‘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...
Untreated: 90% mortality

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
The need for the therapeutic apheresis was mapped using **regional intelligence**.

**Steps towards developing the Regional Roadmap...**

- **2012**: The need for the therapeutic apheresis was mapped using **regional intelligence**.
- **2013**: **Focus groups** were held with service providers.
- **2014**: **Stakeholder events** including users and service providers were held to ensure **clinical engagement**.

R E G I O N A L  R O A D M A P
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...

1. 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

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

3. 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

Apheresis Team, NHSBT

ED / Resus

Laboratory

ITU / CCOT

Radiology
The Regional Referral Portal

Hospitals and Science

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

1 of only 2 UK Centres

From 40 to 100% Patient Survival!
Working with our Patients...

"Explain TTP in words I can understand"

"Tell us what the Drs mean"

"Some one to tell me what is happening"

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

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

LIVE UPDATES

4:26 pm Thu 31 Jan 2019

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

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.
NHS Blood and Transplant

Celebrating collaboration, patient centred care and improved patient outcomes

Royal Liverpool University Hospital

2016