

‘Partnership Working’ & ‘Personalisation of Care’

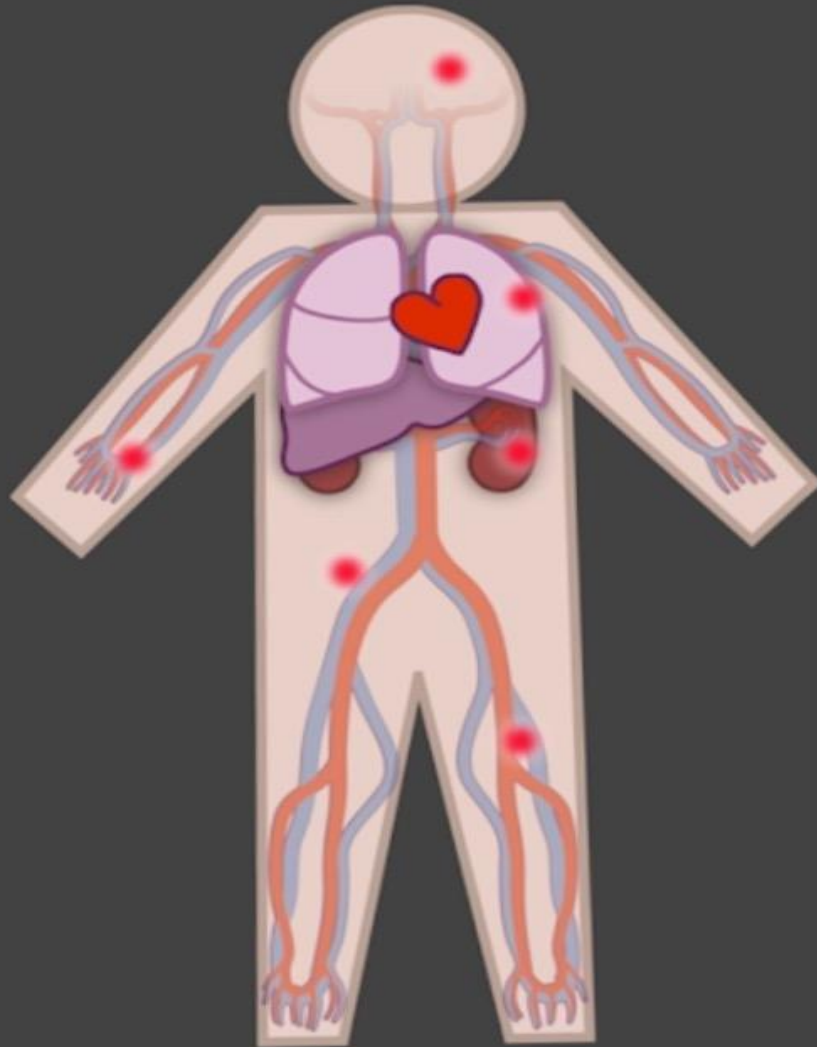
Providing life-saving treatment and care
for patients with rare conditions

**PENNA2015 6th National Awards
& Patient Experience Conference**

2nd March 2016

The Rep, Birmingham





There is only one
thing more painful
than learning from
experience,
and that is
not learning from
experience...



bjh guideline

Guidelines on the diagnosis and management of thrombotic thrombocytopenic purpura and other thrombotic microangiopathies

Therapeutic apheresis services in North West England & North Wales in 2012

Variable service provision

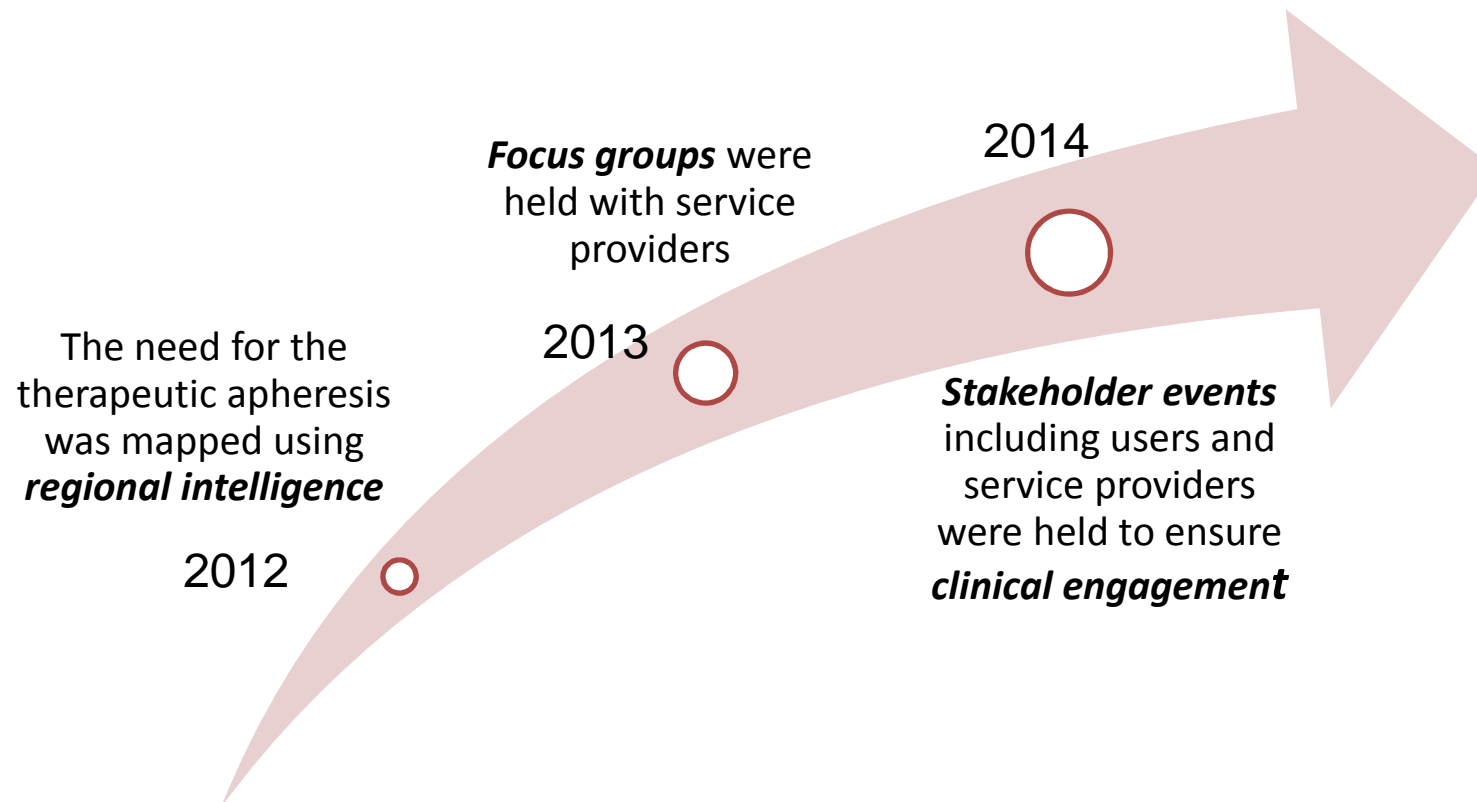
Lack of standardised referral pathways

Lack of uniform 24/7 apheresis services in the region

Avoidable delays in initiating treatment even in conditions where this was time critical

An urgent need for a more consistent and robust approach to the provision of apheresis services

Steps towards developing the Regional Roadmap....



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Conclusions from Regional Survey:

Variable access to Therapeutic Apheresis services in the region

Over 50% of clinicians identified absence of a contingency plan for therapeutic apheresis service with many reporting a need to rely on good will in emergencies



Service delivery not robust, especially on weekdays out of hours and at weekends

44% reported experience of difficulties in accessing timely treatment



Therapeutic apheresis provision could be improved by the establishment of regional services where several hospitals are served by a single service provider

86% of respondents said that they would find a roadmap helpful to guide the referral process

Survey Comments

Right Time

- *“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”*

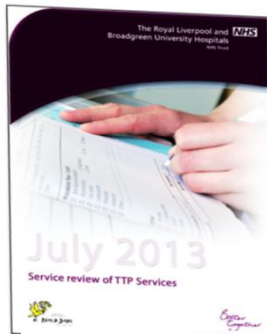
Right Patient

- *“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”*

Right Place

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

Parallel steps towards positive change...



- Internal Service Review of Service for patients with TTP performed by the Royal Liverpool University Hospital with recommendations for change presented to the Trust Board, July 2013



- Survey Monkey™ questionnaire circulated by NHSBT to named clinicians in all hospitals in the North West, Merseyside and North Wales, February 2013



North West Regional Transfusion Committee
incorporating North Wales



- Multi-organisational Project Team established between NHS Blood and Transplant, Royal Liverpool University Hospital and the North West Regional Transfusion Committee July 2013

Delivering Acute Integrated Care



Referring Hospital



ED / Resus



ITU / CCOT



Apheresis Team, NHSBT



Laboratory



Radiology

The Regional Referral Portal

Hospitals and Science



DIAGNOSTIC SERVICES	PATIENT SERVICES	PRODUCTS	TRAINING	RESEARCH	RESOURCES	BUSINESS CONTINUITY	AUDITS	CUSTOMER SERVICES
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You are here: [Home](#) > [Patient Services](#) > [Therapeutic Apheresis Services](#) > [How To Make Patient Referrals To TAS](#) >
Referrals in the North West of England and North Wales



Therapeutic Apheresis Services

[TAS Units](#)

[Patient and User Feedback](#)

How To Make Patient Referrals To TAS

**Referrals in the North West of
England and North Wales**

[Aintree University Hospital NHS
Foundation Trust](#)

Making Therapeutic Apheresis Referrals in the North West of England and North Wales

Please select your organisation from the list below for information about the referral pathways for your Trust:

[Aintree University Hospitals NHS Foundation Trust](#)

[Alder Hey Children's NHS Foundation Trust](#)

[Blackpool, Fylde And Wyre Hospitals NHS Foundation Trust](#)

[Central Manchester University Hospitals NHS Foundation Trust](#)

[Clatterbridge Centre For Oncology NHS Foundation Trust](#)

Liverpool Regional TTP Specialist Centre



From 40 to 100% Patient Survival!

Working with our Patients...

*"Explain TTP
in words I can
understand"*

*"Some one to tell
me what is
happening"*

*"Tell us what
the Drs
mean"*

*"Give us written
information I can
trust and websites
that don't frighten
me"*

*"To be there
if I need
you. Can we
call you" ?*

*"Any support
group? What do
other people say
who have this?"*

*"Someone
I can
trust"*



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News
Royal Liverpool Hospital

Royal Liverpool Hospital patient defies killer blood disorder to walk fiancée down the aisle

12:39, 4 OCT 2015
UPDATED 12:40, 4 OCT 2015
BY JOSHUA TAYLOR

Graham Stansfield tied the knot on his 60th birthday after spending 12 weeks in hospital.

f
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g+
in
587 SHARES
COMMENTS

Graham Stansfield, 60, and Catherine Fletcher, 54, on their wedding day after Graham made a miracle recovery from rare blood disorder TTP



LIVE UPDATES

5:26 pm, Thu 30 Jan 2014

Liverpool Royal is one of only two hospitals in UK to treat TTP

02:50

A North West hospital has become a specialist centre for treating a rare blood clotting condition.

The Royal Liverpool is now one of just two hospitals in the country with a dedicated team able to treat what is called TTP.



Dr Kate Pendry kate.pendry@nhsbt.nhs.uk Dr Tina Dutt Tina.Dutt@rlbuht.nhs.uk

Catherine Howell catherine.howell@nhsbt.nhs.uk

Dr Shruthi Narayan Dr Samah Alimam



@NHSBT @RoyalLpoolHosps



NHS Blood and
Transplant



Royal Liverpool
University
Hospital

2016

*Celebrating collaboration, patient centred care and
improved patient outcomes*