Engagement Report for Service Specifications

Unique Reference Number	1668
Specification Title	TTP
Lead Commissioner	Joan Ward
Clinical Reference Group	Specialised Bleeding Disorders
Which stakeholders were contacted to be involved in service specification development?	RCPATH, BBTS NHSBT RCP RCPCH RCN All the ambulance services in England RCOG Specialised Bleeding Disorders CRG and its registered stakeholders Paediatric Medicine CRG PIC CRG Adult Critical Care CRG Intensive Care Society AOFAC TTP Network
Identify the relevant Royal College or	BSH, a copy of the document was sent electronically for comment

Professional Society to the specification and indicate how they have been involved	
Which stakeholders have actually been involved?	BBTS England, BBTS Scotland NHSBT, Critical care consultant RLBUHT, Chair of Intensive Care Society, NHS Scotland AOFAC Foundation, Paediatric Medicine CRG, TTP Network, NHS Scotland Yorkshire Ambulance Service
Explain reason if there is any difference from previous question	
Identify any particular stakeholder organisations that may be key to the specification development that you have approached that have yet to be engaged. Indicate why?	
How have stakeholders been involved? What engagement methods have been used?	Documents were emailed to the organisations set out above and a meeting arranged with NHS BT.

What has happened or changed as a result of their input?	1.All references to blue light transfers have been changed to critical care transfer. 2. All critical care references changed to level 3 critical care. 3. Co dependencies have been clarified and stroke defined as stroke rehabilitation. 4. Metrics relating to the quality schedule re the timings of arrival to the specialist centre have been amended. 5. Standard clauses regarding the treatment of children in hospital will be added to the document at the request of the paediatric medicine CRG. 6. Greater clarification provided in the service specification as to the role of the specialist centre if there is not a bed immediately available upon referral. 7.Timings relating to the expected start of plasma exchange have been clarified. 8.Obstetrics has been amended to read specialist obstetrics. 9. Dosage regime clarified. 10. Terminology has been systemised throughout the document.
How are stakeholders being kept informed of progress with specification development as a result of their input?	**Stakeholders will be emailed with the SWG comments after the POCB review**
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	The CRG recommended a consultation period of 6 weeks.

Stakeholder/CRG Feedback

Organisation Responding	Feedback Received	SWG response	Resulting Action
Yorkshire Ambulance Service	Transfers to definitive care should be described as 'critical care' transfers rather than 'blue light' transfers as described in the document. This provides for a specific level of response and expectation of, and from, the ambulance service.	Noted, will accept into the document but need to check the terminology, should check out what ambulance HQ say	All references to blue light transfers have been changed to critical care transfer
NHS Scotland	What is the rationale for insisting that central venous line insertion is carried out [only] by intensivists, [dedicated] IV access teams or Interventional Radiology? Why is it unacceptable for a suitably trained Haematology Registrar to insert a femoral venous line under ultrasound guidance, which we sometimes do locally to avoid delay in initiating plasma exchange? Is it really necessary to have on-site Renal and Neurology at all sites? For patients requiring intubation, ICU beds in Glasgow are not all at one site, but only	In England, this is an intervention that only appropriately trained person can do this, in English hospitals this is done by specialist team rather than a haematology registrar. High risk patients can decompensate. The SWG advise that in the document renal is not required to be collocated,	

	one hospital has on-site Neurology, and this could cause issues for us. Renal services are also mainly centred at the QEUH site in Glasgow. Only a minority of TTP patients actually require renal support (haemodialysis / haemofiltration) and patients can be moved urgently if the need for this arises. Maybe more important to include some comment on access to specialist Radiology services - CT/MRI of head in particular available 24/7 if required, plus Neuroradiology expertise to interpret it.	neurology will be changed to being accessible rather than co located. Noted The SWG did not consider this necessary and considered that it could cause undue delay	
Critical care consultant RLBUHT, Chair of Intensive Care Society, Adult critical care CRG	Thank you. A very well written and clear document. I have a couple of minor comments: 1.Wherever Critical Care is described, I recommend that you specify the need for level 3 Critical Care provision. For TTP patients there is a definite need for level 3 care (ie intubation and mechanical ventilation). It is unlikely but possible that only level 2 capacity (ie HDU) might be collocated with TTP services. 2.In interdependencies, again level 3 critical care needs to be specified. I think Stroke services need to be present on site but wonder if neurology could be a service which should be available but not necessarily on site?	Change all critical care references to critical care level 3 Noted, think this is more important in the step down phase, post acute , move stroke and neurology and	All critical care references changed to level 3 critical care Co dependencies have been clarified and stroke defined as stroke

	3.In the outcome metrics, I think you should include time of referral to time of arrival at specialist centre. Perhaps it should be under 4 hours where geography permits. The number selected is not for me to say.	make point that its access to the stroke rehab services we need The timings have been clarified in the document. It is difficult to be more specific in relation to timings relating to patient journey times due to geographical considerations.	rehabilitation. Service Specification has been amended
Paediatric Medicine CRG	1. Document circulated to CRG and discussed at CRG meeting July 18th 2017. Designated providers are not yet included. We would like to highlight a number of items in the generic paediatric specification which applies to all services described in NHS England manual (http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf) for paediatric services and includes any "all ages" sections within other specialised services specification where this is relevant to children. 2. 3.5 Interdependencies with other services/providers Safeguarding: Children and young people must only receive a service from a provider who takes steps to prevent abuse and	Noted and will accept into the document	Added to the service specification

	does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). 3. 2.1b. All hospital settings should meet the standards for Children and Young People in emergency settings http://www.rcpch.ac.uk/emergencycare 4. 2.1c. All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010). 5.2.1d. There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010.		
AOFAC Foundation	1In agreement that "Patients must be referred to the Regional Specialist Centre as soon as the diagnosis is suspected and transferred to a treating centre urgently as delays in treatment impact mortality. " 2 All patients must have started Plasma Exchange within 4-8 hours. I think Established TTP patients who already have their files within the hospital system should be able to undergo Plasma Exchange within 2-4 hours rather than the general 4-8 hours to all patients; these patients are known and their files are easily accessible.	Patients under regular follow up may the opportunity have self refer and have an expedited pathway, each centre will have their own guidelines for the ,	

	3.CNS advice 24 hours	The SWG 's view is that due to the scale of the service CNS advice is unlikely to be available 24/7 but advice is available 24/7 from the haematology ward,	
	4.When considering the location of the proposed centres the distance for patients to travel and the journey time should be realistically within the proposed time limits	Noted, and will be taken into account when providers are selected	
	5.Each proposed Centre should consider facilitating forums for patients and relatives to informally pass on information and gain moral support	This has been included in the service specification	
	6.Direct access to ward rather than A and E; ambulance staffs and all other 'first point of contact' staffs are aware that TTP case is an emergency case, making sure that the person in the call centre is aware that TTP requires an emergency ambulance and that any nursing cover is suitably qualified.	The SWG's view is that each centre will have clear pathways and protocols that set out what is	

		appropriate	
NHS BT	1.1.3 In reality, is it realistic to state that patients must not be refused admission due to non-availability of beds? This caveat will de-select some Trusts from applying because of 'risks' associated with not being able to comply. Is it not better to have a designated group of hospitals taking cross referrals? (Reference to this approach is made in section K) 2. Table 1 Should state that regional centres should ensure that TTP is on their local ambulance list of immediate transfer diagnoses. 3. Table 1 Should specify the level of escort 4.Table 1 Challenge to capture TTPs and few non-TTPs rather than panic transfer all with fragments and low plt counts, more focus on who to transfer to maximise transfer of TTP patients and minimise transfer of non-TTP patients.	This point was considered in great detail by the SWG. This is a HSS Service and Trusts must sign up to this to be a provider. The service specification has been clarified to explain what should happen if a bed is not available This has been agreed nationally. The SWG's view is that escort arrangements will be agreed locally based on clinical judgement The service specification sets out clearly that the policy is to treat any suspected TTP	The service specification has been amended.

	5. 2.2 Specialist Haematology Ward, should have specialist nursing expertise in TTP 6. 2.2 To have paed and adult required on one site may not be best model of care for patients. Adult centres may be separate site with adequate transition model 7. 2.2 ‘obstetrics’ should be replaced by specialist maternal medicine 8. 2.2 Access to a dedicated clinical psychologist,	patients and confirm the diagnosis later The SWG understand the desire to have experienced staff but there are no agreed standards so it is not possible to include in the service specification The service specification describes a clinical partnership which means that services may or may not be collocated, dependent on the organisation of services in that region. The way services describe	The service specification will be amended Service Specification has been be amended

	should add - adults & children & families	themselves nationally varies, this will be changed to specialist obstetrics	
	9.Some of the clinical information needs to be expanded to state that if blood group is unknown, group AB Octaplas should be used to avoid delay to first PEX. If Octaplas unavailable, standard FFP should be used for first exchange. If there is likely to be a delay in transfer, Octaplas / FFP infusion should be given.	The SWG think this is understood in the context of the document	
	10. Some of the timings for treatment aren’t consistent or have a clear rationale. Reference is made to patients starting plasma exchange within 4 – 8 hours and it’s not clear of what? (diagnosis/referral/ admission to hospital?). Reference is then made to starting treatment within 4 hours of admission.	The SWG think this level of detail is not required in the service specification.	
	11. what is definition of diagnosis? suspicion? confirmed with ADAMTS13?	These areas have been clarified in the service specification	
	13. Advise use of AB Octaplas for first exchange if blood group unknown to avoid delay (after two separate grouping samples have been taken).	The service specification states that the definition is suspicion.	

	14. 2.2 Senior cover and cover for the clinical nurse specialist needs to be in place for staff absence on leave, illness etc., This is too vague - please specify all circumstances 15. 2.2 The psychological impact of this disease is major and patients should be referred for psychological support before discharge; may be major - should be assessed prior to discharge re need for ongoing support arrangements 16.The statement that apheresis treatment needs to start within 90 mins of being alerted is unrealistic. There are often delays preventing this which are non-apheresis related e.g thawing of plasma, line insertion. The overall time to access first treatment is the important time to quote acknowledging that there needs to be urgency in all steps of the process to facilitate timely treatment. There is no rationale for a 90-min target time. It should be standard practice to inform the apheresis provider at the time of diagnosis.	The SWG's view is that this is the standard procedure and does not need to include this level of detail in the service specification. The SWG consider that this is the appropriate statement for inclusion in a service specification The SWG consider that the statement in the service specification is good practice and should remain as is. The SWG are aware that there is no evidence to support the 90 min recommendation but consider that it	

	17.2.3. 3 follow up regime considered to be too prescriptive	is well recognised that if people have a time frame to work to things are likely to happen more quickly and patient is prioritised . Timings are to manage patient care effectively, based on the best management of the patient	
	18. 2.3 .4 Regional centres will facilitate e.g. rituximab to prevent relapse, regular plasma or concentrate infusion for congenital TTPs, which may be charged through the regional centre or by the spoke trust. forgive my ignorance - which concentrate?	The SWG consider that these standards are appropriate and the pathway agreed will cover meet the patients' needs. Timings are to manage patient care effectively, based on the best management of the patient.	The service specification will be amended
	19. 2.4.3 Patients who are identified through screening as having low levels of ADAMTS13 activity (at least <15% with additional concerns, or <5%, +-detectable anti-ADAMTS13 antibody and a normal FBC) should be	The SWG think this is to be a locally	

	offered a course of (4 doses of weekly) rituximab. ‘or <5%, +-, +- - does this mean and or?’ 20. 2.4.3 Patients should return to closer monitoring in line with early or intermediate follow arrangement above. ‘This may evolve: suggest take treatment and follow up out of scope’ 21,Table 2 congenital pathway 1-3 weekly, SD-FFP 10-15ml or •Intermediate purity FVIII (8Y) 15-30 u/kg (for home therapy 22. 2.6.1 Maternity pathway, details in clinical guideline considered too prescriptive 23 2.7.3 Paediatric patients presenting with an acute relapse should be admitted to the paediatric trust coupled to the regional adult centre in order to be able to access the highest level of expertise. ‘No, should have paed experts and paed TTP centres - adults should not advise on paediatric care’ 24 2.8 interdependencies, a)clinical haematology , ‘specialists in TTP treatment; b)Stroke, add rehabilitation,	agreed protocol. The SWG note this point, the notation will be corrected SWG think this is the appropriate care pathway for these patients SWG think this is the appropriate care pathway for these patients. SWG are proposing this as the service standard, may be amended dependent on the patient SWG specially consulted with the paediatric	Service Specification has been amended

	c)specialist obstetrics, should read specialist maternal medicine, feto-maternal medicine, d) add psychology 25 4.2 Quality indicators All staff will undertake regular documented CPD, 'in what' 26 4.2 Clinical outcomes a)102 '% of patients starting PEX within 4 hours; of what?;' b)105 % of patients achieving an 80% survival from the point of diagnosis.' c) Percentage of patients achieving survival from point of diagnosis should be greater than 80%	specialists and this is the service model they suggested The SWG agree with these suggestions apart from specialist maternity. As services have different names national the SWG is changing obstetrics to specialist obstetrics This is already included as part of the regional specialist service CPD is defined usually by a profession's regulatory /accrediting organisation on an individual basis; The SWG clarification is of	The service specification has been amended

	d)106 ‘ % of patients will have a central line inserted within 1 hour of admission ‘, more important to audit time to first PEX as can be done via peripheral line to avoid delay 6.Needs consistency in terminology e.g. SD FFP is sometimes used and sometimes Octaplas and sometimes ITU v Critical Care 7.More emphasis is needed on attempting peripheral access for first exchange. First apheresis should not be delayed for line insertion if peripheral access is adequate. 8.The document would benefit from having some more detailed parameters / requirements relating to the apheresis service e.g use of centrifugal technology, a	‘referral to the regional TTP centre’ The survival rate will increase as the new model of care becomes established. This metric can be reviewed with the commissioned services. SWG consider that this is an appropriate indicator, the quality indicators are already monitoring time to first PEX The SWG note this and will standardise through the document. The SWG consider that the service	The service specification will be amended

	team of dedicated trained and competent operators 9.Regarding the statement “All Specialist Centres must have: • 24/7 access to therapeutic apheresis; where this is not directly provided but subcontracted, the clinical responsibility and decision making remains with the regional specialist TTP team” does not accurately reflect the nature of apheresis services in all parts of the country and would result in many trust being unable to provide the service as per this specification. For one or two trusts where the expertise exists within the TTP treating team this holds true but for everywhere else this should be considered in exactly the same way as, for example, requesting a CT scan. The radiologist will assist the referrer in ensuring the correct parameters and modality for the procedure and take responsibility for the patient during the procedure. This is also the same for the interaction with the anaesthetic teams for line insertion or High dependency care.	specification emphasises the need for timely treatment and does not need to reflect this level of detail. The SWG does not think that it is necessary to include this level of detail. The SWG are aware this this different to current practice. This is a key service standard. At all times the clinical responsibility for the patients falls within the TTP commissioned service. The SWG did not consider that the radiologist analogy is relevant. In normal practice if a patient is having apheresis	

	10.Where specialist apheresis services are delivered by another provider, the clinical care of the patient and decisions regarding apheresis should be taken jointly and the clinical responsibility for the patient during the procedure will likely fall to the specialist provider who have a wealth of experience and expertise in this area. This interaction is already well established and works very well in many centres providing expert TTP care. The process for referral and patient management is defined by service level agreements between the specialist apheresis service and the trust and should not be altered by this policy. 11.We would suggest that to ensure expert level care in all centres around the country, a more appropriate statement would read "All Specialist Centres must have: • 24/7 access to therapeutic apheresis; where this is provided by a different specialist provider, the clinical decision making regarding apheresis should be made jointly with the regional specialist TTP team"	experiences a medical problem, the on call haematology registrar from the NHS Trust is called to respond to the problem by the apheresis team, not the NHS BT consultants. Appropriate clinical discussions will take place but the clinical responsibility remains with the TTP provider. The view of the SWG is that there needs to be a clear protocol in place about local communication arrangements The SWG do not agree with this view	
	1.Is it realistic to state that patients must not be refused	These comments	

BBTS England	admission due to non-availability of beds? Some Trusts won't apply to become a specialist centre because of 'risks' associated with not being able to comply. Is it not better to have a designated group of hospitals taking cross referrals? (Reference to this approach is made in section K) 2. Should state that regional centres should ensure that TTP is on their local ambulance list of immediate transfer diagnoses 3. Some of the clinical information needs to be expanded to state that if blood group is unknown, group AB Octaplas should be used to avoid delay to first PEX. If Octaplas unavailable, standard FFP should be used for first exchange. If there is likely to be a delay in transfer, Octaplas / FFP infusion should be given. 4. Some of the timings for treatment aren't consistent or have a clear rationale. Reference is made to patients starting plasma exchange within 4 – 8 hours and it's not clear of what? (diagnosis/referral/ admission to hospital?). Reference is then made to starting treatment within 4 hours of admission. 5. The statement that apheresis treatment needs to start within 90 mins of being alerted is unrealistic. There are often delays preventing this which are non-apheresis related e.g. thawing of plasma, line insertion. The overall time to access first treatment is the important time to quote acknowledging that there needs to be urgency in all steps of the process to facilitate timely treatment.	repeated the points made by NHS BT, responses above	

	6.There is no rationale for a 90-min target time. It should be standard practice to inform the apheresis provider at the time of diagnosis. 7.More emphasis is needed on attempting peripheral access for first exchange. First apheresis should not be delayed for line insertion if peripheral access is adequate. 8.The document would benefit from having some more detailed parameters / requirements relating to the apheresis service e.g. use of centrifugal technology, a team of dedicated trained and competent operators 9.Whilst the overall care of the patient rests with the TTP clinical team, if the apheresis provider is not within the Trust e.g. NHSBT there should be a referral for treatment to another medical consultant to agree the apheresis treatment plan. 10.The document also contained some typos and further comments have been added to the attached pdf document by Dr Sylvie Benjamin, BBTS member and care provider for TTP patients in Oxford and Dr Sue Robinson BBTS member and TTP care provider in Guys and St Thomas' Trust		

BBTS Scotland	1.‘Automatic acceptance’ is desirable but may have to cover an ITU network rather than a single TTP centre. Also the TTP centre/ accepting hospital must have agreed 24/7 support from apheresis services bearing in mind the machine and staff operating the machine may need to travel to the patient. . 2.TTP is a difficult diagnosis and often treated before definitive testing results are available. Agree that PEX should taken place ‘within 4-8 hours’ but suggest that is defined as starting with contact between the referring consultant and the consultant in charge of the TTP team. That is how long it takes to co-ordinate transfer and PEX. If you say ‘within 4 hours of admission’ and ‘8 hours of diagnosis’ it will be difficult to meet the requirement and to audit compliance. Maybe also monitor the time of admission to time TTP team is contacted with the aim of keeping this as short as possible – this is out of the control of the TTP team. 3.Agree that suitable venous access is a rate-limiting step. If you insist on central venous line insertion by intensivists, IV access teams or interventional radiology then other trained, competent and available individuals	No see above The evidence is that patients have to treated as soon as possible, we have set time frames to optimise the patient pathway. Regional centres will work on education and will have to be open to taking patients who have not the diagnosis Quality standard and competency, the service specification sets out the English experience	

	will be excluded and this may cause delay. 4. Are you suggesting that all sites with a specialist TTP team should carry out ADAMTS13 testing? A 24-hour TAT requires 7-day testing and that can only be achieved by using a centralised lab(s) . Scotland sends samples to London for testing. 5.I assume the TTP CNS will be employed by the haematology unit hosting the TTP team. Given the acute nature of some of their work there will need to be cover out of hours and for annual/study leave. Alternatively could this role be assigned or shared with another member of the TTP team such as a haematology StR? These people will be the consultants of the future and we will rely on them to make a quick diagnosis and referral of these patients so excluding them from patient management as not senior or specialised does not make sense. Supervision will come from a senior team member. In addition I would suggest an MDT structure for ongoing management. 6.Use Octaplas (not plasma or FFP) throughout this document although lack of access to Octaplas should not delay initial treatment where standard FFP is better than no PEX. Pathways need to include the ability to give Octaplas prior to transfer if there are any delays to first PEX. In Scotland all hospitals will have access to Octaplas from Sept 2017 directly from SNBTS. 7.Interdependence on other services will vary case-by-case. PEX does not have to be on-site but the service has to be mobile and the limits of that mobility have to be defined. There are some services that have to be	No, must have access to it Noted This would be a local Scottish agreement Scottish services will need to decide on this locally	

	available on-site (critical care, haematology) but other services that have to be available for consultation and to transfer patients if renal failure or cardiac support become the primary problem. The same goes for maternal and fetal medicine and paediatrics. This could be defined in an SLA with the TTP team along with requirement for attendance of specialists at an MDT meeting for selected cases.		
TTP Network Representative 1	1. I am familiar with specialised services and whilst I realise primary care sits outside of this it would seem logical for specialist centres to engage with CCGS in order to raise awareness amongst GPs and other health care professionals. 2.Presumably Health England provides professional development around very rare diseases? If not then it would seem an opportunity for ttp specialists to work with HEE and Royal colleges to develop learning - perhaps e-learning if it doesn't already exist. 3.I am pleased that this is being considered as a specialised service and the spec gives me confidence of how I and others can expect to be treated and cared for.	Regional centres will provide those links This is a very condition and is on the TTP medical student training in haematology role of specialist centres to work in partnership	
Representative 2	1.Patient from Taunton: To be honest I dislike the idea of receiving treatment even further away from home and am very happy having checks and Retux to prevent relapse locally. I also prefer to see my excellent consultant there. While I understand the need to standardise things I	The SWG is pleased to see such good experiences of care. The service specification allows	

	would not want to have to travel great distances for routine blood checks and preventative treatment. E.g.Earlier this year an Adamts test showed that my levels were slipping and treatment was given locally. The whole experience was so much gentler than spending six weeks in a city so far from home. I am very happy with these things being given at my local hospital. With IT medical contact easily being made, advice given from a regional centre, distances could be minimised. Also there is the cost of travel for friends and family to visit. Visits cannot be made daily when distances are great, and contact with family and friends is so important when TTP is acute. Hospital apps would involve travel, parking, none of these are easy in cities, more time off work. I understand that cancer care is offered more locally, there is even a mobile bus that visits a local town to save some patients having to travel for treatment. Most hospitals now have day facilities, treatment centres, surely TTP check ups and preventative treatments can continue to be included locally. I can only comment from my own experience, to be honest much of what is in the document has applied to me, I was transported by ambulance to a hospital where PEX could be arranged. I had good follow up, and was eventually handed back to the referring hospital, which has managed my care very well indeed. I had MRI and CT scans and follow up investigations. The referring hospital arranged counselling. All these things are very important and I'm pleased to see them in the document.	for shared care if this model is requested by the patient. The clinical care and responsibility for the patient remains with the specialist regional centre as they have the expertise to best manage patient's care. Acute care needs to take place in the specialist regional centre.	

Representative 3	2.I guess I'm saying that I agree with most of what the document says, PEX can obviously only be undertaken where the facilities are based, so when TTP is acute and PEX is needed, I understand we would need to be in that place. 3.It would have been good to have some sort of counselling earlier when TTP was acute, and I like the idea of a specialist nurse who understands how TTP affects us. 4.The only things I really don't like is preventative treatment being handed back to specialist centres, when referring hospitals could probably manage this, and mine does. Also a previous doc on here re Retuximab states (I think) that Adamts checks should be every 3 months. 5.The one thing that isn't mentioned is people with symptoms being sent straight to hospital for blood tests by GPs. Perhaps that's another issue. 6.I am actually quite upset by this, I'm all for centres with resources and advice, where medical staff can	Psychology input is part of the service specification SWG view is that this can be agreed between the TTP centre and the local DGH as appropriate The SWG thinks that GPs are unlikely to recognise this disease at the first acute episode. The regional centre will work with patients and GPs in relation to what should happen if a patient starts to relapse. The SWG are concerned with managing expertise and optimal outcomes for patients with	

Representative 4	make contact, (and in this day and age this is not difficult) but care needs to kept nearer to home 2.Location unknown: Wow this is fantastic 3.Patient from Northumberland: I was transferred to another hospital 4 days into treatment. Once there I just had to go to the next ward for PEX which was done by the renal staff. From my point of view everything seemed very joined up in terms of communication between hospitals. My diagnosis was quick and treatment began quickly too which I now understand is crucial for TTP patients. At one point my consultant sought advice from the team at UCLH on where to go next with my treatment. It felt reassuring to me that a network of specialists was out there. I think the idea of eight specialist centres with nursing staff with specialist knowledge and counselling is a good one although patient experience will inevitably depend on how far they live from the centre. Living in SE Northumberland our nearest A&E is at Cramlington but generally you expect to have to go to Newcastle for hospital treatment. Its a 40-minute drive or an hour or more on public transport. I'm getting my outpatient care at the haematology clinic at the RVI in Newcastle. I see the same doctors there as the ones I saw in hospital. I	access to as much care locally as is appropriate The SWG noted the comments and the positive patient experience. Psychology support is built into the new model of service.	

Representative 5 Representative 6	have been given numbers to call if I have concerns including an emergency number for the ward if out of hours. I do of course worry about relapse but generally feel confident in the care I am receiving and that checks are in place to catch any deterioration. I cannot fault the emotional support I received and continue to receive from everyone involved in my care since diagnosis, however I have never been offered formally counselling. I think specialist counselling would be beneficial. Many of the nurses who treated me had treated TTP patients on occasions but most had not been with them through the whole journey. The availability of specialists with understanding of the disease from onset through treatment to remission would be hugely beneficial as part of a structured counselling programme. 4.This is really positive - I particularly like that the clause about referral to a specialist TTP centre as soon as diagnosis has been made - that didn't happen in my case, local hospital tried to treat me with PEX for two weeks - knowing what I know now how I didn't die was a miracle! I am actually quite relaxed about my specialist centre doing follow ups etc, purely because I don't feel my local hospital yet truly understands the condition and past experience has shown me that shared care between the two does not work as well as it should. That said I am lucky my specialist centre is fairly easy to get to.	TTP is not a specialised service in Wales so this service specification does not apply. NHS England shares its service specifications with the devolved administrations who may choose to adopt them.	

	5.In response to the future possibility of patients in Wales making use of the specialist centres: I think the protocols/guidelines are good and needed , but I think I would probably be very worried having to travel across into England for hours in an ambulance before being able to get treatment, whereas now the hospital I attend and Drs are only 10 mins away. As a single parent, I would be away from my children and family for weeks without seeing them having to travel that far.		