PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 36: NON-MALIGNANT HAEMATOLOGY

Feidhmeannacht na Seirbhíse Sláinte
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ROYAL COLLEGE OF PHYSICIANS OF IRELAND

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This section describes the model of care for non-malignant clinical haematology practice. Malignant haematological disease is covered under the model of care section on Cancer Services. Laboratory haematology is covered under the model of care section on Laboratory Medicine.

36.0 INTRODUCTION

Non-malignant haematology (hereafter referred to simply as 'haematology') covers a wide spectrum of issues, including:

- Haemoglobinopathy, including sickle cell diseases and thalassemia
- Disorders of coagulation and haemostasis including congenital disorders such as haemophilia, Von Willebrand's disease, platelet function disorders; and acquired bleeding disorders such as disseminated intravascular coagulation (DIC) and vitamin K deficiency bleeding
- Inherited and acquired thrombophilias, including antithrombin deficiency, protein C deficiency, protein S deficiency, antiphospholipid syndrome; thrombosis and thromboembolism
- Anaemia, including the nutritional anaemias - iron deficiency, megaloblastic anaemia, haemolytic anaemia including hereditary spherocytosis; congenital and acquired and immune causes; red cell aplasia, anaemia of chronic diseases, sideroblastic anaemia and other rare forms.
- Platelet disorders including immune thrombocytopenia and congenital thrombocytopenia
- White cell disorders including the congenital neutropenia syndromes such as Kostmann syndrome, Shwachman-Diamond syndrome, and X-linked neutropenia; and acquired leukopenia/neutropenia including autoimmune neutropenia and chronic idiopathic neutropenia
- Bone marrow failure syndromes, such as Fanconi anaemia, dyskeratosis congenita, and other rare disorders
- Haemophagocytic lymphohistiocytosis and macrophage activation syndrome
- Materno-fetal haematological disorders, including alloimmune neonatal thrombocytopenia and neutropenia
- Investigation of suspected non-accidental injury
- Transfusion requirements, including red cells, platelets, and other blood products, including special requirements for neonatal and paediatric patients
- Conditions requiring plasma exchange such as catastrophic antiphospholipid syndrome
- Children who refuse or whose parents refuse blood transfusions for religious or other reasons
- Cytopenia of non-haematological causes including hypersplenism, osteopetrosis, lysosomal storage disorders, histiocytic disorders, drugs and infection
- Microangiopathic haemolytic anaemias (MAHA) and investigation of underlying causes including Kasabach Merritt syndrome, haemolytic uraemic syndrome, atypical haemolytic uraemic syndrome, drug-induced MAHA and thrombotic thrombocytopenic purpura
- Non-haematological primary diseases with haematologic complications, such as catheter-related thrombosis, DIC, acquired protein C deficiency, to name but a few. Haematology consultation requests are received from multiple other specialities in the setting of a tertiary paediatric hospital

Training in paediatric haematology normally takes place after completion of basic specialist training (BST) in either paediatrics (preferable) or general internal medicine. Higher specialist training in haematology is normally five years, with a minimum of two years training in paediatric haematology in specialised centres, and the remainder in adult haematology. Satisfactory completion of training requires that the trainee acquire the competencies set out in the haematology curriculum. The completion of training also requires that the trainee obtains Fellowship of the Royal College of Pathology (FRCPath). As specialists in haematology are involved in direct patient care and in management of haematology pathology laboratories, specialist training covers both these components, including training in transfusion medicine.

In the last 10-15 years, the workload of the consultant paediatric haematologist has increased dramatically, due to legislation (European Working Time Directive and the European Union Directive on Haemovigilance); regulatory initiatives such as laboratory accreditation; the requirement for consultants to partake in clinical governance, audit and research; the growing paediatric population; changes in population ethnicity in Ireland resulting in an exponential increase in the numbers of children with sickle cell disease; and increasing complexity in medical diagnosis and treatment.

Prevalence Examples

Conditions of relatively high prevalence

There are 394 patients currently registered with Our Lady's Children's Hospital Crumlin (Crumlin) with sickle cell disease or severe haemoglobinopathy. There are approximately 1400 children registered with hereditary coagulation disorders.

Rare conditions

There are many haematology diseases of very low prevalence, e.g. congenital neutropenia, Shwachman Diamond syndrome, Diamond Blackfan anaemia, dyskeratosis congenita, rare inherited bleeding disorders, sideroblastic anaemia. These conditions may have a point prevalence of five to ten patients or less in Ireland. Given the rarity of such diseases, and the requirements for care from multiple specialties and allied services, centralisation of care in the new children's hospital (with local hospital liaison) is required for the best medical care.

36.1 CURRENT SERVICE PROVISION

Tertiary paediatric haematology services for non-malignant haematology in Ireland are provided in two locations in Ireland, Dublin and Cork, and there is also a haematologist with an interest in paediatrics in Galway, although the predominant service commitment of the Galway post is to adult haematology.

- In Dublin, paediatric haematology services are provided by 3WTE paediatric haematologists based in Crumlin (2.3WTE approximately) and Temple Street Children's University Hospital (Temple Street) (0.6WTE approximately). One whole time equivalent post is split between Temple Street, Crumlin and the Rotunda at present, a working arrangement which is no longer sustainable.
- In Cork, there is one paediatric haematologist, who has a commitment to Crumlin also. Approximately half of the workload of the paediatric haematologist in Cork is involved in providing shared care for patients with malignant haematology disease in liaison with the haemato-oncology service in Crumlin.
- There is a haematology consultant post in Galway, which is a haematology post (i.e. involved in adult haematology care) with an interest in haemostasis and thrombosis and an interest in paediatrics. The workload of this post is predominantly adult rather than paediatric haematology.

The Dublin-based haematology services will move to the new children's hospital (once built). This is in line with international recommendations that specialised services are offered in tertiary care centres of excellence. The three Dublin-based haematology consultants currently provide 24/7 continuous consultant cover on a shared rota. The consultants have highly sub-specialised interests within the service. One haematologist provides a specialised haemoglobinopathy service in addition to a general haematology service; one consultant provides a specialised haemostasis and thrombosis service in addition to a general haematology service; and one consultant has a specialised neutropenia/inherited bone marrow failure service in addition to a general haematology service.

36.1.1 Outpatient Services

The bulk of the haematology service is delivered at outpatient level. Outpatient services provided for non-malignant haematology in the Dublin hospitals are outlined below. There are a total of 11 clinics per week. For the sickle cell and haemophilia services, the clinical nurse specialists (CNS) play an essential role.

Sickle Cell and Haemoglobinopathy Service

This is led by one consultant, with 2WTE CNSs providing a highly specialised service, including hydroxyurea clinics, transfusion programmes, and iron chelation programmes. Three specialised clinics are held every week for haemoglobinopathy patients, including a screening clinic, a follow-up clinic and a hydroxyurea clinic.

Total Clinics per Week: 3

Numbers per annum:

	Haemoglobin-opathy	Special haemoglobin-opathy	Drop-in	Total
2014	931	748	49	2,061
2013	1009	873	47	2,259
2012	1006	770	55	2,209

Haemostasis and Thrombosis Service

This is led by one consultant with 3WTE CNSs providing diagnostic clinics, follow-up clinics and supervising inpatient and outpatient treatment of haemophilia and other bleeding disorders. Four clinics per week are held, including a follow-up clinic for haemophilia and other coagulation disorders, a general haemostasis and thrombosis clinic, a nurse-led clinic investigative clinic for particular disorders, a prophylaxis clinic and vaccine clinic. In addition, drop-in patients may attend the service during Monday to Friday. There is an adolescent clinic held less frequently.

Total Clinics per Week: 4 (occasionally 5)

Numbers per annum:

	H and T	Drop-in	Haemophilia	Adolescent	Prophylaxis	Vaccine	Total
2014	434	41	543	10	11	117	1,156
2013	509	40	509	13	14	124	1,209
2012	472	58	389	24	52	141	1,136

Acquired and Inherited Leukopenia, Neutropenia, and Inherited Bone Marrow Failure Syndromes

Seen along with general haematology referrals in clinics in Temple Street (one clinic per week) and Crumlin (one clinic per week) by one consultant.

Total Clinics per Week: 2

Numbers per annum:

	Temple Street	Crumlin	Total
2014	399	272	671
2013	386	204	590
2012	395	183	578

General Haematology

Further general haematology referrals and follow-up patients are seen in a general haematology outpatient clinic run by the haemoglobinopathy consultant (one per week), and may also be seen in one of the clinics run by the haemostasis consultant.

Total Clinics per Week (not otherwise listed): 1

	General (Crumlin)
2014	333
2013	330
2012	378

	TOTAL HAEM OPD
2014	4,221
2013	4,388
2012	4,305

36.1.2 Inpatient Services

Children attending haematology services often need inpatient treatment. Where possible, children are admitted to St. Michael's ward in Crumlin for their treatment, where there is considerable nursing expertise and familiarity with the clinical conditions and protocols used in the treatment.

36.1.3 Consultative Haematology

Consultative haematology forms a large part of the clinical workload. Figures for this workload are not easily captured. Consults and requests for clinical advice for all non-malignant haematology patients are shared among the three haematologists, and will generally be directed to the consultant on call. Requests for consultation and advice come from inpatient services in Crumlin and Temple Street, as well as from neonatal units in maternity hospitals and paediatricians in general hospitals nationwide. While no figures are available, the consultants estimate that upwards of 20 calls per week are received from external hospitals all over Ireland per week seeking paediatric haematology advice.

36.1.4 On-Call Consultant Cover

The Dublin consultants participate on a 1:3 rota, providing cover to all haematology (non-malignant) inpatients in Crumlin and Temple Street, and consultative haematology support for any haematology (non-haemato-oncology) queries nationally. The Cork- and Galway-based consultants take part in adult haematology on-call rotas.

36.1.5 Access

Access to this service is available to all children in the Republic of Ireland. There are no catchment areas in place for haematology referrals. However the specialised haemoglobinopathy and coagulation clinics are based in Crumlin, so referrals received in Temple Street are re-directed if appropriate to the clinics in Crumlin. In addition, the haematologist in Cork may receive referrals from Cork and surrounding counties. However, patients from Cork and surrounding counties may equally be seen or referred to Crumlin/Temple Street.

Where a child is thought to require urgent outpatient review or admission, the referring clinician should discuss the case with the relevant haematology consultant or the haematology consultant on call. Urgent referrals should be made by telephone contact and followed with written referral (faxed); non-urgent referrals can be made by post/fax. Queries from general practitioners or paediatricians regarding anomalies on full blood count (FBC) results are welcomed, by phone or by email. In many cases, it is possible to reassure and recommend a repeat FBC after an interval, which may render an outpatient referral unnecessary.

36.2 PROPOSED MODEL OF CARE

36.2.1 New Outpatient Referrals

The point of contact for any child who may require haematology review should be centralised to one hospital (in the future, this will be the new children's hospital) where all of the relevant subspecialties are available, i.e. haemoglobinopathy, haemostasis and thrombosis, leukopenia/bone marrow failure. Referral may be made by telephone or faxed or mailed. Telephone referrals should be followed up with a written referral. For urgent consultation, the referring clinician should discuss by telephone with the consultant haematologist on call. All referrals will be reviewed and triaged by a consultant haematologist.

36.2.2 Follow-up Outpatient Clinics

- Specialised clinics for sickle cell and haemostasis will continue to be provided.
- An additional consultant and additional CNS post for the growing sickle cell and haemoglobinopathy population is urgently needed. (This recommendation is on foot of a recent audit of the haemoglobinopathy service)
- The development of a specialised neutropenia and bone marrow failure clinic is highly desirable. Currently, children referred with these rare conditions are seen along with general haematology referrals, whereas the development of a dedicated clinical service with multispecialty and multidisciplinary input will facilitate better quality of care for this patient cohort, many of whom have complex requirements, e.g. dermatology for dyskeratosis congenital patients, gastroenterology for Shwachman Diamond patients, psychology for children with associated learning difficulties, etc.. This will require an additional CNS post for benign haematology, with a role for teaching re G-CSF injections, education of patients and coordinating clinical research.
- Follow-up clinics for general haematology patients (non-haemoglobinopathy, non-haemostasis) will continue to be provided by the three consultants as they are currently.

36.2.3 Inpatient Consultation

Consultation is a large part of paediatric haematology. Urgent consultations should be discussed by the referring consultant with the consultant haematologist on call. Non-urgent consultations may be referred to the haematology team via the registrar or consultant.

Consultation on Inpatients in Other Hospitals

It is a frequent occurrence that haematology consultation may be sought on children who are in other hospitals, e.g. the management of haematological conditions such as thrombocytopenia or thrombosis in a neonatal intensive care unit (NICU). In these cases, where a prolonged on-going haematology consultation is not required, it is often not necessary or desirable that the patient is transferred from the hospital of origin, and generally, the consultant haematologist who is on call at the time of the original referral should remain the contact point for on-going care. Outlying patients (those in other hospitals) on whom haematology consultation is sought are discussed in a weekly review meeting, so that the haematology consultant on call is aware of all outlying patients with active haematology issues. The development of a national electronic patient record could greatly facilitate communications between hospitals.

Sickle cell and Haemoglobinopathy Service: the Case for a National Newborn Screening Programme

For children of non-Northern European ethnicity, the provision of a national haemoglobinopathy screening program in all maternity hospitals is highly desirable. This has been instigated in a number of neonatal units, on a voluntary basis. Newborn haemoglobinopathy screening has been proven to be an effective process, and it has been demonstrated that a number needed to screen of just four is required to prevent one potentially fatal crisis.

Regular outpatient clinics and transfusion programmes will remain an essential part of this programme. The current consultant numbers (1 consultant for approximately 400 patients) fall far short of that recommended the NHS Standards for Children with Sickle Cell Disease (2010) which recommended one consultant per 200 children with sickle cell disease or major haemoglobin disorder). In the future, it is likely that bone marrow transplant will play an increasing role for children with sickle cell anaemia.

Sickle cell anaemia children also require frequent admission for crises. As is the current standard of care, these children should be managed on the same ward, where nursing expertise in these conditions is available. Where children with sickle cell are admitted to other hospitals, close liaison with the haemoglobinopathy service and consultant is required. Many conditions may necessitate transfer to the specialist centre for specialised treatments such as exchange transfusion. Guidelines for sickle cell disease are available on the hospital intranet, and to shared care centres.

Haemostasis Service

The current service in haemostasis is led by one consultant with three CNSs. This service is facilitated greatly by the ClinTech Electronic Patient Record. Inpatient management of children with bleeding disorders should be centralised on one ward, where nursing expertise and familiarity with treatment protocols is available. Where children with bleeding disorders are admitted to other hospitals, close liaison with the haemostasis service and consultant is required. Many conditions may necessitate transfer to the specialist centre. Guidelines for the treatment of haemophilia and bleeding disorders are available on the hospital intranet, and to shared care centres.

36.2.4 Services to Planned New Children's Hospital Satellite Units in Tallaght and Blanchardstown

While it is noted that the future plans for the paediatrics in Ireland include the new children's hospital and two satellite centres, it is strongly advised against the placing of paediatric haematologist services in the satellite centres. The reasons for this are referred to in a document produced the RCPath and British Society for Haematology (BSH) in 2008 'Haematology consultant workforce: The next 10 years':

"To deliver an effective service in the 21st century there is no longer a place for single-handed consultants... It is essential that single-handed haematology practice cease"

"Time for clinical governance, audit and research must continue to be identified in job plans in order to ensure the effectiveness and safety of the service."

For patients attending the satellite units, if haematology consult is required, the referring consultant should discuss with the consultant paediatric haematologist on call by phone.

The specialty of paediatric haematology must be centred within a 'hub'. As with the Laboratory Modernisation Programme which is underpinned by a 'hub and spoke' network model, specialised resources are most efficiently implemented when centralised. Paediatric haematologists will also be the providers of clinical input into paediatric haematology laboratory tests, and the clinical and laboratory services should be provided on the same or adjacent sites to facilitate workflow. Fragmentation of the service among sites is at best inefficient and at worst, potentially detrimental to patient safety.

36.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

36.3.1 Staffing Resources

Consultant Numbers in Non-malignant Haematology

There are currently 3WTE consultants providing continuous consultant cover on a 1:3 rota. This involves attendance at at least one hospital for ward rounds every weekend morning, and 24 hour availability for consults. A second consultant with an interest in haemoglobinopathy is required urgently, and this is supported by recommendations of National Health Service (NHS) published Standards and Guidelines for Sickle Cell Disease in Childhood (2010). They suggest a minimum staffing requirement of 1WTE consultant paediatric haematologist for every 200 patients with a major haemoglobin disorder based at any centre. This role should be developed in tandem with a national newborn screening programme for haemoglobinopathy. The services provided in Cork and Galway should be developed to provide regional expertise and support the tertiary service provided from Dublin.

There has been a nationwide shortage of NCHDs in paediatrics, and it has proven difficult to maintain the current NCHD quotas. However the current staffing level of two registrars and two senior house officers (SHOs) remains a minimum requirement. Given the large number of outpatient clinics every week, it is essential that current NCHD numbers be maintained, and the outpatient service supported by CNSs and advanced nurse practitioners (ANPs) to facilitate patient care, and NCHD training.

Nursing

The provision of an additional 2WTE CNS posts, one for haemoglobinopathy and one for non-malignant haematology (including general haematology/neutropenia/bone marrow failure) is required. These roles are essential for patient safety and quality of care, and provide a continuity of care. They are complimentary to consultant and NCHD roles. The appointment of an ANP in haemoglobinopathy and an ANP in haemophilia is recommended. If these roles are taken up by current CNSs, these CNS roles should be backfilled.

Psychology

The Clinical Psychology Department in Crumlin currently provides 0.6WTE to the benign haematology team. The need for psychology in this patient group is recognised by international expert groups, including the World Federation of Haemophilia in their 2012 recommendations, and the NHS (2010) 'Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care'. There are currently approximately 280 active open cases on the benign haematology psychology caseload. In 2014, 100 new referrals seen by psychology and 459 individual appointments were offered within the psychology department. The current allocation of 0.6WTE principal grade needs to be increased to 1WTE principal grade and 1WTE senior grade clinical psychologist.

Support Services

The provision of 1WTE data manager for non-malignant haematology is essential. This role will assist in the categorisation and enumeration of the patient cohorts attending the non-malignant service, as the current methods used, e.g. those based on ICD codes, which were developed more for billing purposes than for clinical care, are not adequate. The data manager will also be involved in maintaining quality in patient care, by auditing of patient standards of care, assisting with clinical trials, and assisting with international patient data registries. A further 1WTE administrative support is required for non-malignant haematology, for outpatient appointments scheduling, patient contact point, correspondence, and other duties.

Staff Category	Current (WTE)	Proposed (WTE)
Consultant	3	4
Specialist Registrar /Registrar	2	2
SHO	2	2
Advanced Nurse Practitioner	0	2
Clinical Nurse Specialist	5	7
Physiotherapist	0.5	2
Psychologist	0.6 Principal Grade	1 Principal Grade 1 Senior Grade Clinical Psychologist
Occupational therapist	0.5WTE which covers all haemato-oncology patients	0.5WTE for non-malignant haematology from 3WTE recommended for haemato-oncology
Quality manager	0	1
Data manager	0	1
Administrative	2.5	3.5

36.3.2 Clinical Guidelines

Clinical guidelines exist for haemophilia, bleeding disorders, sickle cell disease and congenital and non-chemotherapy neutropenia. These guidelines will be maintained and updated on a regular basis as required.

36.3.3 Education and Training

Paediatric haematology is a mandatory part of training for specialist registrars in haematology and a minimum six months (of the five years) must be completed in order to obtain certification of completion of specialist training (CCST). For those interested in pursuing a career in paediatric haematology, at least two years of the five years haematology training should be spent in paediatric haematology and the remainder of their training in adult haematology.

The rotation of paediatric SHOs and registrars through the specialty of paediatric haematology is to be lauded. This should be continued, as there is mutual benefit to the NCHDs and to the clinical service. While the trainees are in the paediatric haematology service, they will remain closely supervised and all clinical decisions will be made at consultant level, after discussion/teaching. As a mandatory part of haematology training, all specialist registrars in haematology should spend a minimum of six months in haematology. Currently this is split between haemato-oncology and haematology. This mandatory training will continue to be facilitated by the paediatric haematology service.

36.4 PROGRAMME METRICS AND EVALUATION

Paediatric haematology care is evaluated by several bodies and will continue to be so. The haemophilia service and haemoglobinopathy services have been externally audited recently; INAB inspection of haemovigilance and blood transfusion takes place annually. Metrics that are currently in place for haematology outpatient services include waiting times, and number of new patients seen by the service per year. Current waiting times are among the shortest of all the paediatric subspecialties, with waiting times for routine new referrals rarely exceeding three months. In addition, the services are developing in-house patient standards for clinic visits and annual review which will be audited regularly.

36.5 GOVERNANCE

Clinical haematology in Temple Street and Crumlin is currently under separate governance for each hospital. Furthermore, laboratory haematology, which is provided by the same three consultants and by two haemato-oncology haematology consultants, is under the separate governance in the laboratories in Temple Street and Crumlin. Integration of the laboratories is already underway in preparation for the planned move to the new children's hospital (see chapter on Laboratory Medicine).

A suggested governance model for haematology is that consultants in haematology and haemato-oncology form a joint haematology and oncology division in the clinical governance structure of the new children's hospital. This joint division will be answerable to higher hospital management structures (hospital executive). A director is nominated from the consultants. This role should rotate on a regular basis, perhaps every 2-3 years. The director may remain in place for two consecutive terms. Regular meetings of the Joint Division of Haematology and Oncology should occur, with consultants and assistant directors of nursing, every 2-3 months to discuss service issues, key performance indicators, patient safety issues, etc. However, within this joint division, the haematology and haemato-oncology service will be recognised as separate entities. The reason to maintain this connection is the many synergies of the two services, including:

- Common initial referral pathways of children with cytopenia for diagnosis and management;
- Care and investigation of patients with haematology disorders, both benign and oncologic, has many common features, including frequent use of transfusions of blood or blood products and the use of bone marrow aspirate and biopsy procedures for diagnosis;
- The use of bone marrow transplant as a treatment modality for many conditions in both haematology and haemato-oncology (congenital neutropenia; inherited bone marrow failure; haemoglobinopathy);
- Haematology education and training for specialist registrars (SpRs) requires exposure to both benign and malignant haematology conditions;
- Similar skillsets at nursing, NCHD and consultant level to both sub-specialties.

Treatment of inpatients and day-ward cases may benefit from the shared nursing and NCHD skillset. The sharing of dedicated outpatient facilities, day-ward facilities and allied services may be efficiently shared between haematology and haemato-oncology.

36.6 KEY RECOMMENDATIONS

- A second consultant with an interest in haemoglobinopathy is required urgently
- Increase CNS posts for non-malignant haematology by 2WTE, and develop new ANP posts
- Increase psychology services from 0.6WTE principal grade to 1WTE principal grade and 1WTE senior grade clinical psychologist
- Increase physiotherapy input to benign haematology from 0.5 WTE senior, to 1 WTE senior and 1 WTE staff grade

36.7 ABBREVIATIONS AND ACRONYMS

ANP	Advanced Nurse Practitioners
BSH	British Society for Haematology
BST	Basic Specialist Training
CCST	Certification of Completion of Specialist Training
CNS	Clinical Nurse Specialist
DIC	Disseminated Intravascular Coagulation
FBC	Full Blood Count
FRCPath	Fellowship of the Royal College of Pathology
MAHA	Microangiopathic haemolytic anaemia
NCHD	Non-Consultant Hospital Doctor
NHS	National Health Service
NICU	Neonatal Intensive Care Unit
SHO	Senior House Officer
SpR	Specialist Registrar
WTE	Whole Time Equivalent

36.8 REFERENCES

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