

CLINICAL PRIORITIES ADVISORY GROUP

Agenda Item No	
National Programme	
Clinical Reference Group	Specialised Blood Disorders
URN	1688

Title (Insert Service Specification title in full)

Thrombotic Thrombocytopenic Purpura (TTP), all ages

Actions Requested

1. Agree the Service Specification Proposition
2. Consider relative prioritisation

Proposition

To put into place a network of regional providers that can provide a timely expert service for patients with Thrombotic Thrombocytopenic Purpura (TTP)

Background

TTP is a very rare, complex condition which can present as an acute life threatening disorder that requires prompt diagnosis, early referral and effective immediate management in a centre with comprehensive provision and a multi-discipline approach. Specialist aftercare is also required. There is also a cohort of patients who have a congenital form of the disease who require on going apheresis. The Specialist led co-ordinated care is key to improving outcomes for this patient group. The prevalence is 330 patients in England, with an acute incidence of 150 patients in England. This specification sets out the model of care for acute and congenital care.

There is a very high mortality rate for patients with this disease, 50% in non-specialist centres. There are two centres in England where there are discrete services for TTP and the survival rate for patients is 80%. The current pathway of care is disjointed, some patients are treated in expert centres, some are treated where they present, with or without access to expert advice. The Prescribed Specialised Services Advisory Group asked NHS England to assume the commissioning responsibility for this service to establish expert centres and clear pathways to improve outcomes.

Proposed Service Model

The service specification describes a service model of regional expert centres which have a treating and educative/outreach role in relation to this disease.

The Integrated Impact assessment and financial model are based on a service model of about 8 centres nationally. The centre allocation is based on geography and demography and recognises that centres may be of different sizes. This model of delivery will replace the current pattern of patients being

treated in up to thirty centres a year; the current proposal is for:

- o South west one centre, supported by air transfer
- o London and the south; one centre
- o West Midlands; one centre
- o East Midlands; one centre
- o East of England ;one centre
- o North west; two centres
- o North East; one centre, supported by air transfer

This modelling recognises the balance between geographical access, population and the need not to dilute expertise by having too many centres.

The final allocation of centres will be agreed when the service, if commissioned, moves to procurement.

The Public and Patient Voice Advisory Group (PPVAG) recognised that the proposed model is a major change in service delivery across England. The PPVAG supported the change and recommended that the public consultation include some engagement and an interactive was agreed as the way to undertake this. A webinar is proposed during the consultation period.

The model of service delivery proposed by this service specification is a change to the current treatment pathways. Whilst it will deliver major clinical improvement there may be some concern in relation to the patient access to centres. The current proposed number of centres across the country aims to balance geographical access and clinical expertise. The inclusion of air transport as an option is intended to alleviate some of these concerns in relation to access.

Financial Implications

The service development requires a transfer of activity and funding from CCGs.

Analysis of data from the NCDR has informed the finance model and sets out the basis for a transfer from CCG funding to NHS England; it is proposed that this will be on a capitation basis given the rarity of the condition. The 8 designated centres will be established at a cost of £1.4m a year which will be funded by NHSE. The model shows a pressure of £4.4m to NHSE of which £1 million could transfer from CCG's.

Costs in excess of tariff in relation to this service have been identified

- The acute care of patients requires additional resources to tariff; these have been identified from work with the providers with the best outcomes who have an established service. These optimal treatment pathways recognise the costs of apheresis accessible 24/7 and the additional clinical input required to manage the acute episode safely.
- A core clinical team is identified in the service specification and this is proposed to be funded via an infrastructure payment.
- There are drugs and blood products used in this pathway that are

excluded from tariff

- **Air transport; up to four air transports a year are included in the costs; this reflects the particular problems in relation to ambulance transport in the furthest regions of England.**

The proposal therefore is to set up a new model of care, of eight specialist centres providing acute and follow up care for patients with this rare blood disorder by improving access to expert care and by doing so improve patient outcomes and patient experience significantly.

Clinical Panel recommendation

Not applicable

The committee is asked to receive the following assurance:

1.	The Head of Clinical Effectiveness confirms the proposal has completed the appropriate sequence of governance steps and includes where necessary an: Evidence Review; Clinical Panel Report
2.	The Head of Acute Programmes/Head of Mental Health Programme confirms the proposal is supported by an: Impact Assessment; Stakeholder Engagement Report; Consultation Report; Equality Impact and Assessment Report; Service Specification Proposition. The relevant National Programme of Care Board has approved these reports.
3.	The Director of Finance (Specialised Commissioning) confirms that the impact assessment has reasonably estimated a) the incremental cost and b) the budget impact of the proposal.
4.	The Operational Delivery Director (Specialised Commissioning) confirms that the service and operational impacts have been completed.
5.	The Director of Nursing (Specialised Commissioning) confirms that the proposed quality indicators have been adequately defined.

The following documents are included (others available on request):

1.	Service Specification Proposition
2.	Consultation Report
3.	Evidence Summary (where completed) not completed

4.	Clinical Panel Report (where completed) not completed
5.	Equality Impact and Assessment Report

The Benefits of the Proposition			
No	Metric	Grade of evidence (where evidence review completed)	Summary of benefit (where applicable)
1.	Survival	Not measured	Where an evidence review has been completed, please include metric of survival (e.g., 30 days benefit, 50 years benefit)
2.	Progression free survival	Not measured	
3.	Mobility	Not measured	
4.	Self-care	Not measured	
5.	Usual activities	Not measured	
6.	Pain	Not measured	
7.	Anxiety / Depression	Not measured	
8.	Replacement of more toxic treatment	Not measured	
9.	Dependency on care giver / supporting independence	Not measured	
10.	Safety	Not measured	
11.	Delivery of intervention	Not measured	

Other health metrics determined by the evidence review (where evidence review completed)			
No	Metric	Grade of evidence	Summary from evidence review
		Grade A	[AS ABOVE]
		Grade A	
		Grade A	
		Grade A	
		Grade A	

Considerations from review by the Rare Disease Advisory Group

Not applicable

Pharmaceutical considerations

Not applicable

Considerations from review by National Programme of Care**POC Board support:****Select appropriate option:**

- 1) The proposal received the full support of the <insert PoC name> Board on the <insert date>
- 2) The proposal received the support of the <insert PoC name> PoC Board on the <insert date>, subject to the following comments <insert comments>
- 3) The proposal received the support of the <insert PoC name> PoC Board on the <insert date> but CPAG is asked to note that the proposal did not have the full support of the Working Group, who have raised the following concerns: <insert reasons>
- 4) Other – free text (only for minority of cases not fitting into the above)

Benefit of Service Specification:

Please set out the material benefits that patients will receive following adoption and implementation of this specification – Patients will receive timely access to expert care, which will include both acute and ongoing monitoring for life and will have improved outcomes including mortality. The service specification includes a requirement for services to support patient engagement actively. Patients will also have access to psychological support.

Implementation timescale:

This service specification will require a competitive procurement. Implementation, if agreed, will take place in the summer of 2019.

- 3) Service reconfiguration / procurement required. Expected implementation date <insert date>summer 2019

SECTION 2 – IMPACT REPORT (Not included in CPAG Papers, section 2 only)

No	Item	N/Cost £K	Level of uncertainty
1.	Number of patients affected in England	Source: IA Report, A1.2	150

2.	Total cost per patient over 5 years	Source: IA Report C2.1 and 2.2, and Model	£40,722
3.	Budget impact year 1	Source: IA Report C3.1 and Model	4,352.1
4.	Budget impact year 2	Source: IA Report C3.1 and Model	4,369.8
5.	Budget impact year 3	Source: IA Report C3.1 and Model	4,391.5
6.	Budget impact year 4	Source: IA Report C3.1 and Model	4,409.1
7.	Budget impact year 5	Source: IA Report C3.1 and Model	4,430.2
8.	Total number of patients treated over 5 years	Source: IA Report A3.2	765
9.	Total cost per patient benefitting over 5 years		£28,696

Key additional information

This is considered to be cost neutral because <insert text>

[TO BE COMPLETED BY NHS ENGLAND FINANCE (Andy Leary / Justine)]