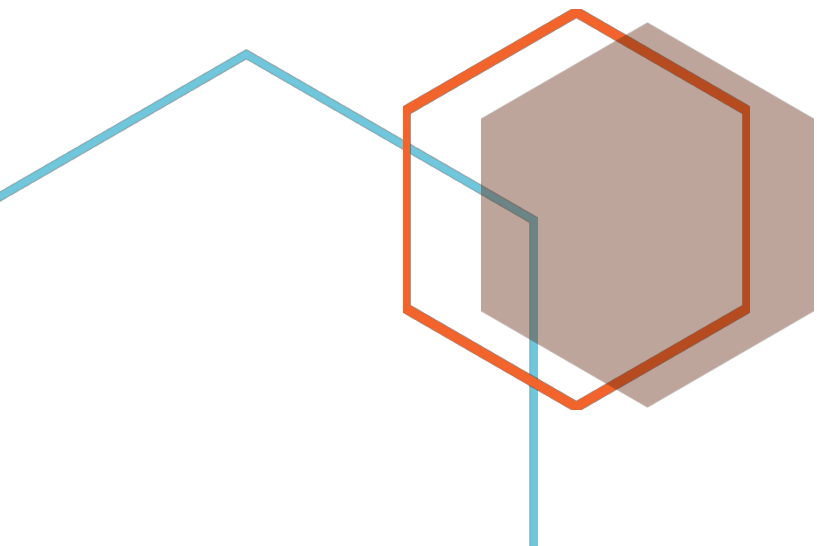




ITP* CLINICAL CENTRE AUDIT REPORT 2018

***Immune Thrombocytopenia**

This report summarises the findings of the first national, electronic, peer led audit of clinical centres in the United Kingdom specializing in the care of patients with ITP. Twenty-two out of 38 centres participated. For adult centres, median compliance with standards by self-assessment was 97% and 67% by evidence provided. For paediatric centres, median compliance by self-assessment was 86% and 68% by evidence provided. The audit captures the status of a new network of clinical centres, highlighting examples of good practice as well as areas for development.





Final summary report from the UK Immune Thrombocytopenia (ITP) Clinical Centre Audit 2018

Introduction

Immune thrombocytopenia (ITP) is an autoimmune disorder characterized by a low platelet count (thrombocytopenia) and typically presents with bruising and mucosal bleeding. It is a rare disorder with an incidence of approximately 3 per 100,000 and a prevalence of approximately 10 per 100,000.

In 2011 the ITP Support Association, under the chairmanship of Shirley Watson MBE, brought UK healthcare professionals together at a meeting hosted at the Houses of Commons. During that meeting, the UK ITP Forum was established (www.ukitpforum.org), a voluntary professional organisation that aims to improve the care and outcomes for patients with ITP in the UK. As part of this work a network of specialist ITP clinical centres was established (www.ukitpforum.org/index.php/en/itp-clinical-centres), led by clinicians with an interest in this rare disorder and able to provide a specialist opinion for complex cases. One reason that the support association helped establish a network was that although Bart's and the Royal London was already a prominent ITP clinical centre, not all patients were able to travel long distances and a network offered patients an opportunity to access specialist support closer to home.

Although ITP is a rare disease there are currently no specialist commissioning arrangements with NHS England or the devolved nations and the responsibility for patient care remains with individual clinicians and their host organisation. The clinicians establishing a network of centres therefore set criteria for an ITP Clinical Centre (Appendix 1) that are effectively quality standards. This is the first audit that clinical centres have carried out against those criteria. This report summarises the findings of a co-ordinated voluntary action to professionally self-regulate these centres.

Audit design and process

This was an internal peer to peer electronic audit carried out by ITP clinical centre leads. Audit forms were designed to determine compliance with the criteria for ITP Clinical Centres. The proforma used are included as Appendix 2 for adult centres and Appendix 3 for paediatric centres. The British Society of Haematology was approached to act as an independent auditor, but felt that this was a significant commitment beyond their scope. The ITP Support Association was invited to contribute patient members to the auditing team. However due to the number of centres being audited and the voluntary nature of the association, there was not resource to participate on this occasion. Finally, the audit team considered physical visits



to clinical centres; however this was also not practical due to lack of dedicated time or financial resources available to participating clinical centres.

The audit forms were circulated to ITP clinical centres for completion between 15th January 2018 and 31st December 2018. Centres were invited to complete the audit forms, describing their service and indicating whether each criterion was met (self-assessment). If indicating yes, they were also asked to submit evidence of compliance with that standard. The proforma provided suggestions for suitable forms of evidence. The completed forms and associated evidence was submitted to the audit lead.

After submission, audits were sent to a peer reviewer, who completed the audit form (grey boxes), indicating whether the evidence provided demonstrated that the centre met each criteria as well as writing a summary and conclusions/recommendations. Reports were completed by the first week of April 2019 and returned to the audit lead. All reports were reviewed by the audit lead to ensure consistency and any changes discussed and agreed with the peer reviewer. All draft reports were then sent to the submitting ITP Clinical Centre lead to provide an opportunity to comment or identify potential inaccuracies before a final report was issued to each clinical centre lead.

Audit results

ITP clinical centres

There were 38 ITP Clinical Centres, hosted by 24 NHS trusts. These consisted of:

- 21 adult centres
- 16 paediatric centres
- 1 adolescent centre

The geographical distribution of centres can be seen in Figure 1 below. The clinical leads for each centre are listed below in Table 1.

Auditors

Drs Quentin Hill (audit lead), Susan Robinson, Rachel Rayment, Philip Connor, Mamta Garg, Vickie McDonald, Catherine Bagot, Tina Biss, John Grainger, Marie Scully and Gillian Evans. Profs Mike Murphy and Marie Scully.



Figure 1: Distribution of ITP Clinical Centres in the United Kingdom



**Table 1. ITP Clinical Centre Leads.**

Adult centre	Centre Lead	Paediatric Centre	Centre Lead
Aberdeen	Prof Henry Watson	Aberdeen	Dr Gordon Taylor Prof Angela Thomas
Glasgow	Dr Catherine Bagot	Edinburgh	Dr Christine MaCartney
Newcastle	Dr Kate Talks	Belfast	Dr Tina Biss
Leeds	Dr Quentin Hill	Newcastle	Dr Mike Richards
Manchester	Dr Jecko Thachil	Leeds	Dr John Grainger Dr Jayashree Motwani
Norwich	Dr Hamish Lyall	Manchester	Dr Michael Gattens
Leicester	Dr Mamta Garg	Birmingham	
Birmingham	Dr Will Lester Dr Emily Symington	Cambridge	Dr Amrana Qureshi
Cambridge	Dr Sue Pavord & Prof Mike Murphy	Oxford	
Oxford	Dr Rachel Rayment	Wales	Dr Philip Connor
Wales	Dr Charlotte Bradbury	Bristol	Dr Emma Philips
Bristol	Dr Tim Nokes	Plymouth	Dr Tim Nokes
Plymouth	Dr Gillian Evans Dr Vickie McDonald	Hammersmith	Dr Nichola Cooper
Kent	Dr Steve Austin	Guy's	Dr Maria Pelidis
Royal London	Dr Nichola Cooper	GOSH	Dr Keith Sibson
Hammersmith	Prof Marie Scully	Southampton	Dr Gregory Harvet
UCL			
St Georges	Dr Susan Robinson	Adolescent centre	Centre Lead Dr Victoria Grandage
Guy's	Dr Rashid Kazmi	UCL	
Southampton	Dr Benjamin Bailiff		
Coventry			

Of 38 ITP Clinical Centres, 22 (58%) submitted an audit of which 14 were adult centres and 8 were paediatric centres. Four out of 22 submitted a self-assessment without evidence and the remaining 18 also submitted evidence of their compliance with criteria.

Figures 2 (adult centres) and 3 (paediatric centres) summarise how centres met criteria by self-assessment and the evidence provided. For adult centres, the median compliance with 18 criteria by self-assessment was 97% (range 33-100%) and by evidence provided was 67% (range 0-100%). For paediatric centres, median compliance with 14 criteria by self-assessment was 86% (range 50-100%) and by evidence provided was 68% (range 0-100%).

Each centre received an individual report. Some examples of good practice and areas for development at each centre are summarised in Table 2 (adult centres) and Table 3 (paediatric centres).



Figure 2a: Adult ITP Clinical Centres compliance with 18 criteria (%)

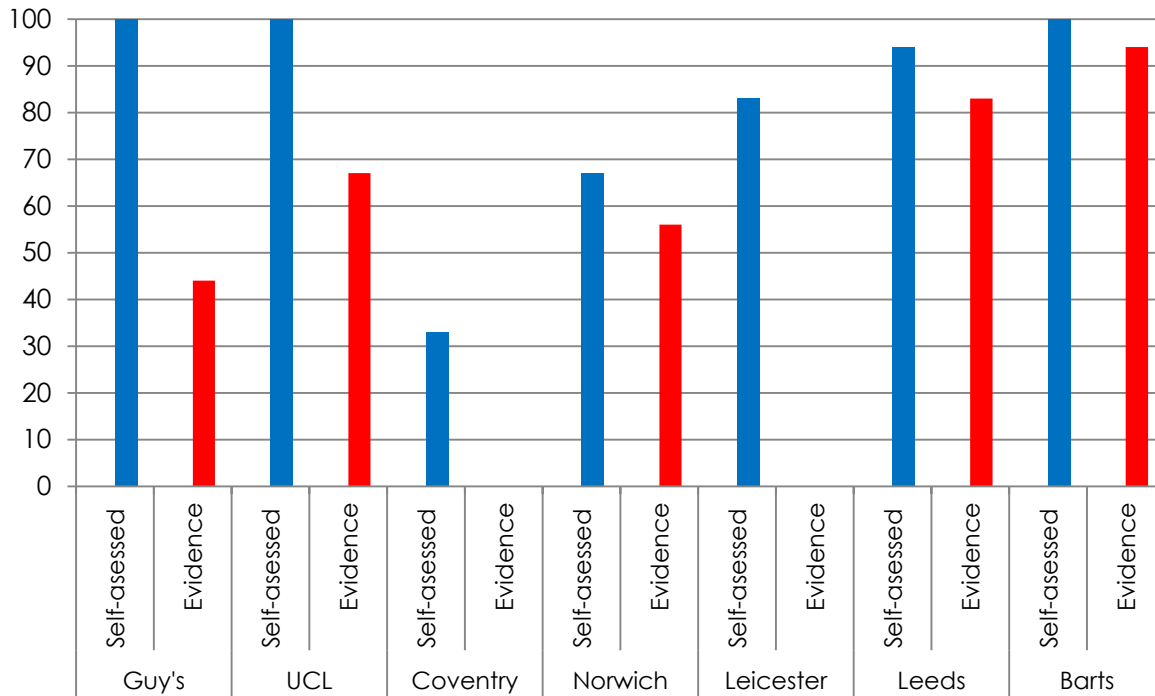


Figure 2b: Adult ITP Clinical Centres compliance with 18 criteria (%)

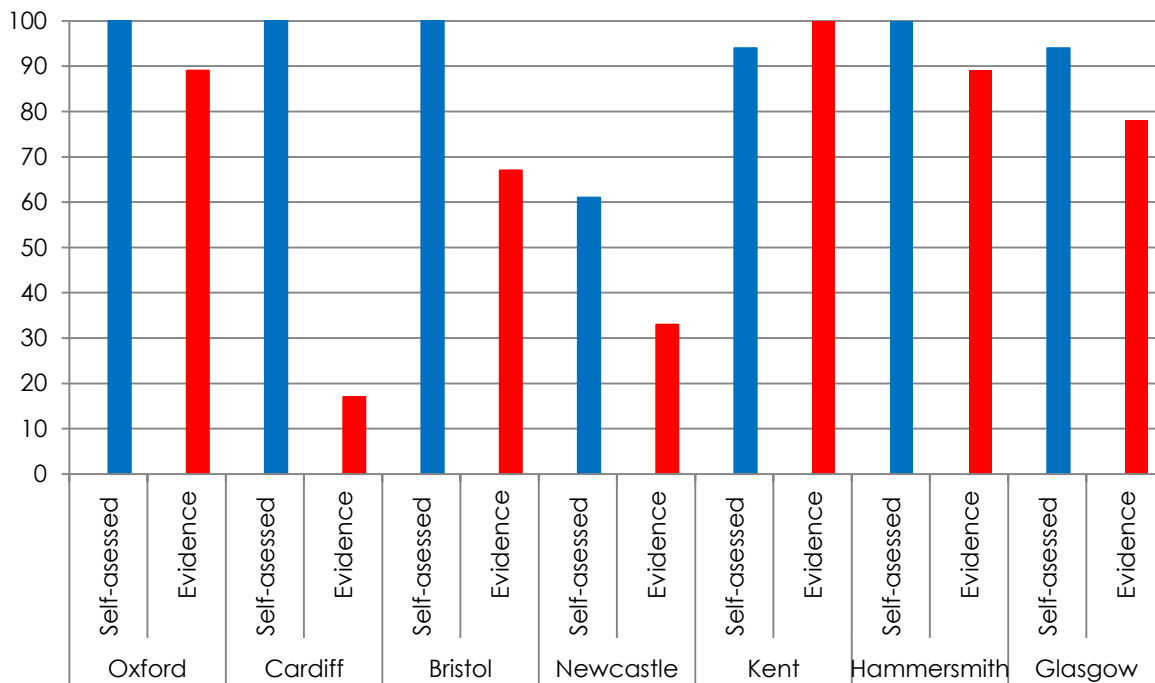




Figure 3: Paediatric ITP Clinical Centres compliance with 14 criteria (%)

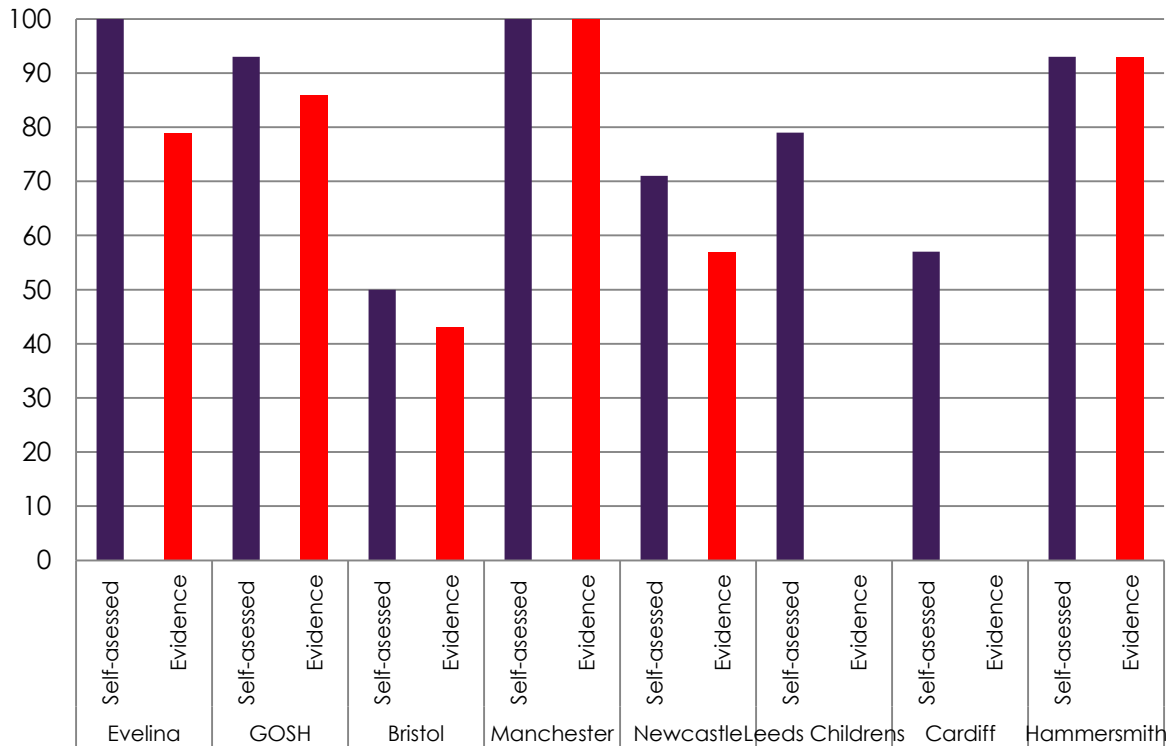


Table 2: Areas of good practice and development needs in participating adult ITP Clinical Centres.

Adult Centre	Examples of good practice	Areas for development
Guy's	Guidelines covered patient management including obstetric ITP with excellent flow diagrams for treatment.	Provide evidence of written peri-operative plans.
UCL	Centre meets criteria with specialist medical and nursing provision, a dedicated clinic, good audit results, patient information and peri-operative and obstetric planning.	No issues identified. A small number of requirements will require provision of evidence.

ITP Clinical Centre audit report 2018



Coventry	<p>There are a number of aspects of specialist care that are being carried out including good recruitment into the Adult ITP Registry, MDT discussion of difficult cases and provision of advice to colleagues.</p>	<p>The current consultant has been recently appointed and this is an ITP service in evolution. There is a need to formalise the ITP clinical lead status and referral pathway. Also work towards meeting and evidencing standards.</p>
Norwich	<p>There was evidence of consistent regularly audited care, supported by a clinical nurse specialist and an enthusiastic clinical lead who is to be commended for maintaining a good range of CPD, support for clinical trials and evidence of expertise in ITP care through publication and presentation.</p>	<p>Areas for development include recognition of ITP lead status in job plan, ITP registry recruitment and provision of written patient information</p>
Leicester	<p>Self-assessment indicates a large ITP practice and that most requirements are met. Although not presented within this audit, the clinical lead has designed and uses an excellent patient information booklet and handheld record.</p>	<p>Difficult to draw conclusions without supportive information. Some concern about lack of co-ordination of 2 ITP clinics run by different consultants and no protocols for ITP management.</p>
Leeds	<p>The haematology department and the Trust management should be proud of the excellence of the ITP service delivered.</p>	<p>There should be recognition for the provision of the service in the consultant and nursing job plans.</p>
Barts	<p>An exemplar site for ITP care and should be commended on the service that the team have built for the clinical care of their patients.</p>	<p>Given the size and complexity of the ITP patient population it would be preferable to have additional consultant time formally job planned for the other haematology consultants. This may help to support a weekly ITP clinic allowing for greater flexibility of patient care. Local audit.</p>
Oxford	<p>Local guidelines and patient information were clearly written and easy to follow. There was good participation in audit and clinical trials. The international expertise of the lead clinicians was recognised and Oxford was found to be an excellent ITP clinical centre</p>	<p>This is a specialist ITP clinical centre and there is a need for CNS time to care for these patients.</p>



Cardiff	<p>The department have a very comprehensive diagnosis and management proforma for ITP and management plans for ITP in pregnancy. Self-assessment indicates that there is good MDT review of patients, access to the wards and CNS support.</p>	<p>Self-assessment indicates that Cardiff is meeting criteria for an ITP clinical centre and the evidence provided supports this. More comprehensive evidence of meeting centre criteria will be looked for at the next review.</p>
Bristol	<p>The overall impression is that an exemplary level of service is provided. Highlights include excellence in research at a national level, comprehensive MDT review, excellent patient information and a system that alerts the team electronically when a known patient with ITP is admitted to any hospital within the trust.</p>	<p>For future audits, evidence of local guidelines, surgical plans and the summary sheet for ITP patients mentioned would be useful supporting documentation</p>
Newcastle	<p>An active ITP clinical centre that is providing consistent care, supported by a clinical nurse specialist and enthusiastic medical and nursing leads.</p>	<p>Support is needed from the department/trust with regard to formal recognition of the ITP centre lead role of the physician and nurse specialist within job planning.</p>
Kent	<p>The East Kent adult ITP centre meets all requirements. Written patient information is particularly good.</p>	<p>Develop or apply an ITP specific proforma for pregnancy/surgery.</p>
Hammer-smith	<p>The clinical lead is a recognised international expert in this field. The centre has a very good set up for ITP locally and support a patient group and the ITP forum</p>	<p>Results of audit, patient feedback, management proformas and treatment guidelines will support future audit.</p>
Glasgow	<p>The report demonstrates the dedicated, specialist service provided enabling focused disease specific clinical care and research access for the patient.</p>	<p>Development of local policies will help support future audit.</p>



Table 3: Areas of good practice and development needs in participating paediatric ITP Clinical Centres.

Centre	Good practice	Areas for development
Guy's (Evelina)	Evelina is a newly established ITP centre and has already established many essential components such as written information for patients, a dedicated clinic and specialist nursing support.	Strengthen links with other paediatric centres in the region and encourage more referrals. Also undertake local audit of practice.
GOSH	GOSH has collaborated on a number of important papers reviewing treatment. Based on evidence from audit, GOSH should be recognised as an ITP Clinical centre	Undertake audits of ITP management and provision of advice to local centres in next 12-24 months. Aim to reach recruitment target for ITP registry in the next 12 months.
Bristol	Some evidence of good practice that included local management protocols, registry recruitment, written information and a specialist clinic.	Some deficiencies including a lack of audit and a local lead. A local lead has been identified since the audit was undertaken.
Manchester	Manchester is an exemplar site. This is due to a combination of excellence in research and evidence of high quality care and good governance, serving the city and wider region.	To maintain and develop this comprehensive regional ITP service, more consultant PA time is needed.
Newcastle	Many aspects of a clinical centre are in place, including appropriate 24 hour consultant cover, written information for patients and local protocols for management.	Further develop ITP management protocols. Audit ITP management and patient satisfaction. Clarify role as ITP centre within job plan of clinical staff. Centralise ITP care within one clinic (in process)
Leeds	Self-assessment indicates that most aspects of specialist ITP care are being carried out.	It is not possible to draw conclusions from audit without supportive information. It would be recommend that the clinical lead job plan is reviewed with respect to recognition of ITP centre clinical lead status



Cardiff	<p>This is the only paediatric haematology department in Wales and therefore has a large geographic catchment area. Patients are being recruited into trials when available and the registry when patients with chronic ITP are referred. There is an agreed protocol for management of acute ITP and an open access clinical area for these patients.</p>	<p>Self-assessment indicates that some but not all requirements of a specialist centre are being met. It is not possible to draw detailed conclusions without supporting documentation. The centre would benefit from clarity within job plans of the lead clinician and CNS. There is a need for guidelines, audit and supportive information provided at the next centre audit.</p>
Hammer-smith	<p>The medical lead is a recognised international expert in ITP. Audit demonstrates compliance with all standards other than registry recruitment.</p>	<p>A work plan is needed to ensure paediatric registry recruitment. The plan for a clinical fellow to support recruitment is noted.</p>



Audit Outcomes

- Each participating ITP Clinical Centre lead received an individual report of the audit findings and recommendations. We hope that the report will be used to highlight and progress local developmental needs and assist clinical leads in discussions with their host trust in order that they have the support required to provide a comprehensive service for patients with this rare disorder.
- The audit findings have been reported to the UK ITP Forum at the British Society of Haematology Annual Scientific Meeting in April 2019. This summary report of the audit will also be made available to download from the UK ITP Forum website.
- The audit will be repeated in 3 years. Two centres will be re-assessed in 18 months to look for progress in meeting standards.
- All 16 clinical leads that did not submit an audit were contacted.
 - The paediatric lead at Edinburgh had retired. On discussion with medical staff in Edinburgh, no replacement could be identified and Edinburgh is no longer an ITP Clinical Centre
 - The paediatric lead at Oxford did not receive initial correspondence and therefore was not aware of the audit. She will continue as a clinical lead and participate in the next round of audit.
 - Of the remaining 14 centres, non-return was most frequently due to clinician workload although some had been on extended leave during the audit period. All 14 clinicians indicated that they would continue as ITP Clinical Centre leads and participate in the next round of audit.
 - It was agreed that centres not participating in two sequential service audits would not retain ITP Clinical Centre status.
- Consenting ITP Clinical Centre leads would share examples of good practice such as local treatment guidelines and patient information sheets, in order to improve care.

Discussion and conclusions

There are a number of important limitations to this audit. Firstly, less than 50% of centres submitted evidence of practice (18/38). It is possible that centres not submitting evidence or self-assessment due to high work load may have also been able to meet fewer of the criteria being assessed. The absence of patient involvement, external assessors and direct inspection of sites are all limitations on the objectivity and depth of the assessment.

By self-assessment, the median compliance with criteria was 86-97%. The ability of centres to meet essential vs. desirable criteria was similar. There was no single criterion that had particularly poor compliance. Although most centres had both a clinical lead and nurse practitioner support by self-assessment, 10/14 adult centres and 4/8 paediatric centres could not provide evidence that these were in place through job plans. **Clinical centres are providing comprehensive specialist care that is not available to all hospitals and that activity should be recognised in the job plans of clinical leads and specialist nurses who provide the service.** The UK ITP Forum is currently working with the British Society of Haematology to write a national framework document that will aim to describe a model of service provision. This document may impact on the future criteria and role of ITP Clinical Centres.



Although separate to this audit, the ITP Support Association conducted a patient satisfaction survey 2017-18, asking its members about their experience of being managed at an ITP Clinical Centre. There were 245 responses and the full report can be downloaded from the association website (<https://www.itpsupport.org.uk/index.php/en/16-home/108-itp-clinical-centre-survey-results>). Briefly, 100% of respondents found that staff were friendly, polite and attentive, 99% were happy with their ITP management and 85% rated their ITP Clinical Centre as 9-10/10.

This is the first audit of a new network of clinical sites, some of whom are developing their service. There are grounds for optimism, with many examples of good practice found during review, plans for sharing good practice and recommendations for change and future audit.

Finally, I would like to thank the auditors for their hard work reviewing the evidence and writing individual centre reports.

Dr Quentin A Hill
Consultant Haematologist, Leeds Teaching Hospitals
Chair, UK ITP Forum



Appendix 1: Criteria for ITP Clinical Centres

Adult ITP Clinical Centre

Essential

A consultant haematologist who:

- Has a specialist interest in ITP
- Is available to give advice/accept referrals regarding difficult cases of ITP, from consultant colleagues both within their own hospital and outside the hospital's catchment area
- Is a member of the UK ITP forum
- Regularly takes part in CPD to remain up to date in the management of ITP

The hospital must:

- Have 24 hour consultant haematology cover
- Be able to offer expert advice on the management of ITP in the following clinical areas; obstetrics, gynaecology, dentistry, surgery, others as appropriate
- Have protocols for the management of ITP, both general and for specific situations e.g. pregnancy
- Be actively involved in recruitment to the UK ITP Registries
- Take part in local/national audit related to ITP
- Be active in post marketing surveillance of new/off licence drug treatments for ITP

Desirable

- Review all ITP patients in one specified clinic, which is led by a consultant haematologist with a special interest in ITP
- Be consistent in its management of ITP
- Nurse practitioner who provides support for ITP patients
- Dedicated phlebotomy service in inpatient and outpatient areas
- An obstetrician with a specialist interest in haematology
- Take part in clinical trials investigating treatments for ITP
- Printed information available for patients with ITP e.g. The Platelet
- Raise awareness amongst ITP patients of available ITP support groups

Paediatric ITP Clinical Centre

Essential

A consultant paediatric haematologist who:

- Is a named lead in ITP cases at the centre
- Is available to give advice/accept referrals regarding difficult cases of ITP, from consultant colleagues both within their own hospital and from surrounding centres
- Is a member of the UK ITP forum
- Regularly takes part in CPD to remain up to date in the management of ITP

The hospital must:

- Have a named nurse lead for paediatric ITP
- Have local protocols for the management of ITP
- Be actively involved in recruitment to the UK Childhood ITP Registry
- Take part in local/national audit related to ITP
- Printed information available for patients with ITP
- Raise awareness amongst ITP patients of available ITP support groups

Desirable

- Have 24 hour consultant haematology cover
- Review all ITP patients in one specified clinic, which is led by a consultant haematologist with a special interest in ITP
- Be consistent in its management of ITP
- Take part in clinical trials investigating treatments for ITP



Appendix 2: Adult ITP Clinical Centre Audit (Blank Proforma)

NAME AND ADDRESS OF CENTRE

Lead Clinician(s)

Lead Nurse

Additional staff

.....

DATE OF SUBMISSION OF AUDIT REPORT



1. THE ITP CENTRE

Description of the inpatient and outpatient arrangements for ITP patients.

2. SERVICE REQUIREMENTS

Requirements	Evidence	Y/N/ Notes	Y/N
24 hr haematology consultant cover	Job description/rota		
Expert advice: e.g. O&G, dentistry, surgery	Surgical or obstetric plans		
Local protocols in place for management of ITP (including pregnancy)	Evidence of protocols		
Active involvement in recruiting to adult UK ITP Registry	Evidence of recruiting at least 50% of eligible patients		
Participate in local/national ITP audits	Evidence of audit		
Active in post marketing surveillance of ITP medicines	Submitted forms		



3. LEAD CLINICIAN

Requirement	Evidence	Y/N/ Notes	Y/N
Designated ITP lead	Job description		
Available for advice to consultant colleagues and surrounding hospitals	E.g. Patient demographics, referrals (no clinical information)		
Member and regular attendee of the ITP forum	Minutes of meetings		
Maintains up to date ITP-related CPD	CPD returns		

4. ADDITIONAL SERVICES

Desirable	Evidence	Y/N/ Notes	Y/N
Designated specialist ITP clinic	Clinic templates		
Consistent ITP management	Results of audit		
Nurse practitioner providing ITP support role	Job description		
Dedicated phlebotomy (in/outpatient)	Intranet, image, statement		
Obstetric lead	Job description		
Participation in clinical trials	Evidence of trials		
Printed patient information	Information leaflets		
Raise awareness amongst ITP patients of ITP support groups	Information leaflets		



Appendix 3 Paediatric ITP Clinical Centre Audit (Blank Proforma)

NAME AND ADDRESS OF CENTRE

Lead Clinician(s)

Lead Nurse

Additional staff

.....

DATE OF SUBMISSION OF AUDIT REPORT



1. THE ITP CENTRE

Description of the inpatient and outpatient arrangements for ITP patients.

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2. SERVICE REQUIREMENTS

Requirements	Evidence	Y/N/ Notes	Y/N
Lead paediatric ITP nurse	Job description		
Local protocols in place for management of ITP	Evidence of protocols		
Active involvement in recruiting to UK Childhood ITP Registry	Evidence of recruiting at least 50% of eligible patients		
Participate in local/national ITP audits	Evidence of audit		
Printed information available for patients	Evidence of information		
Raise awareness amongst ITP patients of ITP support groups	Evidence from information leaflets		



3. LEAD CLINICIAN

Requirement	Evidence	Y/N/ Notes	Y/N
Designated ITP lead	Job description		
Available for advice to consultant colleagues and surrounding hospitals	E.g. Patient demographics, referrals (no clinical information)		
Member and regular attendee of the ITP forum	Minutes of meetings		
Maintains up to date ITP-related CPD	CPD returns		

4. ADDITIONAL SERVICES

Desirable	Evidence	Y/N/ Notes	Y/N
24 hr consultant haematology cover	Job description/rota		
Designated specialist ITP clinic	Clinic templates		
Consistent ITP management	Results of audit		
Participation in clinical trials	Evidence of trials		

