
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Don't know	21-50						
Salford Royal NHS Foundation Trust	>100	6-20	1-5			21-50	21-50	
St Helens and Knowsley Hospitals NHS Trust	None							
Southport and Ormskirk NHS Trust	No response							
Stockport NHS Foundation Trust		1-5				1-5		
Tameside Hospital NHS Foundation Trust	None							
University Hospital of South Manchester NHS Foundation Trust	None							
University Hospitals of Morecambe Bay NHS Foundation Trust - Furness General Hospital		1-5						
University Hospitals of Morecambe Bay NHS Foundation Trust – Royal Lancaster	1-5	1-5					1-5	
Walton Centre NHS Foundation Trust						1-5		
Warrington & Halton Hospitals NHS Foundation Trust	None							
Wirral University Teaching Hospital NHS Foundation Trust	6-20							
Wrightington Wigan and Leigh NHS Foundation Trust					6-20			

Table 3 indicates the current apheresis service providers by Trusts across North West England and North Wales. Some Trusts have provider arrangements but did not indicate any procedures over the 12 month period. Some Trusts have utilised NHSBT to provide a service utilising a 'one off treatment request form' in the absence of a service level agreement (SLA). Some Trusts have assumed support from NHSBT but where there is no SLA in place. There are several areas where the service provider is not known because the survey was not completed in full by all the relevant specialties (for the purposes of the roadmap, these gaps will be completed following further consultation with key stakeholders)

**Table 3: Apheresis Service Providers**

<b>Trust</b>	<b>Provider 1 Haematology (plasma exchange)</b>	<b>Provider 2 Neurology</b>	<b>Provider 3 Renal / rheumatology</b>	<b>Comment</b>
<b>Service Provider</b>				
Aintree University Hospitals NHS Foundation Trust	NHSBT	NHSBT	NHSBT	SLA with NHSBT
Betsi Cadwaladr University Health Board	In house renal / haematology (Christie for leucodepletion)	In house renal	In house renal	
Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	In house haematology or one off request NHSBT	Transfer to Preston	Transfer to Preston	No SLA with NHSBT
Central Manchester University Hospitals NHS Foundation Trust	In house haematology	Transfer to Salford renal (one off request to NHSBT)	In house renal	No SLA with NHSBT
Christie NHS Foundation Trust	In house Haem	N/A	Not known	
Countess of Chester NHS Foundation Trust	NHSBT	NHSBT	NHSBT / in house ITU	SLA with NHSBT
East Cheshire NHS Trust	Not known	Not known	Not known	
East Lancs NHS Trust - Royal Blackburn Hospital	NHSBT	Not known	Not known	No SLA with NHSBT
Lancashire Teaching Hospitals NHS Trust - Royal Preston Hospital	NHSBT at Preston	NHSBT at Preston	NHSBT at Preston	SLA with NHSBT
Mid Cheshire NHS Trust	Would refer to University Hospital North Staffs			
Noble's Hospital, Isle of Man	NHSBT at RLUH	NHSBT at RLUH	NHSBT at RLUH	
North Cumbria University Hospitals NHS Trust	In house renal / NHSBT	Not known	In house renal / NHSBT	No SLA with NHSBT
Pennine Acute Hospitals NHS Trust	In house haematology / NHSBT / refer to CMFT	Not known	Not known (renal service to Bury, Rochdale & Oldham)	No SLA with NHSBT (being set up)

			provided by Salford, renal service to NMGH provided by CMFT)	
Royal Bolton NHS Foundation Trust	Refer to CMFT	Not known	Not known (renal service provided by Salford)	
Royal Liverpool & Broadgreen University Hospitals NHS Trust	NHSBT	Not known	Not known	SLA with NHSBT
Salford Royal NHS Foundation Trust	In house renal	In house renal	In house renal	
St Helens and Knowsley Hospitals NHS Trust	Would refer to RLUH	Not known	Would refer to RLUH	
Southport and Ormskirk NHS Trust	No response			
Stockport NHS Foundation Trust	Would refer to NMGH	Not known	Not known (renal service provided by CMFT)	Has had one off delivered by NHSBT No SLA
Tameside Hospital NHS Foundation Trust	Transfer to CMFT or one off NHSBT	Not known	Not known (renal service provided by CMFT)	No SLA with NHSBT
University Hospital of South Manchester NHS Foundation Trust	Transfer to CMFT or try one off NHSBT & Christie for leucodepletion	Not known	Not known (renal service provided by CMFT)	
University Hospitals of Morecambe Bay NHS Foundation Trust - Furness General Hospital	NHSBT / transfer to Blackpool	Not known	Not known (renal service provided by Preston)	No SLA with NHSBT
University Hospitals of Morecambe Bay NHS Foundation Trust – Royal Lancaster	NHSBT	Not known	In house ITU (renal service provided by Preston)	No SLA with NHSBT
Walton Centre NHS Foundation Trust	N/A	NHSBT	N/A	SLA with NHSBT
Warrington & Halton Hospitals NHS Foundation Trust	Refer to RLUH	Have used NHSBT one off	Refer to RLUH	No SLA with NHSBT
Wirral University Teaching Hospital NHS Foundation Trust	NHSBT	Not known	In house renal	No SLA with NHSBT

Wrightington Wigan and Leigh NHS Foundation Trust	Refer to Salford (renal) or CMFT haem	Not known	Refer to Salford renal
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Figure 1 indicates the split in providers of apheresis services for plasma exchange in haematology across the 26 Trusts. NHSBT provides the service in 5 Trusts, in house renal or haematology provides the service in 6 Trusts; in 10 Trusts, patients would be referred elsewhere and in 4 Trusts there was no response.

**Fig 1: Apheresis Providers for Plasma Exchange in Haematology**

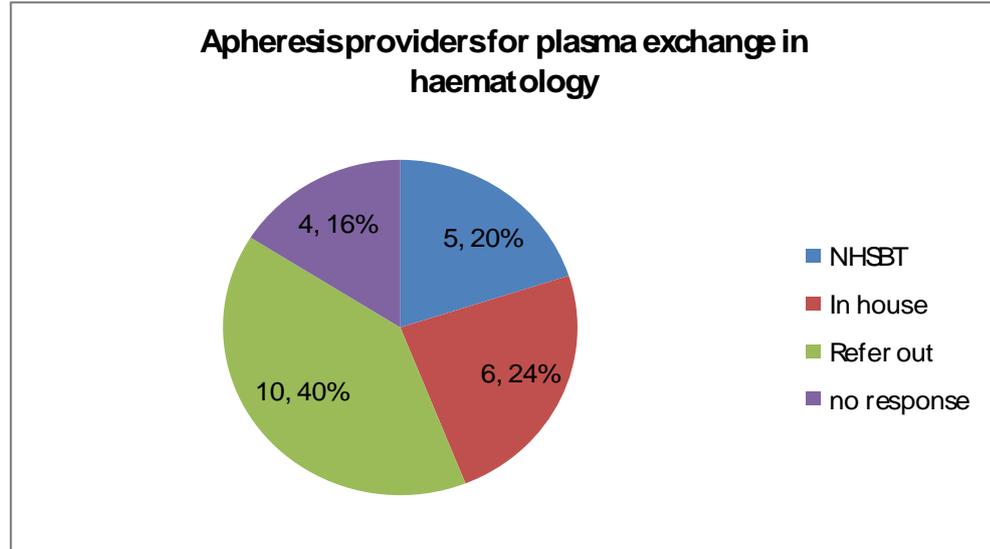
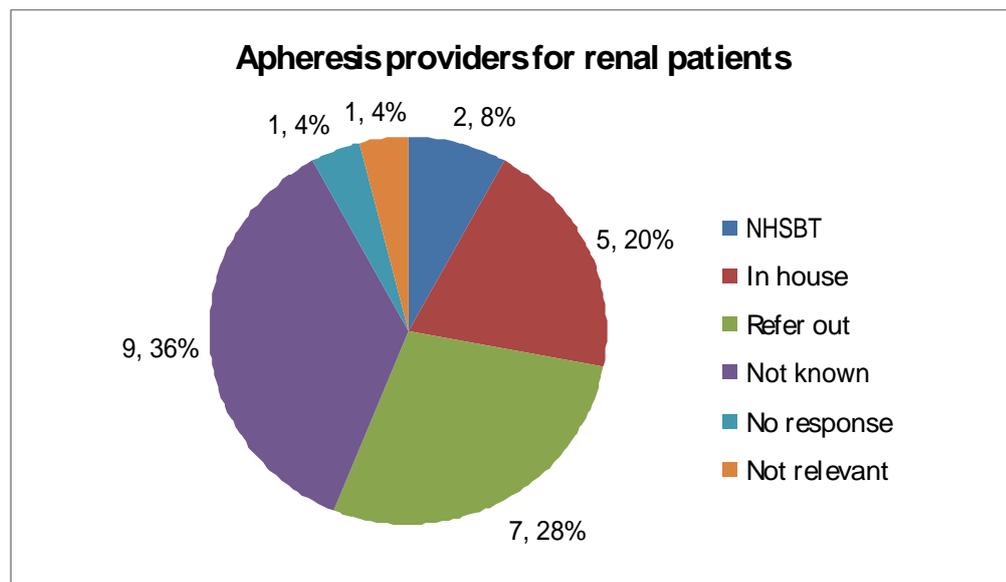


Figure 2 indicates the split of providers of apheresis services for renal patients across the 26 Trusts. The service provider was not known in 9 cases, there was no response from 1 Trust and the service was not relevant for one Trust (Walton). In 2 Trusts, the renal patients were managed by NHSBT and in 5 Trusts by the in house renal team.

**Fig 2: Apheresis Providers for Renal Patients**

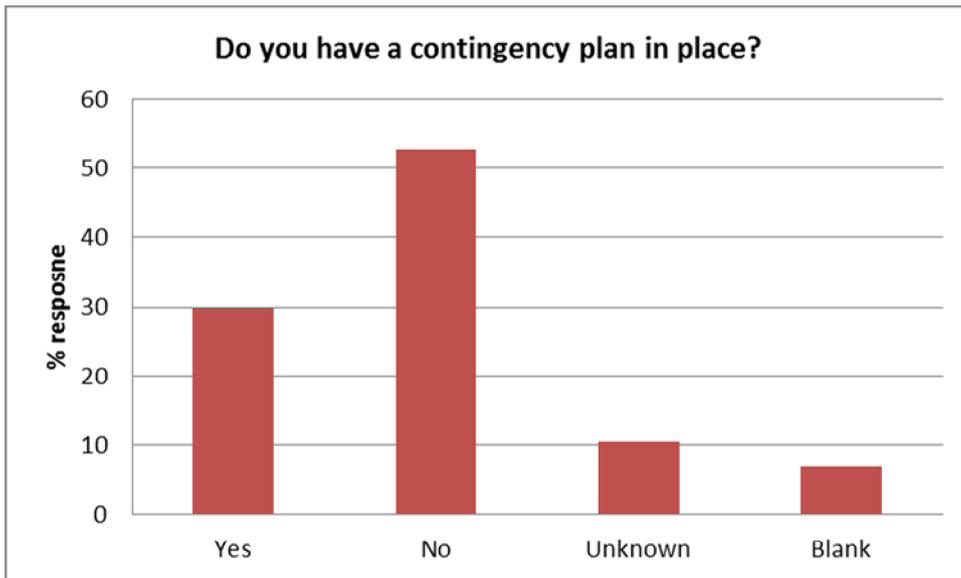


**Fig 2: Apheresis Providers for Plasma Exchange in Renal Patients**

Questions (Q4-8) were

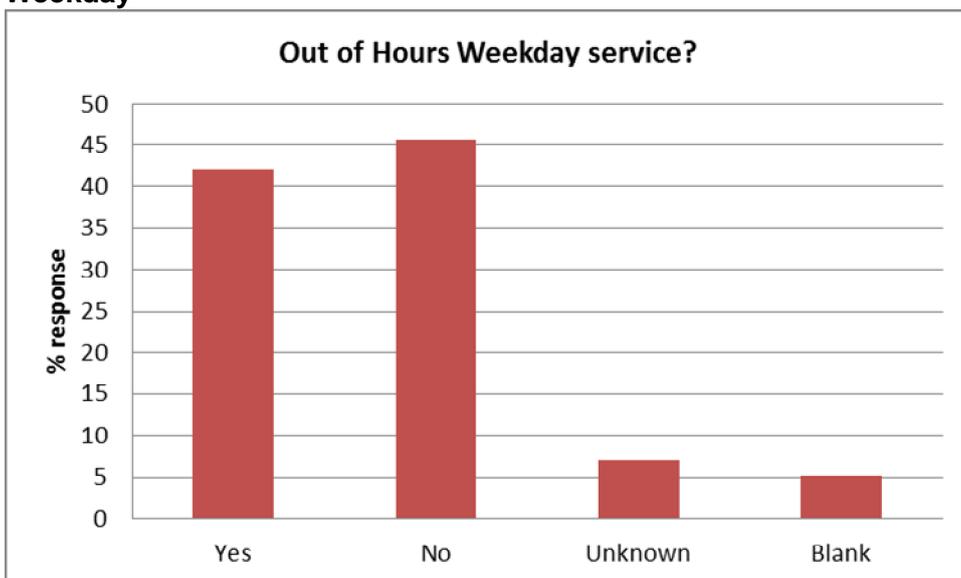
analysed from individual responses from haematology, renal specialists, neurologists and rheumatologists (57 responses) and excluded paediatrics (21), cardiology (8) and dermatology (6). Paediatric analysis will be the subject of a separate report. Cardiology and dermatology have been excluded since the need for therapeutic apheresis in these specialties is seldom urgent. The results show that there are significant gaps in service provision with a lack of contingency plan reported by 53% of respondents. Lack of access weekdays out of hours was reported by 46% and at weekends by 26%. 44% of respondents recalled having had difficulty accessing therapeutic apheresis for their patients over the last few years.

**Fig 3: Q4 – If your current service provider is unable to provide the service, do you have contingency plans in place (denominator = 57)?**



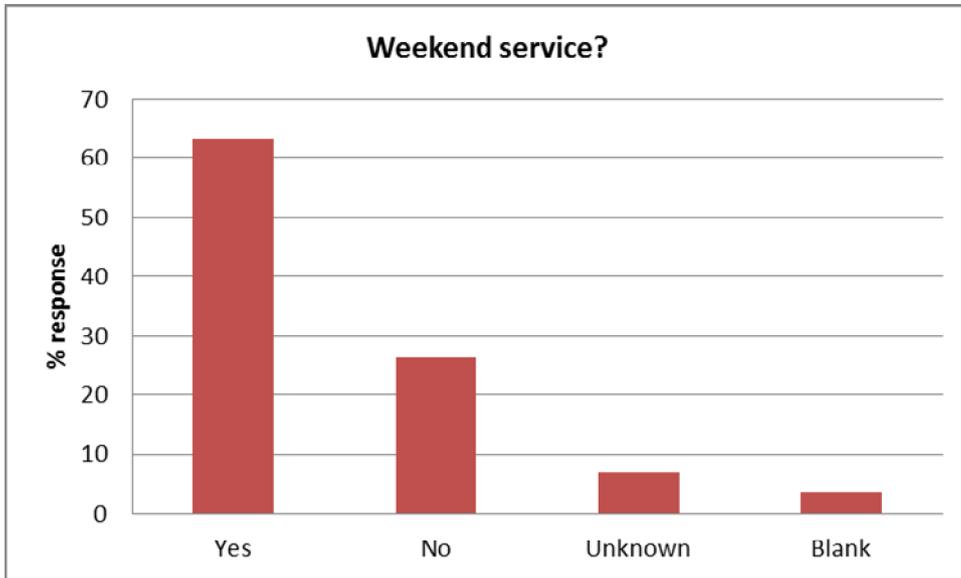
**Fig 4: Q5 – Does your current service provider offer out of hours/weekend services (denominator = 57)?**

**Weekday**

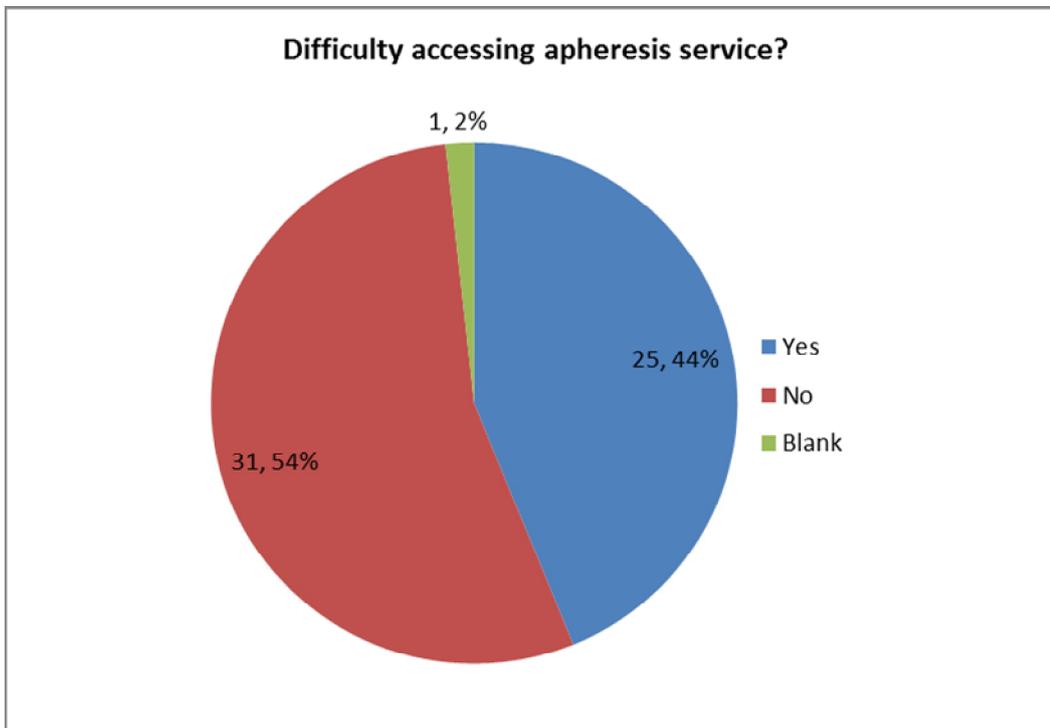


**Fig 5: Q5 – Does your current service provider offer out of hours/weekend services (denominator = 57)?**

**Weekends**



**Fig 6: Q6 Can you recall any difficulties gaining access to therapeutic apheresis procedures over the last few years (denominator = 57)?**



## Additional Comments from Responders

There were several comments associated with the above questions. In the absence of an SLA or other formal arrangements “ringing around” was one solution offered. Other statements suggest the “ad hoc” nature of some processes. For example:

*“No SLA agreement with Liverpool but they have helped with one off arrangements in the past”*

*“Struggle - no designated place to send patients”*

*“Usually struggle - needed to call several hospitals before found a solution”*

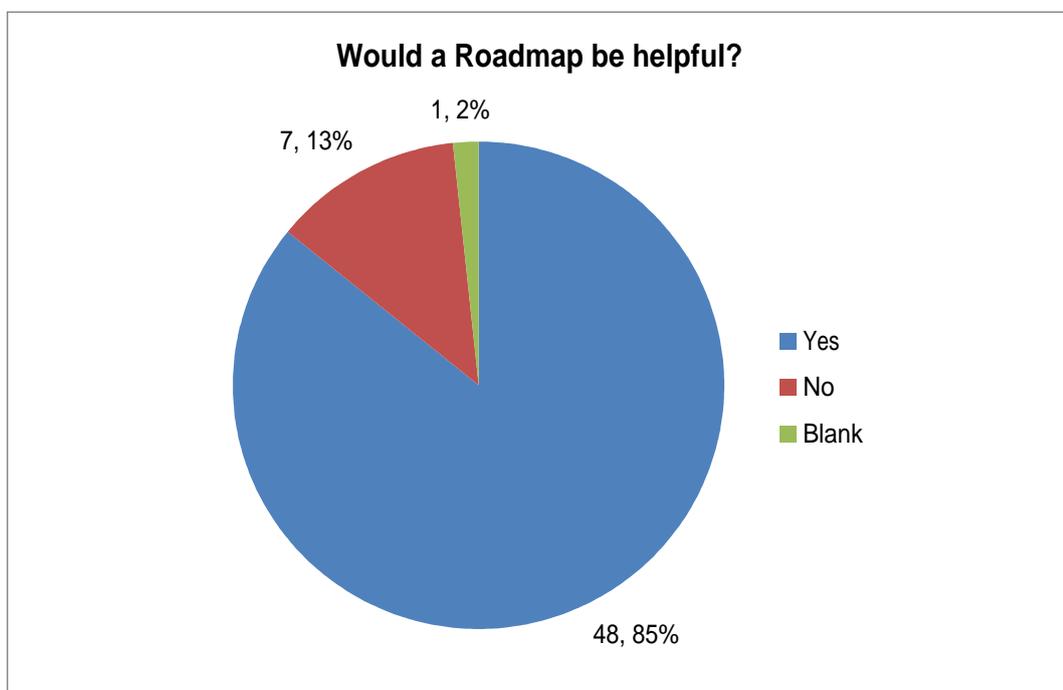
*“All have been difficult – no beds- called everybody in the end – management got involved and patient sent to another Trust ”*

*“Leucapheresis for Hyperleucostasis Leukaemia not available. Difficult to arrange TTP plasma exchange - reliant on goodwill”*

*“1 or 2 instances - difficult to organise at weekends out of hours / transport. At least one occasion large volume FFP given to TTP patient to hold for 24 hours”*

8/57 (14%) of respondents stated in comments that they would contact NHSBT in an emergency even if they did not have an SLA in place.

**Fig 7: Q7 – 8 Would you find it helpful to have a regional roadmap available to guide the referral process for patients requiring access to these specialist procedures (denominator 56)?**



48/57 respondents (86%) said they would find a “roadmap” helpful. 7 (12%) did not think this would be helpful. 1 respondent did not answer the question.

Additional comments were also provided (Q9).

*“A regional emergency- out-of-hours service could be of substantial clinical benefit. However many of these procedures can be planned and managed in a predictable way without clinical impact.”*

*“Would like network approach with 'defined' pathways. (Network = Lancashire & Cumbria)”*

*“It would be helpful to have a single body that can be contacted anytime (day or night or weekend) for plasma exchange that can be provided locally”*

*“The case of TTP is one of the most stressing as service for plasma exchange is very patchy, difficult to have access to, awful to be substandard for life threatening condition”*

*“It has been clear a regional service is vital for many years”.*

All comments can be provided on request

## Conclusions

This report provides information on the availability of therapeutic apheresis service delivery for adults in the North West of England and North Wales based on responses to a survey sent out to key clinicians in the spring of 2013. The survey has demonstrated that Hospitals / Trusts have variable access to apheresis services. NHSBT provides services either directly or indirectly for over 50% of Hospitals in this sample, but this may be ad hoc and where no formal service level agreements exist. In the remaining sites, the service was provided in house by renal and / or haematology teams. Service delivery is not robust and this is particularly evident out of hours on weekdays and at weekends. 45% of respondents documented that they could not access the service out of hours during the week and 25% had difficulty at weekends. 44% reported experience of difficulties in accessing timely treatment.

There were some reports of sub-optimal care for patients because of delays in treatment.

## Discussion

This questionnaire survey has shown that there is a lack of clarity about access to therapeutic apheresis service in the North West of England and North Wales. There was a response from at least one specialty from 23/26 Trusts (88%). The views of haematologists were the best represented as a concerted effort to elicit a response from this group involved direct telephone calls. The views of renal specialities as the other main provider / user of apheresis services are likely to be under represented in this report.

Respondents from the key adult specialties reported a lack of contingency plan (53%), lack of access to therapeutic apheresis out of hours on weekdays (46%) and at weekends (26%). 44% reported having had difficulty accessing therapeutic apheresis services for their patients over the last few years. Some examples of patients coming to harm due to delays in treatment were quoted, particularly those patients with TTP. Many conditions requiring therapeutic apheresis are potentially life threatening and treatment should be commenced as soon as possible. For example, the latest guidelines from the British Committee for Standards in Haematology for the management of TTP<sup>1</sup> recommend that treatment commences within 8 hours of presentation.

86% of respondents said that they would find a roadmap helpful to guide the referral process. Therapeutic apheresis provision could be improved by the establishment of regional services where several hospitals are served by a single service provider. This will provide more robust access for management of the 'peaks' in referrals and will provide for flexibility for clinicians to access a service 24/7.

There is some evidence of the development of regional services in the North West, but further development is required to ensure that such services are resourced sufficiently in order to have the flexibility and responsiveness required to treat patients who need urgent access to treatment. The types of conditions requiring such treatment are often unpredictable and severe and frequently require specialist medical / critical care as well as access to the apheresis procedure itself.

Key stakeholders including users and service providers have been engaged in the development of the regional roadmap which will be the start of the improvement of therapeutic apheresis service provision in the North West of England and North Wales. This project could serve as a model for other Regions of England where similar issues are likely to exist.

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### **Disclaimer:**

This report is based on the responses to a survey sent out to key clinicians in the spring of 2013. The authors are not responsible for the accuracy of the data provided by respondents.