PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 29: PAEDIATRIC INFECTIOUS DISEASES & IMMUNOLOGY

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ROYAL COLLEGE OF PHYSICIANS OF IRELAND

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29.0 INTRODUCTION

Paediatric Immunology and Infectious Diseases (PIID) are two individual paediatric sub-specialties with different, although overlapping training requirements. Paediatric Infectious Diseases (pID) and Paediatric Immunology work in a complementary fashion with natural synergies such that a combined Department of Infectious Disease and Immunology serves well to meet the needs of patients. They are closely aligned with Clinical Microbiology however, and while there are areas of shared responsibility, they remain distinct in training and in overall service provision.

29.0.1 Paediatric Infectious Diseases

Infectious diseases remain a major cause of morbidity and mortality in children. Infections in children differ from adults in aetiology, epidemiology, pathogenesis, management and prevention. Although there have been major strides in the control and prevention of many childhood infectious diseases (polio, tetanus, measles, Haemophilus influenzae type B meningitis, group C meningococcal, invasive pneumococcal disease), the infectious disease challenge remains greater than ever before. The emergence of relatively new infections such as HIV/AIDS, hepatitis C, severe acute respiratory syndrome (SARS), MERS-coV; the re-emergence of old foes with new complexity, e.g. multi-drug resistant tuberculosis; multi-drug resistant organisms and increasing numbers of vulnerable patients; critically ill patients in the paediatric intensive care unit (PICU); and patients that are immunocompromised as a result of disease or its treatment, means that need for expertise in the area of paediatric infectious diseases has never been greater.

pID specialists diagnose, treat and work to prevent infections in children and adolescents. Additionally, they often function like 'medical detectives' and evaluate young people with symptoms that are recurrent, atypical or unexplained. pID physicians combine clinical care with work as researchers, educators, administrators, hospital epidemiologists and/or work in antimicrobial stewardship. Up to 50% of paediatric hospital admissions are for infection. The management of many of these fall well within the scope of the general paediatrician. However, even for some common conditions, uncertainty in diagnosis, development of complications, or emergence of resistant organisms means that the input and advice of a pID specialist is sought to benefit the patient – as often through the limitation of inappropriate antimicrobial use as the substitution or addition of antimicrobial agents.

The majority of the inpatient pID physician workload relates to infections complicating hospital admission for other diagnoses, e.g. up to 50% of leukaemia patient undergoing transplant can be expected to develop infection, as can 20% of patients with solid tumours and 3 % of patients post-cardiac surgery. For these patients, once consulted, the pID specialist investigates and manages all aspects pertaining to the infection, generally assessing the patient on a daily basis until the infectious issue is resolved or a clear management plan in place. Thus a significant portion of the pID specialist workload relates to the support of other sub-specialties in the management of children and adolescents with, or suspected to have, complicating infection.

The availability of paediatricians trained in infectious diseases, and ready and willing to meet the challenge of caring for patients, even with potentially very contagious infections, is an essential component of a comprehensive paediatric health care service. Although epidemics such as the 2014-5 ebola epidemic remain extremely rare events, over recent years emerging and re-emerging infectious diseases continue to challenge (see Figure 1) (Morens, 2004). Even since Morens' 2004 publication, new infections, and detection of infections in new geographic locations, have been recognised, e.g. MERS-CoV in the Middle East, new influenza strains, spread of antimicrobial resistant bacteria, emergence of chickungunya and leishmaniasis in Europe. Although the threat

of these conditions to the health of Irish children may be low, considerable expertise, time, and effort must be invested in developing contingency protocols and procedures. The PIID service is relied upon for their expertise in this area. The locations of some of these disease 'hot spots' are remote however, with reduction in transport times and increasing global migration diseases (up to now confined to a geographic region), can now spread with alarming rapidity (Morens, 2008). pID specialists are well placed to investigate, diagnose and manage patients who may be at risk for such conditions.

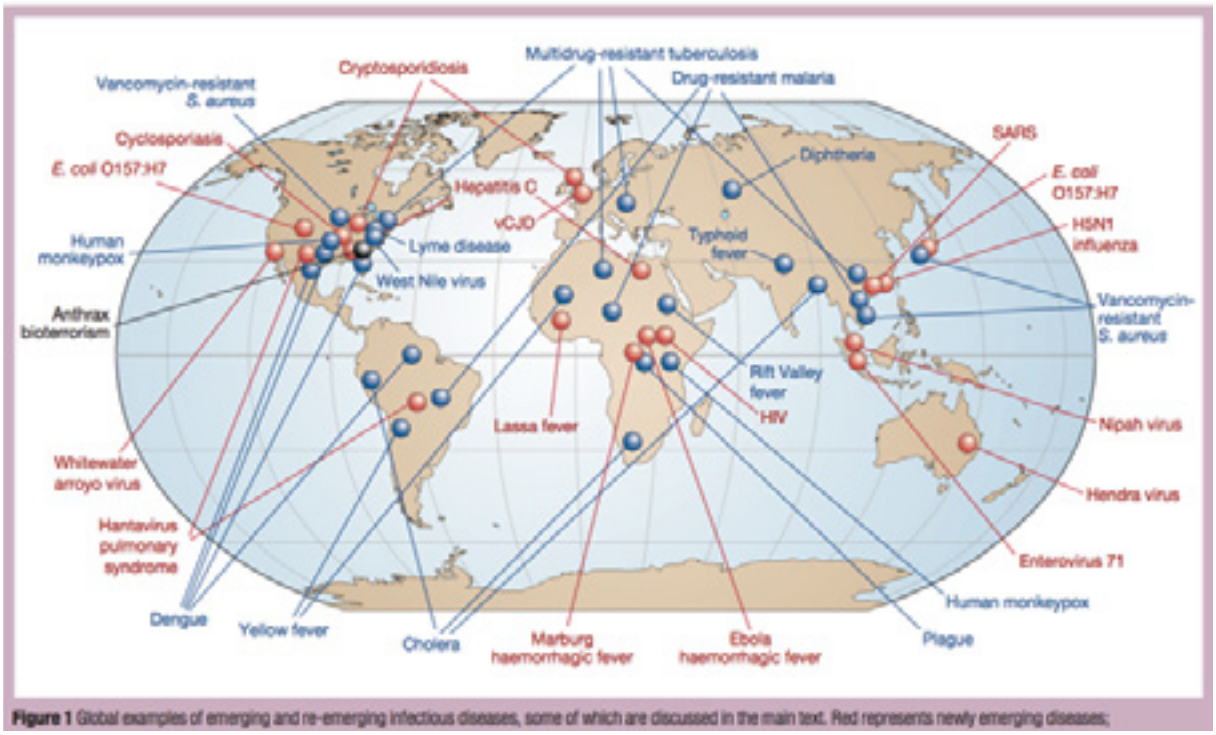


Figure 1 Global examples of emerging and re-emerging infectious diseases, some of which are discussed in the main text. Red represents newly emerging diseases;

pID specialists directly manage young people with relatively uncommon but complicated systemic infections and fever syndromes (tuberculosis, HIV/AIDS, hepatitis B, hepatitis C, Kawasaki syndrome, congenital infections). Much of this work is carried out in the outpatient setting. New developments in pID ambulatory services include provision of HCV eradication therapy with outpatient delivery of injectibles. One rapidly expanding area is the roll-out of outpatient antimicrobial therapy (OPAT) which, for non-cystic fibrosis patients, is being co-ordinated through the pID service.

Today, there is increasing need to limit the duration of hospitalisation for children. For the patient this is not only socially desirable but, importantly, limits the risk of hospital-acquired infection or colonisation with hospital-acquired resistant organisms. From the hospital perspective it reduces inpatient pressure, frees beds to relieve emergency room congestion, and results in greater efficiency in use of limited resources. Roll out of OPAT is one way to reduce length of stay, without compromising health. Prolonged courses of intravenous antibiotics are a common reason for protracted hospitalisation, beyond that needed for acute recovery from illness. In the development and supervision of OPAT services for children, the pID service has a major role to play in reducing need for hospitalisation. The provision of a service of excellence has resource implications in terms of administration, nursing, pharmacy and physician inputs.

The pID service is the de facto national service for HIV medicine in children. With the ultimate goal of eliminating paediatric HIV infection, the pID service (in collaboration with colleagues in the adult infectious diseases and obstetric services) coordinates the national prevention of perinatal HIV transmission programme. Through these efforts, and with the production of national guidelines and an outreach programme that extends support to every maternity unit and to every HIV positive pregnant woman, vertical HIV transmission rates have been reduced to <1%. Through this service, and with the established network of adult and obstetric providers, HIV transmission has been averted for hundreds of infants (Ferguson 2008, Ferguson 2011). Research shows that infectious diseases specialty care generates significant value for the healthcare system, while improving patient outcomes, thereby improving the individual experience of healthcare (Schmitt, 2014).

29.0.2 Paediatric Immunology

Paediatric immunologists focus on study of the immune system in both health and disease. Traditionally, the focus has been on investigation and management of disorders associated with increased susceptibility to infection. This includes but is not limited to severe combined immune deficiency syndromes (SCID), primary antibody deficiencies, complement deficiency, phagocytic cell abnormalities, or other impairments in innate immunity and acquired immune deficiency related to therapeutic immune suppression, stem cell, bone marrow and/or organ transplantation. Advances in molecular testing, particularly next generation sequencing however, has demonstrated that many primary immunodeficiencies have a broader disease spectrum than previously appreciated, including not just increased infections, but also autoimmunity, allergy, malignancy and dysregulated inflammation.

Next generation sequencing has also led to a greater understanding of both the molecular, and ultimately the biochemical and immunological basis of disease. In this context, with the expansion of therapeutic options (in particular monoclonal antibodies), establishing a molecular basis for disease is becoming increasingly important and requires the time and expertise of dedicated immunology specialists.

Advances in paediatric haematopoietic stem cell transplantation (HSCT) techniques have also lead to significant improvements in both mortality and morbidity figures for conditions for which HSCT is the only treatment option (such as SCID), as well as for conditions for which HSCT is a treatment choice (CGD, XLT, CD40L deficiency, severe autoimmunity) and an increase in the demand and need for this treatment. Patients who are candidates for HSCT need careful management pre and post-transplantation, and lifelong follow up to monitor for complications.

Immunologists are increasingly involved in the diagnosis and management of diseases associated with autoimmune responses, auto-inflammatory syndromes and immune dysregulation. Modulation of the immune system through use of biologic agents (monoclonal antibodies, receptor antagonists etc.) is an increasingly important tool in their therapeutic armamentarium. The input of specialist expertise in this area is critical. As disorder or deficiency in this area often results in vulnerability to infection, children with these conditions can present with disease reactivation (e.g. tuberculosis (TB), zoster, hepatitis B virus), recurrent or atypical infection, again the close cooperation of pID and immunology specialists is necessary for optimum outcomes to be achieved.

Prevalence - Primary and Secondary Immunodeficiency

Current estimates of the prevalence of paediatric immunodeficiency vary, with estimates of 1:2000 from a recent study in the United States. However, recent advances in genomics have led to an expansion in the number of paediatric immunodeficiency syndromes being recognised, including many autosomal dominant inherited conditions. Early diagnosis and management is essential as appropriate timely intervention can avert the

associated morbidity and normalise and extend the life of the affected child. Achieving this, however, requires close clinical contact and monitoring by a paediatric immunologist, often extending throughout childhood and into adult life. Thus, although the incidence of primary immunodeficiency is relatively low, there is a cumulative patient population as these are lifelong conditions. A crucial body of expertise is necessary to recognise and diagnose these conditions.

Furthermore, as many of the early signs, recurrence of infection, can be fairly non-specific, a much greater number of children will require investigation to exclude PID (primary immunodeficiency) than are eventually diagnosed. Failure to diagnose PID can lead to avoidable death or long term debilitating and expensive illness. There is a need to screen more patients in clinical services than actually found to have the immune disorder. It is estimated that this ratio of investigated to diagnoses is generally about 10:1. Thus, the burden on the service is significantly greater than might be anticipated based on disease incidence alone. In addition, there is the ever increasing cohort of children with secondary immunodeficiencies due to use of therapies designed to manipulate the immune system; increasing use of immunosuppressive agents, novel biologic agents, disease modifying anti-rheumatic drugs (DMARDs), ever more intense chemotherapy regimens and the expansion in clinical indications for HSCT.

29.0.3 Paediatric Infectious Diseases and Immunology Collaborations

pID and immunology specialists often work in an interdependent fashion, recognising which children presenting with infection warrant further investigation to identify underlying immune deficiency and preventing and treating infection in those who are immunocompromised. At Our Lady's Children's Hospital Crumlin (Crumlin), at least one weekly clinic session consists of a pID and an immunology clinic run in parallel with consultants from both specialties attending, facilitating easy access of the patient to these interdependent disciplines. There are plans to establish a multidisciplinary autoinflammatory clinic, again with attendance of pID, immunology and rheumatology specialists. Such is the nature of these rare but complex conditions that the combined input of these specialties is required. By scheduling such multidisciplinary clinics the focus is on facilitating the patient journey, providing quality of care and increasing efficiency within the system. pID and immunologists work in close collaboration with other clinical sub-specialists and diagnosticians including allergists, clinical microbiologists, radiologists and pathologists to enhance the quality of care and patient outcomes, prevent unnecessary use of resources and set standards for the diagnosis, management and prevention of infection and diagnosis and management of immune deficiency and disorder.

The increasing complexity of care in tertiary children's specialties requires strong antimicrobial stewardship due to increasing use of broad spectrum antibiotics, increasing rates of antibiotic resistance and the increased cost of antibiotic spending in the health service (HPSC, 2011). Over 10% of all children are admitted to hospital with an infection in their first year of life. There are 1,500 cases of healthcare associated infection bloodstream infections in children each year in the United Kingdom (UK). Infectious diseases specialists work in close collaboration with clinical microbiology, infection control and clinical pharmacy to promote sound antimicrobial stewardship including, but not limited to, development of antimicrobial formulary and clinical antimicrobial guidelines, serving on infection control and hospital therapeutic committees.

29.0.4 Paediatric Infectious Diseases and Clinical Microbiology Collaboration

There is significant overlap between the specialties of pID and clinical microbiology. The two specialties work closely together. For the clinical microbiologist, patient interaction generally emanates from the laboratory diagnostic testing. For the paediatrician who is an infectious diseases specialist, the starting point is generally

the patient, their symptoms and the clinical disease presentation. Each discipline has specific and unique areas of expertise and clinical practice in addition to their common ground. As McKinsey (2006) recognised, PIID and Clinical Microbiology are among the critical interdependent core specialties necessary in a tertiary level paediatric centre.

29.0.5 Integrated Subspeciality Care and Network Service

pID and immunology specialists provide consistent, case-by- case basis interactions with:

- other tertiary paediatric specialties, e.g. immunological or infectious investigation of child treated primarily by other speciality group;
- PICU;
- system-based specialities, e.g. orthopaedics, ENT, neurology etc.;
- secondary general paediatric care, e.g. advice on investigation of child with fever of unknown origin;
- primary care, e.g. advice on immunisations;
- adult speciality colleagues, e.g. microbiology, including diagnostic services;
- clinical immunology, including diagnostic services;
- genitourinary medicine (GUM);
- adult infectious diseases and respiratory physicians.

Provision of comprehensive tertiary level paediatric services requires availability of wide range of interdependent specialty and subspecialty services which include PIID (Department of Health UK, 2008; Department of Health UK, 2011).

For regional paediatric services to develop to their full potential and to keep children as close to home as is appropriate, there is need for ready access to support from national tertiary centres. pID and immunology services provide significant support in terms of telephone consultations and advice. Such ready access, provided 24/7, on many occasions averts patient transfer, facilitates local patient management, thus benefiting families and results in improved tertiary level bed utilisation.

National Context

An integrated PIID service is provided in Dublin for children with complex primary immunodeficiencies and infectious diseases and countrywide referrals are received. The service should be recognised as, and funded to deliver, a national service. Delivery of the specialist services requires a core PIID multidisciplinary team (medical, nursing, clinical psychology, clinical pharmacy, dietetics, physiotherapy, occupational therapy and administrative services) with ready access to other health and social professionals, specialist laboratory-based testing, imaging (including MRI) and other specialties as required.

Contribution to National Standards of Care

From a national perspective, the development of a pID service has provided a core of expertise that, through their contributions to a variety of national committees (Scientific Advisory Committee of the Health Protection Surveillance Centre (HPSC), the Viral Haemorrhagic Committee, National Tuberculosis Advisory Committee, National Immunisation Advisory Committee, STI Advisory Committee, Committee on Blood Borne Pathogens, Meningococcal Advisory Committee, and others) and to guideline development (e.g. Rainbow clinic guidelines for preventing perinatal transmission, meningococcal sepsis and meningitis guidelines), contributes significantly to national strategies on infectious diseases and to the development of national standards of care.

29.0.6 Conditions Managed by Specialist Infectious Diseases Services

These include but are not limited to:

- Bacterial infections
- Systemic (e.g. sepsis, meningitis) and organ-specific (e.g. endocarditis, osteoarticular, shunt infections) infections
- Multi-drug resistant bacterial infection
- Mycobacteria (e.g. TB - congenital, central nervous system, extra-pulmonary disease, complicated pulmonary disease, drug-resistant TB)
- Viral infections
- Systemic viral infections (e.g. HIV, CMV, EBV, HBV, HCV)
- Viral infections in immunocompromised (such as bone marrow transplant) host (e.g. adenovirus, influenza, RSV)
- Invasive fungal infections
- Systemic candidiasis, invasive aspergillosis, zygomycoses
- Zoonosis
- Coxiella, bartonella, brucella, psittacosis
- Tropical infections
- Malaria, Typhoid, Dengue, Chicungunya, etc.
- Opportunistic infections
- PCP, disseminated CMV, BK virus
- Congenital infection
- CMV, toxoplasmosis, syphilis, HSV, enterovirus, and others
- Recurrent infections
- Fever syndromes
- Kawasaki disease
- Rare, imported and emerging paediatric infections, e.g. Lyme disease, brucellosis, leptospirosis, slow infections of the central nervous system (e.g. subacute sclerosing panencephalitis (SSPE), spongiform encephalopathies), worldwide emerging new infections (e.g. dengue, SARS, influenza), imported infections (e.g. visceral and cutaneous leishmaniasis)

Examples of Patient-specific Indications for Infectious Diseases Input

Infection in the PICU Patient	Meningococcal disease, staphylococcal / streptococcal sepsis and toxic shock syndromes, necrotising fasceitis, bacterial meningitis, encephalitis, brain abscess, sinusitis, mastoiditis, ophthalmic infections and inflammatory conditions, empyema, endocarditis, abdominal sepsis and gastrointestinal infections, viral hepatitis, complicated urinary tract infections, complex musculo-skeletal infection, complex skin infections
Infection in the Cardiac / Cardiothoracic Surgery Patient	Endocarditis, myocarditis, pericarditis Central line infections Post-procedural pneumonia, empyema Surgical site infections (sternal osteomyelitis, mediastinitis)
Infection in the Surgical Patient	Spinal rod infection, osteoarticular infections, complicated skin and soft tissue infection

Infection in the Haemato-oncology Patient	Febrile neutropenia, pneumonias, central line infections, typhlitis, invasive fungal infection
Infection in the Transplant Patient (Bone Marrow or Solid Organ)	Systemic viral infection (adenovirus, CMV, HSV, EBV, VZV, BK virus, etc.) Pneumonia (bacterial, fungal or viral) Central venous access device infections Sepsis CNS infection (mucormycosis, aspergillosis)
Infections in the Orthopaedic Patient	Spinal rod infection, osteoarticular infections, complicated skin and soft tissue infection
Infections in the ENT Patient	Orbital and periorbital cellulitis Cervical lymphadentiis Retropharyngeal abscess Infected branchial cysts Mastoiditis
Neonatal Infections	Sepsis/meningitis, central venous access device infection, necrotising enterocolitis, congenital infection
Infection in the Burns Patient	Burn infection, toxic shock syndrome
Vaccinology	Complex vaccine advice for passive and active immunisation (non-response, failures, immunocompromised, adverse events)
Other	Community needlestick injury, blood and body fluid exposures

The purpose of specialist PIID assessment is often to 'rule out' infection in children with complex inflammation so preventing unnecessary investigations and inappropriate antimicrobials.

29.0.7 Conditions managed by Specialist Immunology Services

These include, but are not limited to:

- Primary immunodeficiency syndromes
- Severe combined immune deficiency
- Combined immunodeficiency, e.g. Wiskott Aldrich syndrome, DOCK 8 deficiency
- Neutrophil disorders, e.g. leucocyte adhesion disorder, chronic granulomatous disease (CGD)
- Hyposplenism
- Primary antibody deficiencies, e.g. X-linked agammaglobulinemia, common variable immune deficiency (CVID)
- Common infections, e.g. respiratory syncytial virus (RSV) in the immunocompromised host
- Complement disorders, e.g. Factor H deficiency, C2 deficiency
- Hereditary angioedema
- Auto-inflammatory conditions affecting children e.g. periodic fever syndromes
- Syndromic immunodeficiency, e.g. 22q11, Trisomy 21, Jacobsen syndrome
- Complex autoimmunity
- Secondary immunodeficiency, e.g. intestinal lymphangiectasia, nephrotic syndrome, persistent hypogammaglobulinemia post-Rituximab

29.1 CURRENT SERVICE PROVISION

The development of a pID service in Ireland was instigated following the emergence of paediatric HIV infection in Irish born children. The first published reports of HIV/AIDS in young men appeared in June 1981. That same year the first HIV-1 infected Irish child was born. By 1993, 23 children had been diagnosed with HIV infection in Ireland and 25% had already died. In 1988, the first antiretroviral drug were being evaluated in clinical trials and by 1995, with a small but growing cohort of HIV-infected children in Ireland, the need for a clinical infectious diseases service was recognised. The first consultant paediatrician with special interest in infectious diseases was appointed in 1995.

Between 1981 and 1996, HIV in children in Ireland occurred primarily in the context of parental drug abuse and 100% of clinic attendees were caucasian Irish. Thereafter, reflecting the rapidly changing demographics in Ireland, there was significant growth in the numbers of immigrants from areas of high HIV endemicity, with consequent rapid expansion in the numbers of infants born to HIV infected mothers. Additionally, whereas previously the problem of HIV infection had been concentrated in Dublin city, and thus well served by Dublin based outpatient services, the planned policy of geographic dispersal of asylum seekers resulted in patients scattered far and wide across the country. To meet the new challenges posed by the increase in patient numbers, ethnic and cultural diversity and geographic scatter, the Rainbow clinic, the ambulatory arm of the pID service, was created. The concept was to provide a unified service of excellence from a single geographic base, delivered over a number of sites through network development, use of outreach to local clinics, and development of shared protocols.

The Rainbow clinic aimed to respond to the challenge of multiculturalism, provide a service of inclusivity for indigent and immigrant alike, and deliver equal standards of care even when confronted with language and cultural barriers. It evolved to provide a holistic, multi-disciplinary approach to the medical care of HIV-infected children and focused major efforts on preventing mother to child transmission of HIV infection. The Rainbow clinic is based in Crumlin and Temple Street Children's University Hospital (Temple Street), with an associate specialist-led clinic in the Rotunda. It is supported by affiliated network clinics in Cork (Dr. Brendan Murphy) and Galway (Dr. Edina Moylett), and offers educational seminars, written guidelines, clinical nurse specialist (CNS) support and telephone access to every maternity unit throughout the country.

Very early in the course, a newly emergent infection in infants, Hepatitis C (HCV) infection, was recognised. Vertically transmitted HCV infection shared many features in common with HIV infection in Ireland. Highly prevalent in intravenous drug users, who were often co-infected with HIV, the Rainbow clinic team was well placed to undertake the monitoring and follow up of HCV exposed and infected children (Healy, 2001). Similarly with the waves of immigration, other previously low prevalent conditions in Irish children assumed new importance (HBV, syphilis, TB, malaria) expanding the remit of the pID service.

The ambulatory or outpatient arm of the services encompasses not only HIV, HBV, HCV, TB, and syphilis, but provides a referral service for investigation, diagnosis and management, or indeed exclusion, of a wide variety of pID, an active post-inpatient follow up service facilitating earlier discharge of children with a variety of complicated infectious disease who would otherwise have extended hospital stays. The service is now committed to begin the process of coordinating paediatric OPAT services for patient at Crumlin. Throughout its history, the service has undergone cycles of new problem identification, development, refinement and streamlining the service delivery plan such that outpatient visits can be safely reduced in frequency to free resources and allow their realignment

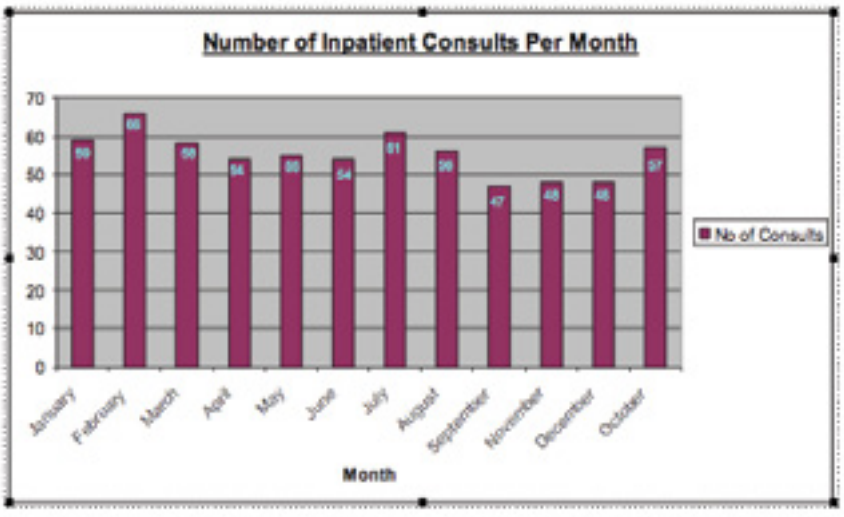
to tackle new issues as they arise. It is never static. The pID service focuses not only on diagnosis and treatment of infection but also on infection prevention, especially in the most vulnerable.

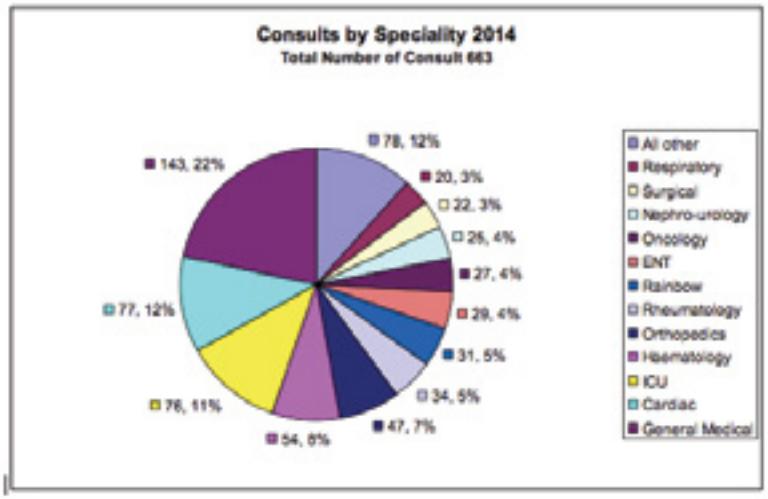
The nurse specialist-led RSV prevention programme whereby vulnerable Crumlin patients who meet preset criteria are recommended to receive palivizumab prophylaxis either in the outpatient setting or within the home is also part of the pID service activity. Advice and support for patients and general practitioners (GPs) with respect to the national immunisation programme is also provided as needed.

Ambulatory or outpatient services however account only for a portion of the pID service activity. Year on year the demand for inpatient support from the pID service has increased. Although the number of inpatients admitted directly under the care of the pID service in small, consultation rates are high. When consulted, the pID service manages the patient with respect to the pID issue from consultation to resolution of the problem in all respects as would be expected for a patient admitted directly under pID services, thus the nature of the consultation service is effectively one of co-management for the duration of the pID problem. Patients for whom consultation or co-management is requested are generally the most complex, with patients in PICU, haemato-oncology, bone marrow transplant, cardio-thoracic, orthopaedic and rheumatology services being the heaviest service users. In addition to ambulatory and inpatient services the pID service plays and often under-recognised role in supporting paediatric services throughout the country. Telephone consultations from regional centres account for a significant workload involving phone time, imaging and laboratory data review, and follow up contact.

Inpatient Services

The service has a small number of patients admitted directly (fever of unknown origin, fever/rash syndromes, autoinflammatory conditions, HIV, TB, etc.). The bulk of the clinical inpatient service relates to support of other services. Paediatric medical specialities in tertiary centres increasingly make use of and rely on PIID clinicians for advice on management of complex infections across the whole range of paediatric sub-specialities (see Figure 2: Services requesting input from pID service; and Figure 3: Consults). The median duration of inpatient attendance is five days with approximately 20% requiring less than two days attendance and 20% more than 10 days. There is continued increase in the demand for the service as evidenced by a 21% increase in consult numbers in Crumlin between 2012 and 2014 (2012: 547; 2013: 628; 2014: 663).





Figures 2 and 3: Inpatient Consults (Crumlin) and Referring Specialties

Outpatient and Ambulatory Care Clinics

Outpatient and Ambulatory Clinics	Rainbow Clinic pID Service
Citywide there are three consultant-led clinics and one associate specialist clinic each week	Four outpatient sessions/week (2x Crumlin, 1x Temple Street, 1x Rotunda)

Referral Pathways

Crumlin and Temple Street referrals received from general practitioners (GPs), public health, emergency department, regional paediatric centres, local consultants, maternity hospitals and follow up from inpatient consultation service.

Patient Populations

1. Very short term patients:
   No more than one or two visits, e.g. follow up visit post-inpatient treatment, specific testing
2. Short term patients:
   Require assessment, investigation and management plan, may take two or more clinic visits, e.g. acute cervical adenopathy
3. Intermediate
   Require follow up for a defined period, e.g. HIV exposed but uninfected infants have 4–6 visits over two years, TB patients have monthly visits for 6–9 months
4. Long term patients
   Indefinite follow up often to transition to adult services, e.g. HIV, HBV, HCV infected

Workload

In Crumlin there were just over 1500 visits scheduled with 1147 attendances and a return to new ratio of 2.84:1. Modifications to schedules have been made to reduce, where possible, numbers of routine follow up visits and with a notable reduction in return to new ratio now approaching 2:1. There were 775 visits in Temple Street of whom 170 were new patients. There has been relative stabilisation in numbers over the last three years which, despite increasing referral, has resulted from a significant reduction in follow up visits offered for some of the more long term conditions.

29.1.1 Immunology Services

In 1999, the pID service undertook to provide support for an occasional immunology clinic that would, in the absence of a local immunologist, be attended by a visiting immunologist Prof. Andrew Cant from Newcastle-upon-Tyne to service, what at that time were considered the needs of a very few patients. Between 1999 and the end of 2013, the pID service were the primary providers of care for an ever increasing number of immunology and for limited (limited by resource constraints) numbers of allergy patients. Over those years that service grew exponentially until 2013, when finally with the appointment of Dr. Aideen Byrne, Consultant Immunologist with responsibility for Allergy, a separate allergy service was established; and with the appointment of Dr. Ronan Leahy, Consultant Immunologist with responsibility for immunodeficiency, a service to cater to the needs of those with immune deficiency or immune disorder was established.

Today there is an integrated Department of Infectious Diseases and Immunology, and a separate Department of Allergy. There are two consultants in pID with sessions split between Crumlin and Temple Street along with a minor commitment to the Rotunda hospital, and one consultant immunologist with sessions split between Temple Street and Crumlin (with a minor commitment to St. James's Hospital). The team works in a multidisciplinary format. Staffing for immunology and infectious diseases is listed below.

Current Staffing in Crumlin, Temple Street and the Rotunda

Consultants	Associate Specialist	SpRs	Registrars	SHOs
3 (2 pID, 1 Immunology)	1 (Rotunda)	2 (1x Temple Street, 1x Crumlin)	1 (Crumlin)	0

Clinical nurse specialists: 4.25WTE in total
(1.5x immunology, 2.5x pID, 0.75x RSV prevention programme)
Senior Clinical Psychologist: 0.5WTE (Crumlin)
Senior Medical Social Worker: 1WTE shared with ED (Crumlin)
Senior Clinical Pharmacist: 1WTE (Crumlin) assigned but now shared
Administrative support 2.6WTE Crumlin, 0.33WTE Temple Street

Immunology Outpatient Services

Since commencement in December 2013, Dr. Leahy has commenced twice weekly dedicated immunology clinics. On average, approximately 90-100 patients are seen monthly, currently at approximately a 1:1 ratio of new to return patients. In addition, 12-15 patients attend the medical day unit weekly for immunoglobulin infusions, medical review, and receipt of monoclonal antibody therapy or pre/post-HSCT assessment. The first paediatric autoinflammatory clinic, a joint clinic attended by Rheumatology, pID, Dermatology and Immunology will commence in November 2015. Preliminary plans are in place for a dedicated 22q11ds clinic as well as pre- and post-transplant clinics and primary antibody deficiency clinics.

Referral Pathways

Referrals are received from Infectious Diseases, consultant paediatricians and other paediatric subspecialists, maternity hospitals, GPs and patients may be folowed up from inpatient consultation services.

Patient Populations

The majority of patients seen in the immunology clinic are referred with a history of recurrent infections/fevers/autoimmune/autoinflammatory symptoms. A proportion of these cases can be seen and discharged from clinic within two visits. There is also a substantial population with established primary immunodeficiency. Since Crumlin is the only dedicated centre catering for the needs of these children, the population is substantial. Within that population are:

- Children with SCID and other combined immunodeficiencies who require HSCT. These children are followed both pre- and post-transplantation by the immunology team and require ongoing intensive investigation and management, particularly in the first year after transplantation. On average, 4-5 patients are transplanted per year.
- Children with Primary Antibody Deficiencies (PAD) – this cohort of patients require ongoing monitoring with aggressive antibiotic treatment of infection, vaccinations, and a proportion will go on to require antibody replacement therapy. Approximately 50 children are receiving replacement immunoglobulin due to PAD. Many of these children attend the medical day unit for their infusions and to monitor for complications associated with disease and treatment.
- Children with Syndromic Immunodeficiency – occurs as a component of genetic/syndromic illness in many instances. Prominent examples include Trisomy 21 and 22q11 deletion syndrome. In addition, there are a number of genetic conditions occurring with a particular high frequency in Ireland, e.g. partial MCM4 deficiency. These children attend for regular review and follow up for treatment and prevention of infections and their complications.
- Children with complex autoimmunity – many children present with multiple sites of autoimmunity or lymphoproliferation that can have an immunological basis, e.g. IPEX, APECED. These children again require ongoing monitoring and interventions in the form of immunomodulation.
- Children with ill-defined conditions – the immunology clinic has a population of children with clinical syndromes including increased susceptibility to infection for which no diagnosis yet exists. A considerable workload arises from their investigation and management, frequently involving complex genetic and immunological testing in international laboratories.

Nurse-led RSV Prevention Service

Respiratory syncytial virus (RSV), a respiratory pathogen, is a leading cause of hospitalisation in infants during the winter months. Certain identified groups (very premature infants, oxygen dependent chronic lung disease, complex congenital heart disease) are at increased risk of developing severe RSV disease requiring prolonged hospital stays. Palivizumab (Synagis®), a monoclonal antibody, can reduce the risk of hospitalisation with RSV disease amongst this vulnerable population. It requires monthly intramuscular administration over the five month peak winter season. The development of an RSV prophylaxis service in Crumlin began in 2004, with 29 patients receiving palivizumab injections. These patients attended the medical day unit each month from October to March, placing significant demand on an already overstretched resource.

In 2005, the indications for palivizumab expanded to include high risk cardiac conditions. 87 babies were referred for palivizumab injections prompting set up of a designated clinic. Between 2006 and 2015, referrals to the infectious diseases department for RSV prophylaxis increased to more than 100 per year which, with the requirement for five monthly visits, represented a potential additional 500+ hospital visits. In 2008, following

the initiation of a drug company-funded home care service that provided paediatric nurses to visit the infants in their own home each month for administration of palivizumab, an onward referral pathway to the home care programme was established with initial assessment for suitability at Crumlin, referral to the community-based drug company sponsored services and reservation of attendance at the hospital for those infants with the most complex conditions where additional supervision was necessary.

The model of care and coordination of service has proved very efficient. It supports the referring physicians (cardiologists, neonatologists, and others) ensuring good communication between hospital and the community in a consistent and streamlined fashion, and has significant advantages for the family as infants with complex medical needs often require a lot of equipment, oxygen, suction machine, feeding system to travel with them making journeys to hospital difficult and time consuming. Furthermore there is risk reduction to the infants of contracting infection while waiting in crowded clinic waiting rooms or GP surgeries. Currently an average of 110 infants each year are assessed for suitability and referred for ongoing support to the home care service. This includes infants geographically dispersed throughout the country but who are attending a national referral service at Crumlin, e.g. cardiology service. 50% of the patients referred to the home care service will receive one or more doses of palivizumab in Crumlin during their inpatient stay. To avoid delayed or missed doses it is essential that a good system of communication be maintained between the hospital and the home care provider. The home care service has been welcomed by parents who greatly value the reduced number of trips to the hospital during the winter months.

29.1.2 Affiliated Clinics

Associate Specialist Rainbow Clinic in the Rotunda
(Clinical Lead: Dr. Wendy Ferguson)
Infants born in the Rotunda to mothers with HIV, HBV, HCV or syphilis, infants with congenital infection (cytomegalovirus (CMV), toxoplasmosis) or with other pID issues are followed up at the Rotunda Rainbow clinic and transitioned to the Rainbow clinic at Temple Street if follow up beyond early infancy is required. In 2012, 299 infants, and in 2014, 357 infants, attended the Rainbow clinic at the Rotunda.

Affiliated Regional Network Clinics

1. Dr. Brendan Murphy, Cork University Hospital, undertakes care of HIV exposed infants, supported by CNS Michele Goode and the Rainbow clinic team
2. Dr. Edina Moylett, University Hospital Galway undertakes care of HIV exposed infants and supported by CNS Michele Goode and the Rainbow clinic team

In Development

1. OPAT – the goal will be to reduce inpatient stay, thus improving bed utilisation, delivering quality care with improved patient experience with potential cost reduction.

Development Required

1. Dedicated paediatric TB clinic with DOT capability co-managed with public health
2. Consideration of development of a dedicated transdisciplinary and multidisciplinary 22q11 clinic with cardiology, plastic surgery, endocrinology, developmental paediatrics and psychiatry
3. Post-HSCT clinic with links to psychology, dietetics and other associated health and social care professionals
4. Consideration to develop a bronchiectasis clinic, linking respiratory paediatrics and immunology

Development Desirable

1. Congenital infection clinic – linking developmental paediatrics and infectious disease with access to health and social care professionals including SLT, audiology and dietetics, and to other specialties, e.g. neurology, ophthalmology, as required.

Additional Services

On Call Service

The pID/immunology service provides a 24/7, 365 day on call service covering Temple Street and Crumlin. Weekend ward rounds are on an 'as needed' basis but generally involve 1-3 hours in-house on one or more weekend days. There is cross cover between pID and immunology with operation of a shared on-call rota.

Telephone Consultation

The pID/immunology service is the de facto national service for pID and immunology. There is significant demand for pID/immunology consultant availability for telephone consultation from maternity hospitals, regional paediatric centres, public health, and to a much lesser extent from primary care. Significant time is spent in this regard, occurring primarily during the working day, and with a significant amount of phone calls from regional hospitals at weekends.

In summary, the PIID services have developed into extremely busy services, with scope of activity much beyond that originally envisioned at their inception but striving to meet patient needs with emphasis on holistic approach to patient care, smoothing the patient journey, minimising inpatient stay and building networks with regional and local services.

29.2 PROPOSED MODEL OF CARE

29.2.1 Patient Journey through the Service

Inpatients

Direct admissions may arise following an outpatient visit or are arranged following request from a regional consultant paediatrician requesting transfer of care, further investigation and patient management. The general pathway for inpatient admission is followed, i.e. contact with the hospital bed manager and prioritisation according to level of urgency. Inter-specialty co-management of patients with complex issues is common, e.g. the febrile neutropenic haematology-oncology patient with invasive fungal infection, the patient post-spinal rod surgery with spinal rod infection, cardiac surgery patient with mediastinitis, and others.

Many serious infections are managed by shared care arrangements between a regional centre and the tertiary service in PIID. A patient may initially present to their local hospital, be referred to the tertiary centre for specialist investigations and initiation of treatment, and is subsequently transferred back to their local hospital for completion of their treatment. Advice and support will continue to be provided by the tertiary centre during and after completion of their therapy. Previously lengthy inpatient stays for delivery of intravenous antimicrobial therapy are being shortened though the use of intravenous OPAT. The pID service aspires to develop a well-functioning, coordinated OPAT service for paediatrics, similar to that currently being rolled out for adults – provided appropriate resource allocations can be made. Progress in this regard is being made with recent reassignment of 0.5WTE CNS within the department from HIV services to undertake responsibility for infusion based therapies and co-ordination of OPAT services.

Consultations

Consultation requests are received usually following telephone contact or by written request. Within core hours (0900-1800) Monday-Friday, patients are generally seen on the day of consultation. After hours consults are triaged by telephone and seen emergently, if required, or the following day. 24-hour telephone advice for emergency support to interdependent tertiary specialities is always available.

Outpatients

Referral source

Patients are referred from maternity and infant services, paediatricians, general practitioners and public health services, i.e. from local, regional, and national centres of care. On occasion, international referrals are also received, e.g. child with one of the above conditions relocating or returning to Ireland.

Referral mechanism

Referrals are received by fax, mail and less commonly email. Initial contact may be by phone. Some referrals are automatic, following diagnosis of specific maternal infections in pregnancy or defined infectious diseases exposures and follow standardised protocols with pre-scheduled appointments. The Rainbow clinic team will contribute to the newly development of the national maternal and neonatal clinical management system with standardised referral proformae for key referral indications.

Patient management

Patients attending the Rainbow clinic are managed in a holistic fashion by a multidisciplinary team, with the involvement of members depending on the specific needs of the patient. Referrals are triaged by the consultant and timely review arranged as appropriate. For specific infections, same-week review is provided, e.g. fever of unknown origin, new HIV diagnosis, HIV drug problems, new cases of suspected TB. For others, appointments according to a pre-set schedule for attendance are made. Waiting lists are kept to a minimum and there is in effect no waiting list for acute infectious disease problems with appointments given for the next clinic as required.

Multidisciplinary and Cross-site Activities

Where required, there is limited access within the core team to clinical psychology, medical social work, clinical pharmacy and specialist nursing as well as medical services. Activities include:

- Crumlin weekly multidisciplinary team meeting wherein relevant cases seen in outpatients the preceding week, scheduled for review in the following week or with outstanding live issues are discussed and agreed plans formulated.
- Temple Street weekly cross site meeting (pID & Immunology from Crumlin and Temple Street, and pID, Immunology, Microbiology & Clinical Pharmacy from Temple Street and the Rotunda) focussing on the specific medical issues relating primarily to the inpatients with infectious diseases.
- Rotunda-based monthly intercity HIV in pregnancy meeting attended by adult HIV, maternity, and pID services. The goals are formulated, a treatment and delivery plan for the mother and neonatal prophylaxis for the infant agreed, and to ensure exchange of the necessary information between the sites (i.e. adult, maternity and paediatric) to enable such planning. This ensures a continuity of care for the monther-infant duo.
- Crumlin monthly script meetings are held, participants include the pID consultant, CNS and clinical pharmacist. The aim is to provide safe antiretroviral prescribing. This is coupled with 3-monthly audit of HIV service delivery, with the goal being 95% viral suppression for HIV infected children on therapy.
- Direct interdisciplinary communication is an important facet of PIID team working day. Face to face consultations with imaging services, pathology and other clinical services are important components of the service.

- The PIID teams are regular contributors to multidisciplinary team meetings for PICU, haematology/oncology and other patients.
- Antimicrobial stewardship including responsibility for local antimicrobial guidelines (interdependent with clinical microbiology and clinical pharmacy)
- Provision of clinical link between children's services and hospital infection prevention team
- Provision of transitional care services for chronic patients requiring ongoing care in adulthood. The process of transition, greatly facilitated by the CNS, aims to effect seamless transfer of care without loss of continuity and to support the patient on their journey.
- The Immunology team contributes regularly to Dublin Allergy Immunology Group (DAIG) monthly meetings and also to joint meetings with our colleagues in GNCH, Newcastle upon Tyne.

29. 2.2 The Multidisciplinary Team (MDT)

The PIID should have MDTs who have specialist experience in treating primary immunodeficiency and specific complex infectious diseases. The existing core team consists of:

- Consultants in infectious diseases and in paediatric immunology
- Clinical nurse specialists in Immunology, HIV and infectious disease
- Senior clinical pharmacist
- Senior medical social worker
- Non-consultant Hospital Doctors (NCHDs)

Beyond the core team the service has limited access to the range of paediatric subspecialties, health and social care professionals, diagnostic laboratory services, specialist paediatric radiology and neuroimaging (but access to MRI services at Crumlin does not meet the current need). Deficits include lack of access to Speech and Language Therapy, and limited access to occupational therapy and physiotherapy services, mental health services for adolescents, and absence of regular peripherally inserted central catheter (PICC) line service (Crumlin). The pID service supports a wide range of clinical sub-specialties but equally it in turn relies on the support those sub-specialties in order to deliver the highest level of care. Such interdependency is a recognised part of any well-functioning tertiary level hospital (McKinsey, 2004; UK Department of Health, 2008).

Roles of Core Multidisciplinary Team Members

1. Clinical Nurse Specialists

   The multi-faceted role of the pID CNS is to assess, plan, implement and evaluate patient care as part of a national infectious diseases multidisciplinary service. Services include:

Direct care	Inpatient, but predominantly outpatient and community, care, support and education to children and families with chronic diseases and those exposed to chronic infections (HIV, HCV HBV, TB, CMV, Syphilis and Toxoplasmosis), providing the link between the child and family living with a chronic infectious disease at home and the pID multidisciplinary team in hospital. Prevention, treatment and support strategies including (but not limited to) administration of vaccines, interferon/ribavirin and nebulised pentamidine, tuberculin skin testing, disclosure of HIV diagnosis to children and supportive education and counseling regarding HIV diagnosis, treatment, adherence, and ultimately transition to adult services. Development and co-ordination of paediatric OPAT services.

National remit	As part of the Preventing Perinatal Transmission Programme, supporting regional paediatric clinics and maternity units throughout the country, providing direction and practical advice and are actively engaged in the education of local health care givers.
Communication and liaison	Develop strong links with the medical team and hospital wards. Provide telephone support service to families and triaging of phone calls to medical team. Communicate with other health care organisations, e.g. GPs, PHNs, maternity hospitals and psychosocial agencies. Advocate on behalf of children and their families.

2. Clinical Nurse Specialist – Immunology

The role of CNS in Immunology is to provide clinical service for children and their families, living with a broad range of immunological disorders. The CNS in Immunology provides leadership in clinical practice and acts as a resource and role model for our specialist area. Activities include:

Direct care	Participation in twice weekly consultant led outpatient clinics and outreach clinics with a visiting immunologist 3-4 times per year. A nurse led drop-in clinics to support families with emergency clinical needs is also provided. Coordination and provision of the high intensity day unit service which include education, training and provision of immunoglobulin and biologic infusions for children. A structured parental training programme for home immunoglobulin treatment is also provided.
National remit	As the service is de facto the national service for primary immune deficiency, patients attend from every region. Support is provided to regional paediatric clinics for shared care management of selected patients and the management of children on home immunoglobulin and other home based therapies coordinated.
Communication and liaison	To work closely with community services as well as primary and secondary healthcare providers and support families of children undergoing HSCT, liaising closely with UK Northern Supraregional Centre for primary immune deficiencies. Liaison and transition support to adult immunology services is also provided

3. Clinical Nurse Specialist – Infectious Diseases & Immunology

Activities common to both CNS roles include:

Education	Providing infectious diseases/immunology related education and information to health and social care professionals in hospitals, community and universities, attending relevant meetings and courses to update skills and maintain standards and acting as a specialty resource.
Guidelines	Writing, dissemination and implementation of guidelines, e.g. Preventing Perinatal Transmission: a practical guide to the antenatal and perinatal management of HIV, Hepatitis B, Hepatitis C, Herpes simplex and Syphillis. Contribute to the development and other relevant guidelines (Guidelines for immunoglobulin infusions) and develop Standard Operation Procedures.
Research	Participation in research and audit.

4. Clinical Pharmacist

A pharmacist and a pharmacy technician are active participants in providing PIID services. This service involves the pharmacist attending weekly multidisciplinary meetings; checking prescriptions and dispensing antiretroviral medication to patients attending Crumlin and Temple Street; and counselling patients / carers with regard to prescribed medications. The Pharmacy Department produces parent /carer-friendly patient information leaflets (PILs) for HIV medicines and medication charts for parents/carers when required to assist with safe administration of medicines.

Intravenous Information Sheets for administration of medicines are also produced; guidance on potential drug interactions with HIV medicines is available as well a medicines information service for medical and nursing staff in Crumlin. Practice is informed and delivered in line with the PENTA treatment guidelines (Bamford, 2015) and other approved sources (Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission, 2015; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2015). The clinical pharmacist also supports research and development within the ID/Immunology services.

5. Senior Medical Social Worker

The medical social worker is a key team member whose services are much in demand both by the pID and immunology services. The pID service by its nature has a large cohort of patients from the most disadvantaged, marginalised and disenfranchised sections of our community. The complexity of family circumstances often present major obstacles to delivery of adequate health care to children. The medical social worker plays a key role in negotiating pathways and interacting with community services to ensure families are supported and enabled to access care for their children.

The immunology service has a disproportionate proportion of families afflicted not by just one child with illness or condition but often more than one child in a family. Conditions are generally life long, often potentially seriously debilitating if not potentially lethal thus the needs of the families extend far beyond prescription of medications or treatment plans. The medical social worker is a key worker helping to support the families and enabling them access care for their children. The social work position on this team is one that demands a level of seniority and experience that entry level positions do not have.

6. Senior Clinical Psychologist

The team psychologist fulfils many roles important to service delivery. As HIV infection is a neurotropic virus, assessment of cognitive ability/impairment forms an important part of the assessment and monitoring of infected children. HIV exposed but uninfected children have greater incidence of speech and language impairment than other children. They generally come from marginalised communities and many have other features of developmental disorder. There is a high prevalence of developmental disorder in this cohort of children, thus developmental/cognitive assessments are often required in order to fully evaluate the patient. These assessments, and those for children with other neurotropic infections (congenital CMV infection, congenital toxoplasmosis), are carried out by the clinical psychologist.

HIV infected children have to cope with disclosure of their diagnosis, the secrecy and surrounding stigma, the restrictions of direct provision settings, the ensuing parental stress, parental depression, to mention but a few challenges,. Mental health issues are a major concern for us in this cohort. Add to that the need for a daily cocktail of medications, often with side effects, and the absolute need for ready access to psychological

support can be readily appreciated. HCV exposed and infected children often, not always, are born into a chaotic social situation of parental drug use and poor parenting skills. Many ultimately end up in care. Children with primary immune deficiencies cope with chronic illness, frequent hospitalisations and lifelong therapies. These are just a few of the reasons that clinical psychology is very important facet of the team support provided.

MDT Deficits

There is a real and growing need for regular access to liaison psychiatry services. Occupational therapy, physiotherapy, and speech and language services are inadequate with very long waiting lists for community access and limited intervention periods available. The importance of a core multidisciplinary team is an important standard in the provision of PIID services (Lyall, 2010).

29.2.3 Site of PIID Care Provision

Inpatient Care Provision - pID

In a tertiary inpatient environment, PIID clinicians provide services within all clinical areas. It is a recognised standard for new hospital construction to house patients in single rooms appropriately equipped with sanitary facilities. The current situations both at Crumlin and Temple Street are sub-optimal. There is limited availability of single rooms, and for some of the wards the provision of toilet facilities is inadequate.

Most infectious disease conditions can be managed within a single room provided there are adequate facilities. There are, however, patients and conditions which require a higher level of care. While beyond the scope to this document to detail the requirements, some immunocompromised patients and some patient with specific conditions are optimally nursed in single rooms with anterooms and appropriate ventilation filtration systems. In general such facilities can be accommodated within the specific disease/patient specific unit, e.g. within PICU, or within the bone marrow transplant ward, such that patients are nursed in isolation but where there is the core expertise necessary for their condition.

There are some conditions where the risk of transmission to other patients and the consequences of that transmission, should it occur, is so great that specific isolation facilities of the highest standard are required and override the need for housing within a specialty unit, e.g. isolation facilities adequate for the care of a patient with viral haemorrhagic fever, MDR TB, SARS, MERS-CoV. The current paediatric care pathway for children at high risk of such infection recommends transfer to the national isolation unit. That unit is considered unfit for the care of critically ill children in its present format and the ability to provide such care for children, removed from the paediatric hospitals places a burden on existing services that cannot be possibly met given existing manpower resources. There is urgent need for the development of an isolation facility for children where such services can be safely provided and allocation of manpower resources to enable safe delivery of care within the unit when needed. Consideration must be given to this in the context of development plans for the new children's hospital.

Inpatient Care Provision – Immunology

As with pID, care of the immunology patient is generally undertaken within the general paediatric arena. These children are, however at greater risk of contracting infection and developing severe complications. There is need for single, appropriately ventilated patient rooms to safely house such infants and children. Currently infants and children with primary immune deficiency are transferred to the UK each year for HSCT, this occurs at a significant social and financial cost to the parent and considerable economic cost to the state. There is a need to

develop transplantation services in Ireland such that they can accommodate not only malignant haematology and oncology patients, but also children requiring transplant for metabolic or primary immune deficiency conditions. A business case for the appointment of a dedicated transplant physician and expansion of the paediatric transplant service has been submitted and must incorporate the needs of patients with primary immunodeficiencies. Admission rights to the HSCT unit and accommodation appropriate for immunodeficient patients is crucial to service development and delivery.

Day Unit Service Provision

The current configuration and limitation of space for day unit services mean that there is frequently overcrowding within the day unit. Children with primary immune deficiency are high uptake users of day unit service and as such warrant specific consideration. Emphasis must be on preventing acquisition of infection while attending service – thus a dedicated or restricted access unit is desirable, Single rooms are essential.

Outpatient Services

The PIID services require significant outpatient space if services are to be efficiently and safely delivered. There is need for a greater number of clinic rooms that might be allocated to a general paediatric clinc. Reasons for this include requirements for:

- Isolation rooms - at times to protect the patient, e.g. if index patient is immunocompromised including post HSCT patients, and at times to protect other patients, e.g. index patient with VZV, MRSA etc.
- Appropriately ventilated with sufficient air exchanges, e.g. for highest risk patients or for use during administration of nebulised pentamidine
- Good viewing facility so that patient may be observed without the constant physical presence of the clinician or parent in the room, e.g. during pentamidine nebulisation. The pID services undertakes this for haematology–oncology patients as required. This also allows the child to see their carer even when the carer cannot remain in the room.
- Safe housing of the most vulnerable infants with complex medical conditions attending to receive monthly palivizumab injections

To meet the diversity of need, the rooms need to be of good size (to cater for parents, buggies and equipment), appropriately ventilated, and with discrete viewing possibility. Requirements also include piped oxygen and suction, both necessary to support safe delivery of palivizumab to vulnerable cardiac babies and for children undergoing skin prick testing and food challenges.

29.2.4 Mechanism of PIID Service Provision

Specialised PIID services may be delivered in the following ways:

- Direct care by PIID specialist
- Co-management with other specialist within tertiary centre - both inpatient and outpatient including joint clinics, e.g. PIID/rheumatology for auto inflammatory conditions, PIID/respiratory for immunodeficiency with chronic respiratory infection etc.
- Expert advice from the specialist in PIID to other paediatric specialists within a tertiary centre, e.g. intensive care, neonatology, oncology, orthopaedics, cardiology, neurology
- Expert advice from the PIID specialist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP
- Expert advice from other multi-disciplinary members of the PIID team to other healthcare providers

- Attendance by supporting CNS at regional paediatric clinic
- Liaison and co-ordination with community bases services, e.g. RSV prevention programme, home based immunoglobulin infusion, OPAT
- MDT visits to the patient's home and school to provide training and support to the child, family and other carers.
- Leadership in improving the diagnosis, treatment and prevention of infectious disease through research.

The aim is to manage children as close to home as possible with the local hospital delivering the majority of care whenever possible.

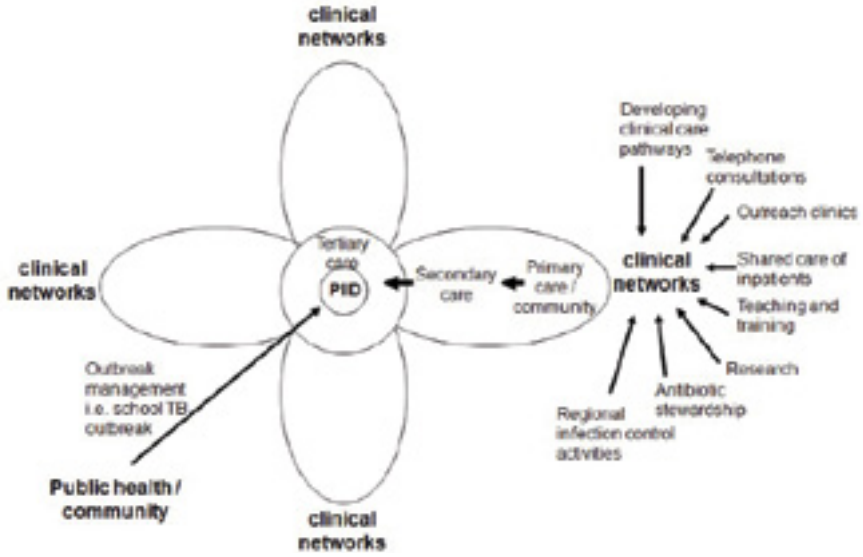


Figure 4: Schematic Representation Of Care Pathways

29.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

29.3.1 Staffing

Staff Category	Current (WTE)	Proposed (WTE)
Consultant ID in tertiary centre		
(expansion to cover OPAT roll out and redesignation of associate specialist position as consultant)	2	4*
Consultant immunologist	1	3
Consultant paediatrician with special interest in ID & Immunology (with responsibility for satellite centre activity)	0	2
Associate specialist with materno-fetal infection responsibility (Rotunda)	1*	0*
Regional consultant paediatricians with special interest in pID & immunology	0	4
Specialist registrars: pID Immunology	 2 0	 3 2
Registrar	1	0
SHO	0	1
CNS pID	2.5	3
CNS OPAT	0.5	2.0
CNS RSV prevention	0.75	0.75
CNS Immunology	1.5	3
Senior Clinical Pharmacist Clinical Pharmacist (OPAT)	1	1 0.5
Senior Medical Social Worker	0.5	1
Senior Clinical Psychologist	0.5	1
Speech and Language Therapist	0	0.5
Radiographer MRI/Ultrasound services	0	0.25
Radiologist (MDT/Consultation)	0	0.25
OPAT clinical pharmacy support	0	0.25
Occupational Therapy	0	0.25
Physiotherapy	0	0.25
Administration: OPAT co-ordinator	0	1.0

Consultant Staffing

Tertiary Centre

The existing staffing is inadequate to sustain current service levels cater for future development. Two pID consultants cannot provide adequate cover. The case for a third pID consultant shared between Tallaght and Crumlin, with links to the Coombe Women and Infants University Hospital has already been made, accepted and the post advertised prior to the moratorium whereby all posts were frozen. The need remains.

Currently one consultant post is based at Crumlin with a lesser commitment to Temple Street. A second post is shared equally between Temple Street and Crumlin with minor commitment to the Rotunda. The proposed model included a third post with commitments to Crumlin, Tallaght and providing support to the Coombe. Three posts would provide a solid core of expertise, even at times of leave, and cover would extend to the three pediatric sites with support to each maternity unit. In this scenario, there will be two posts between Temple Street and Crumlin and a third post between Crumlin and Tallaght, with each consultant having a minor commitment to each maternity hospital. These posts would ultimately be based in the single tertiary children's hospital. This is the minimum requirement if a fully functioning pID service, with excellence inpatient care, education, audit, research and development, i.e. fulfilling good clinical governance criteria, is to develop.

A single handed consultancy should no longer exist in a national tertiary referral centre. The need for collegial interaction and support is well recognised if patient care standards are to be met. However, there is just one immunologist with responsibility for primary immune deficiency and immune dysfunction (excluding allergy) in Ireland. There is urgent need for the creation of a second similar post based in the tertiary pediatric centre. A core of three immunologists working within the broader pID/Immunology network would allow for development of tertiary immunology services that could provide outreach to regional centres, with shared care patient co-management akin to the shared care model of care proven successful in the hematology-oncology arena. Scope exists for cross-specialty appointments, e.g. Immunology/Rheumatology or Immunology/HSCT.

Satellite Ambulatory Centres

In addition, the appointment of two general pediatricians with specialist pID interest to the future new children's hospital with responsibility for the satellite ambulatory centres would meet the dual requirements of enhancing the core of general paediatrics, and at the same time providing pID support within the satellite units.

Regional Centres

This core of expertise could then link to the regional unit where general paediatricians with specialist interest in paediatric infectious diseases should be appointed, e.g. one each in Cork, Galway, Drogheda and Limerick. Thus a hub and spoke network extending from there into the primary care area and cross-linking with public health services might be enabled. Further development of shared care protocols and investigations pathways would streamline the process, enhance the patient journey and reduce travel to tertiary centers.

NCHD Staffing

There are two pID SpRs (1x Temple Street, 1x Crumlin) and one registrar (Crumlin) appointed to the pID service. No additional support was provided for the immunology service. The NCHD resources are thus shared and overstretched. Amalgamation of the two tertiary centres will provide for improved efficiencies. The development of the immunology service, and in particular the increasing numbers of complex inpatients directly under our care, the increase in day care activity and increase in consultations which will be added to by the amalgamation with Tallaght and need there is need for the appointment of additional NCHDs (see previous staffing table) . The appointment of an SHO to the team with the upgrading of the existing registrar post to a specialist registrar (SpR) post in Immunology and the creation of a second immunology SpR post could be the first steps toward providing an appropriate level of NCHD support to deal with the acuity level of the immunology casemix and maintaining adequate NCHD cover for the service. The availability of an SHO post would provide an additional excellent training opportunity. Posts with the pID/Immunology services are usually amongst the most highly ranked posts in the SpR and registrar interviews. Overall NCHD support within the hospital would be enhanced.

CNS Staffing

The 1.5WTE currently allocated to the immunology service is inadequate to their needs, given the recent expansion of service provision and planned repatriation of immunology services from Newcastle. Currently, 0.5WTE of ID CNS time will be allocated to infusion services including OPAT. With the anticipated roll out of OPAT services the need is anticipated to rapidly exceed capacity and it is anticipated that at least 2.0WTE CNS will be required to fulfill this role together with increase in pharmacy and administrative support. Specific funding for adult OPAT services has been delivered but funding for pediatric OPAT, with the exception of Cystic Fibrosis OPAT, has not been delivered.

Medical Social Work Service

There is need to revert to the 1.0WTE senior social work commitment, as was the case prior to the HSE moratorium. This need is largely consequent to the addition to immunology service for which no provision was made.

Clinical Psychology

The Rainbow team in Crumlin has a dedicated input from a senior clinical psychologist (0.5WTE). This is consistent with international (CHIVA Standards of Care for Infants, Children and Young People with HIV, 2013) standards of care. A comprehensive range of psychological services is needed in order to meet the complex and diverse needs of people presenting to a paediatric HIV service. The role of the psychologist on the Rainbow team has significantly grown to include assessment and treatment of children with Hepatitis B and C, other infectious diseases, and a range of Immunological Disorders. The current staffing level of 0.5WTE is inadequate to meet the needs of this population.

Speech and Language Therapy (SLT) Service

Greater access to SLT services is required. This could be within the context of increased availability of SLT within the hospital in general.

Occupational Therapy

Access to Occupational Therapy in Crumlin and Temple Street is currently provided from the general pool with no dedicated funding for PIID. While there is often an overlap of presentations with other specialties there is a need to adjust the work force figures for the provision of services in the new children's hospital. With improved staffing other roles could be explored, such as including the occupational therapist in the core MDT for chronic disease management within this specialty. Self-management support is considered best practice within chronic disease management and is very compatible with the client centered approach used by occupational therapists. Goal setting and action planning are evidence-based tools which occupational therapists use. An occupational therapist provides functional assessments as well as health education and promotion activities.

Physiotherapy

Access to Physiotherapy in Crumlin and Temple Street is also currently provided from the general pool with no dedicated physiotherapy staffing to provide services to children referred by the PIID teams. While there is often an overlap of presentations with other specialties there is a need to adjust the work force figures for the provision of services in the new children's hospital to reflect the physiotherapy needs of these children and families. Physiotherapists have a key role to play in educating and empowering children with chronic disease, and in particular are skilled in introducing and progressing appropriate rehabilitation and physical activity programmes. Early physiotherapy intervention can prevent deconditioning and encourage independence. Physiotherapy also has been shown to assist in the management of fatigue and increase community participation, with resultant improvements in quality of life measures

Imaging Services

There is a major deficit in Crumlin in terms of access to MRI services. There is often no option but to request CT scanning with the associated radiation risk for children from whom in many situations an MRI examination would be preferable. On many occasions, clinical decisions are delayed, hospital stays extended and appropriate therapies delayed because of lack of access to MRI scanning. The pID service relies heavily on diagnostic imaging; in particular on ultrasound and MRI scanning. Therapeutic decisions and inpatient stays are often unnecessarily delayed because of lack of or delayed access to these facilities. MDT meetings with consultant radiologists are an integral part of the pID consultant work practice. Such consultations are usually on complex cases, placing a heavy time commitment on the radiology services. Workforce planning must take this into account.

Laboratory Services

Rapid diagnostics on site can reduce inappropriate treatments, facilitate early appropriate intervention and result in earlier discharge. Methodologies have advance such that multiplex PCR testing carried out on site can address many of these issues. This is optimally done within a paediatric-specific laboratory as needs of adults and children in terms of diagnostic microbiology services differ not only in terms of range of common pathogens but also in ease of availability of sample size. Within a tertiary pediatric centre, there should be an emphasis on the importance of providing dedicated paediatric laboratory diagnostic services. The close interaction of pID with paediatric clinical microbiology and the interdependencies of these related but distinct services means that to have an excellent 'infection service' both must be developed.

Any expansion in the immunology service provided in Ireland is dependent on a parallel expansion in our capacity to undertake diagnostic testing for primary immunodeficiencies. We intend to work with the Immunology laboratory in the Central Pathology Laboratory in St James's Hospital to take this forward. Any ambition to expand the HSCT programme in Crumlin or the new children's hospital must be accompanied by improvements in the in-house rapid diagnostic capacity for infections associated with transplant.

There is now irrefutable evidence that early diagnosis and treatment (<90d) of SCID leads to improved outcome. The availability of reliable and cost effective screening technology to diagnose SCID from the neonatal dried blood spot (Guthrie card) offers us the opportunity to diagnose these vulnerable patients within days/weeks of birth. Expanding the neonatal screening programme to include SCID will be an essential component of improving care for children with primary immunodeficiency in Ireland.

29.3.2 Infrastructure

Structural elements required for a tertiary level PIID service of international standard:

- All inpatients to be housed in single rooms of appropriate sanitary/hygiene standard (as per infection control)
- Single isolation rooms with ante-rooms, gowning and hand washing facilities and appropriate ventilation in key areas.
- A higher level isolation unit for highly contagious diseases or for those where the consequences of transmission to others is significant is also required. This unit could remain part of the general hospital bed complement for general use when not required for isolation and used for isolation when needed. This unit should be located such that it can strategically isolated from normal thoroughfare, e.g. for the management of viral hemorrhagic fever patient, yet retain ease and of access for key interdependent specialties such as PICU, nephrology, such that highly contagious infections could be safely managed even where PICU level care is required, e.g. active varicella in patient with toxic shock associated with secondary streptococcal infection.

- An increased in the number of isolations rooms in the outpatient setting (currently one in Crumlin and none in Temple Street available) is required. Arrival of a patient with VZV or patients colonised with MRSA or other multiple drug resistant organisms to the general pID clinic can result in loss of a room space for the entire clinic and represent a hazard to other patients if appropriate isolation cannot be effected. It is not unusual to have patients with TB, MRSA, VZV, RSV and immunodeficiency all attending during the same clinic time, occupying shared space and without adequate isolation rooms for their safe housing. Such facilities should have appropriate ventilation (and thus can also be used for administration of agents such as pentamidine) and viewing windows.

Hospital design has been proven to have a significant impact on incidence of nosocomial infection and on staff morale and staff sickness levels (Harris, 2008). Design consideration should be given to the potential ease for clinicians to adhere to standard infection control procedures and to use of materials that are amenable to cleaning and associated with lower risk of infection transmission (Ulrich, 2004; Harris, 2008).

29.3.3 Education and Training

Postgraduate Education

- Continuing medical education (CME) and continuing professional development (CPD)
- Meetings are generally trans-disciplinary with attendance of medical, nursing, and pharmacy service
- Continuing education of core staff members are provided for through specific training sessions (in- house and Royal College of Physicians of Ireland (RCPI)) for trainees and a variety of intramural and extramural meeting including intercity case discussion forums with paediatric and adult colleagues, regional, national and international meetings

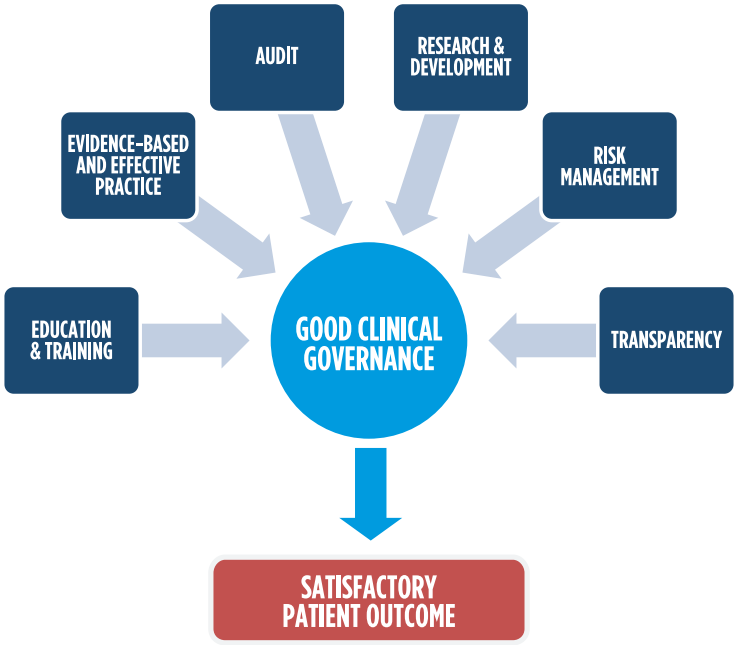
SpR Training

The service has two SpR trainers (Prof. Karina Butler, Dr. Patrick Gavin) with one SpR at each hospital site. The clinical experience is unbalanced with the bulk of complex PIID at Crumlin but without exposure to critical areas such as renal transplantation and neurosurgical infections, which are at Temple Street. This will be remedied with transition to a single tertiary centre. In the interim, however, a more balanced training structure could be offered if the trainees were to rotate each taking a 3-month period at either site.

Undergraduate Education

Students rotate through the service for relatively brief periods during the academic year. This experience really only provides a glimpse of the PIID service. More rewarding for the students and for the team are the elective periods whereby students elect to spend a 2-4 week period with the team. These have become increasingly popular with students as most have completed small projects and been associated directly or indirectly with presentations at National meetings.

29.4 PROGRAMME METRICS AND EVALUATION



The PIID service operates under and adheres to the general governance structures of the HSE and the hospitals. The common goal is to provide evidence-based effective clinical care, delivered by high quality staff, in an atmosphere of transparency and with due cognisance of the patient and carer experience and involvement. Outcomes should be optimised and risks minimised.

Education and Training

All medical and nursing staff have had appropriate education and training, are members of the appropriate professional bodies and participate in the relevant CME/CPD schemes.

Evidence-based and Effective Practice

There is a single administrative leader within the department, however clinical leadership is devolved with designated clinical leaders for key clinical areas, e.g. Prof. Karina Butler – HIV; Dr. Patrick Gavin – HCV; Dr. Ronan Leahy – Immunology; Dr. Wendy Ferguson – Perinatal Infection.

Standards of Care

Standards are derived from the appropriate professional bodies: local, national and international. It is beyond the scope of this document to provide an exhaustive list but examples include:

- International:
  CHIVA (Children's HIV Association) Standards of Care for Infants, Children, and Young People with HIV, (including infants born to mothers with HIV) (2010), UK PIN standards for diagnosis and management of primary immunodeficiencies 2009) and others (Infectious Diseases Society of America Clinical Guidelines, Idsociety.org) NICE (https://www.nice.org.uk/guidance)

- National:
  National Immunisation Advisory Committee Guidelines (immunisation.ie),
  HPSC guidelines (www.hpsc.ie)

- Local:
  - Crumlin and Temple Street antimicrobial prescribing guidelines
  - Rainbow clinic practical guidelines for prevention of perinatal transmission of HIV, HBV, HCV, HSV and Syphilis
  - Paediatric European Network for treatment of AIDS (PENTA) HIV treatment guidelines
  - Childrens HIV association standards for HIV care
  - European AIDS Society clinical guidelines
  - British HIV Association Guidelines
  - Clinical practice guidelines of the Infectious Diseases Society of America
  - European Society of Immunodeficiency

Audit

Clinical audit is recognised as an important tool for service improvement. Some examples include:

- Three monthly audit of outcome of HIV therapy
- Participation in UK and Ireland Collaborative HIV Paediatric Study with annual audit of performance indicators and comparison with other UK centres
- Current audit of HBV vaccination of HBV exposed infants ongoing
- Participation in British Paediatric Surveillance Unit surveillance and audit programme

Key Performance indicators - HIV

- Follow up of HIV exposed infant to exclusion or confirmation of infected status
- Children with newly diagnosed HIV infection seen within 2 weeks of diagnosis
- Access of HIV infected children and adolescents MDT with emphasis on psychological support for adolescents
- All HIV infected children to receive antiretroviral therapy in accordance with PENTA treatment guidelines
- Proportion of children virally suppressed on HAART (target 90 – 95%)

Research and Development

Research drives performance and underpins quality of care. The ID/Immunology service is engaged in research at several levels from prize entry-level medical student projects, clinical supervision of MD projects, through collaborative international multicentered clinical strategy trials.

Transparency

The ethos of the department is one of a collaborative partnership with parents and children, in which a trusting relationship based on full information disclosure and informed decision-making is formed.

Risk Management

Where risk is identified or recognized the practice is of rapid response to the risk with open disclosure and early notification of stakeholders in line with HSE Risk Management Strategy (2007).

Programme Metrics

Data capture and management remains an underexploited and difficult area within the clinical service. As service activity is often assessed based on inpatient activity, given the model of care for PIID services, with the exception of outpatient visits, much activity is not captured in hospital based data collection service.

Current metrics include:

- Outpatient activity
- Consultation database
- Mother to child transmission database
- RSV database

There is need to establish databases pertaining to OPAT, congenital infection and immunodeficiency.

Key service outcomes are defined both in terms of the service aims and service delivery:

Aim:
To optimise the diagnosis and management of children with primary and secondary immunodeficiency, and severe infections
Outcomes: • Condition-specific mortality rates • Hospitalisation rates • Maintenance of low admission rates of children with recurrent infections • National guideline adherence rates • Performance against local/regional network requirements/needs of tertiary/secondary specialists seeking advice/support • Recruitment rates to NIHR portfolio trials in PIID

Aim: To eliminate vertical transmission of HIV infection
Outcomes: • Uptake of antenatal testing • Maternal antiretroviral therapy uptake • Rates of maternal viral suppression at delivery • Appropriate and timely neonatal post-exposure prophylaxis • Vertical transmission rate of HIV
Aim: To coordinate/oversee antibiotic stewardship across tertiary paediatric units and provide advice on antimicrobial stewardship to the local/regional network
Outcomes: • Adherence to empiric guideline prescribing • Adherence to infection-specific antimicrobial prescribing guidelines • In-hospital antimicrobial use • Infection specific cure rates/bed days
Aim: To provide clinical link between tertiary paediatric services and microbiology infection prevention activities
Outcomes: • Provision of harmonised guidelines across paediatric sites • Provision of condition specific care pathway from presentation incorporating diagnostic and therapeutic guidelines • Adherence to Infection control guidelines/policies • Reduction in healthcare associated infections

29.5 KEY RECOMMENDATIONS

- Paediatric infectious diseases and paediatric immunology are two individual core subspecialties, a necessary part of any tertiary paediatric hospital, which must be adequately resourced if full health benefits are to be achieved.
- The existing service, based at Temple Street and Crumlin is defacto a national service and should be recognised and resourced accordingly.

Paediatric Infectious Diseases

- Reactivate the previously approved pID consultant post with sessional commitments to Tallaght, Crumlin and Coombe hospitals.
- To facilitate development of materno-infant infection service, reconfigure the associate specialist post (Rotunda) to consultant level and incorporate sessions in the new children's hospital.
- Prioritise the development of a national paediatric OPAT service and resource appropriately with protected consultant sessions to provide national oversight.
- Prioritise development of rapid microbial diagnostic services.
- Increase availability of diagnostic imaging, in particular MRI and ultrasound imaging for children.

Paediatric Immunology

- The appointment of a second consultant in paediatric immunology is urgently required.
- To provide haematopoietic stem cell transplantation (HSCT) for infants and children with primary immunodeficiencies and autoinflammatory disorders in Ireland, a consultant specialising in HSCT should be appointed.
- To allow for more efficient and cost effective service delivery, as well as to allow training opportunities for paediatricians in training, the appointment of a specialist registrar in paediatric immunology is a necessity.
- Consideration needs to be given to incorporation of a screen for SCID in the neonatal screening programme.
- Provide full MDT services to include psychology, speech and language therapy, physiotherapy, occupational therapy, a data manager and expansion of immunology CNS provision.

29.6 ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CGD	Chronic Granulomatous Disease
CME	Continuing Medical Education
CMV	Cytomegalovirus
CPD	Continuing Professional Development
CVID	Common Variable Immune Deficiency
DAIG	Dublin Allergy Immunology Group
DMARD	Disease Modifying Anti-rheumatic Drugs
ENT	Ear, Nose and Throat
GP	General Practitioner
GUM	Genitourinary Medicine
HBV	Hepatitis C Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HPSC	Health Protection Surveillance Centre
HSCT	Haematopoietic Stem Cell Transplant
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NCHD	Non-consultant Hospital Doctor
OPAT	Outpatient Antimicrobial Therapy
PAD	Primary Antibody Deficiencies
PENTA	Paediatric European Network for Treatment of AIDS
PICC	Peripherally Inserted Central Catheter
PICU	Paediatric Intensive Care Unit
pID	Paediatric Infectious Diseases
PID	Primary Immunodeficiency
PIID	Paediatric Immunology and Infectious Diseases
PIL	Patient Information Leaflet
RSV	Respiratory Syncytial Virus
SCID	Severe Combined Immune Deficiency Syndromes
SHO	Senior House Officer

SLT	Speech and Language Therapy
SpR	Specialist Registrar
SSPE	Subacute Sclerosing Panencephalitis
UK	United Kingdom
WTE	Whole Time Equivalent

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