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Committee

# **Paediatric Immunology & Infectious Diseases Service**

## **Service Specification: SS276**

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|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
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| <b>Description</b>               | NHS Wales routinely commission this specialised service in accordance with the criteria described in this policy                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |

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# Abbreviations

|                    |                                                       |
|--------------------|-------------------------------------------------------|
| <b>Adult ID</b>    | Adult Infectious Diseases                             |
| <b>AMS</b>         | Antimicrobial Stewardship                             |
| <b>BMT</b>         | Bone Marrow Transplant                                |
| <b>BSI</b>         | British Society of Immunology                         |
| <b>CARIS</b>       | Congenital Anomalies Register and Information Service |
| <b>CHfW</b>        | Children's Hospital for Wales                         |
| <b>C Difficile</b> | Clostridium Difficile                                 |
| <b>CMV</b>         | Cytomegalovirus                                       |
| <b>CNS</b>         | Central Nervous System                                |
| <b>CPD</b>         | Continuing Professional Development                   |
| <b>CYP</b>         | Children & Young People                               |
| <b>DMARDS</b>      | Disease Modifying anti-rheumatic drugs                |
| <b>EWLIA</b>       | Equality and Welsh Language Impact Assessment         |
| <b>GI</b>          | Gastro-Intestinal                                     |
| <b>GOSH</b>        | Great Ormand Street Hospital                          |
| <b>GP</b>          | General Practitioner                                  |
| <b>GRID</b>        | Paediatric Sub-specialty Training                     |
| <b>HCAI</b>        | Health Care Associated Infections                     |
| <b>HCID</b>        | High Consequence Infectious Diseases                  |
| <b>HIV</b>         | Human Immunodeficiency Virus                          |
| <b>HLH</b>         | Hemophagocytic lymph histiocytosis                    |
| <b>HSCT</b>        | Haematopoietic Stem Cell Transplants                  |
| <b>IEI</b>         | Inborn Errors of Immunity                             |
| <b>IgRT</b>        | Immunoglobulin replacement therapy                    |
| <b>IUIS</b>        | International Union of Immunological Societies        |
| <b>IPFR</b>        | Individual Patient Funding Request                    |
| <b>KPI</b>         | Key Performance Indicator                             |
| <b>MDT</b>         | Multi-Disciplinary Team                               |
| <b>MERS</b>        | Middle East Respiratory Syndrome                      |
| <b>MHRA</b>        | Medicines and Healthcare Products Regulatory Agency   |
| <b>MRSA</b>        | Methicillin-resistant Staphylococcus aureus           |
| <b>NHS</b>         | National Health Service                               |

|                |                                                        |
|----------------|--------------------------------------------------------|
| <b>NHSE</b>    | National Health Service - England                      |
| <b>NICE</b>    | National Institute for Health and Care Excellence      |
| <b>NIHR</b>    | National Institute of Health Research                  |
| <b>NRI</b>     | National Reportable Incident                           |
| <b>HSV</b>     | Herpes Simplex Virus                                   |
| <b>NICU</b>    | Neonatal Intensive Care Unit                           |
| <b>NWJCC</b>   | NHS Wales Joint Commissioning Committee                |
| <b>ODN</b>     | Operational Delivery Network                           |
| <b>p-OPAT</b>  | Paediatric outpatient parenteral antibiotic therapy    |
| <b>PAS</b>     | Paediatric Antimicrobial Stewardship                   |
| <b>PHW</b>     | Public Health Wales                                    |
| <b>PICU</b>    | Paediatric Intensive Care Unit                         |
| <b>PIDs</b>    | Primary Immune Deficiencies                            |
| <b>PIID</b>    | Paediatric Immunology & Infectious Diseases            |
| <b>PIMS-TS</b> | Paediatric Inflammatory Multisystem Syndrome           |
| <b>PREM</b>    | Patient Reported Experience Measure                    |
| <b>PROM</b>    | Patient reported outcome measure                       |
| <b>QPIDS</b>   | Quality in Primary Immunodeficiency Services           |
| <b>R&amp;D</b> | Research & Development                                 |
| <b>SARS</b>    | Severe Acute Respiratory Syndrome                      |
| <b>SCID</b>    | Severe Combined Immunodeficiency                       |
| <b>SPIN</b>    | Special Interest (SPIN) training modules (paediatrics) |
| <b>SSPE</b>    | Subacute sclerosing pan encephalitis                   |
| <b>SWAN</b>    | Syndrome Without A Name                                |
| <b>TB</b>      | Tuberculosis                                           |
| <b>THB</b>     | Teaching Health Board                                  |
| <b>UHB</b>     | University Health Board                                |
| <b>UKAS</b>    | United Kingdom Accreditation Service                   |
| <b>VRE</b>     | Vancomycin-resistant Enterococci                       |
| <b>VZV</b>     | Varicella-zoster virus                                 |
| <b>WHO</b>     | World Health Organisation                              |

# Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the service of Paediatric Immunology & Infectious Diseases in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

## Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the [Welsh Language \(Wales\) Measure 2011](#) and the [Welsh Language Standards \(No.7\) Regulations](#) 2018.

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered. Where possible, links to local teams should be maintained during the period of care.

## Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient's needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

## Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

# 1. Introduction

This document has been developed as the Service Specification for the planning and delivery of Paediatric Immunology and Infectious Diseases for children and young people (CYP) aged up to 16 years registered with a general practice in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to all seven Health Boards and Trusts in Wales and external providers in NHS England.

## 1.1 Background

Paediatric Immunology and Infectious Diseases (PIID) specialists provide a paediatric tertiary specialty with two interrelated parts, which to equitably serve the population, require integration with research, close collaboration with public health and an extensive managed clinical network with tertiary, secondary, and by extension, primary care.

### **Paediatric Immunology**

Paediatric Immunology leads on diagnosis and management of CYP with immune deficiency, which is classically associated with increased susceptibility to infections, but also auto immunity, auto inflammation, complex allergic disease, bone marrow failure and/or malignancy. In CYP, immune deficiency is often due to inborn errors of immunity (IEIs, also termed 'primary immune deficiencies' or PIDs), which cause changes in specific genes that encode proteins involved in the functioning of the immune system. However, immune deficiency can also arise secondarily from immune suppressive therapies for other diseases (e.g. disease modifying anti-rheumatic drugs -DMARDS), post organ transplant, post chemotherapy and as a consequence of novel immune modulatory cancer treatments, and an increasing number of immune modulating biologics used in Rheumatology, Gastro-enterology, Dermatology and a range of other specialties. While numbers of secondary immune deficiency are currently much more significant in adults, some paediatric cases are emerging and their management does fall under the remit of PIID (NHS England 2013). Importantly, it is increasingly recognised that immune deficiencies initially attributed to secondary causes can turn out to be partly be due to an underlying primary immune deficiency (IEI)<sup>1</sup>. Clinical management of the immune deficiency follows the same principles either way.

Immune deficiency can be diagnosed throughout the lifetime of a person, with the most severe forms usually being diagnosed in childhood. Early diagnosis and long-term management are critical to optimise outcomes for patients. The initial work up of patients with suspected immune deficiencies often requires complex immunopathological and genetic investigations to establish a definitive diagnosis. Wales currently does not

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<sup>1</sup> [Secondary Immune Deficiency and Primary Immune Deficiency Crossovers: Haematological Malignancies and Autoimmune Diseases - PMC](#)

have new-born screening for IEIs, but some areas of England do. If/when introduced in Wales, this will provide further opportunities for very early diagnosis and reduced mortality. However, as genomic screening pilots in England have shown, even small numbers of flagged cases can create considerable clinical work, including interpretation, confirmatory testing, and parental counselling. Occasionally, urgent cases such as Severe Combined Immunodeficiency (SCID) would need rapid transfer to Newcastle for life-saving treatment. While these cases are rare, the workload from false positives and investigations will likely be significant.

The management of patients with inborn errors of immunity or other immune deficiency phenotypes often requires life-long therapy with an expensive blood product with limited availability (immunoglobulin replacement therapy - IgRT), other biological agents such as C1-inhibitor concentrate, monoclonal antibodies, other biologicals, small molecule inhibitors or complex procedures such as bone marrow or thymic transplantation. Therapies are often 'high cost-low volume', and require highly specialist precision medicine, and individual funding requests (IPFRs).

Taken together, with rapidly evolving diagnostic, gene discovery and treatment modalities, including in some cases curative options, and increasing long term survival, this growing cohort of CYP with immune deficiency require highly specialist centralised Immunology expertise across the life course.

### **Paediatric Infectious Disease**

Infection is very common in children and mostly not serious. However, the overall complexity of serious infectious disease management is rapidly increasing. In the contemporary global context of extensive travel, immigration and displacement, climate change, (re)emergence of infectious diseases, epidemics and pandemics, including high consequence infectious diseases (HCIDs, e.g. Ebola), vaccine discovery alongside increased vaccine hesitancy, antimicrobial resistance, new diagnostic tools and new antimicrobial treatments, highly specialist Paediatric Infectious Diseases expertise is increasingly required. PIID specialists provide a key clinical link between microbiology/virology/ TB/mycology and clinical paediatric colleagues, on management of an increasing range of complex, severe/life threatening, chronic, drug resistant, uncommon, tropical or congenital infections.

Paediatric Infectious Diseases specialists make key contributions to development and governance of paediatric antimicrobial stewardship (PAS aka AMS) programs, prevention of health care associated infections (HAIs) and paediatric outpatient parenteral antibiotic therapy (p-OPAT) services close to home, both for CYP with normal and abnormal immune systems. AMS, HAI and p-OPAT programmes require collaborative working between AMS pharmacists, microbiologists and virologists, paediatric infectious disease consultants and Public Health Wales.

**Table 1** below summarises the wide range of conditions that fall within the remit of tertiary PIID specialists. This list is based on the NHSE service specification (2013)<sup>2</sup>, adjusted to reflect recent advances and condition specific standards of care, as well as the classification of Human inborn errors of immunity from the International Union of Immunological Societies Expert Committee (IUIS 2025)<sup>3</sup> and will be subject to changes as insights progress.

**Table 1 PIID conditions**

|                                                                                                                                                                  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Immune disorders</b>                                                                                                                                          |
| combined immunodeficiency syndromes                                                                                                                              |
| combined immunodeficiencies with syndromic features                                                                                                              |
| predominantly antibody deficiencies                                                                                                                              |
| diseases of immune dysregulation                                                                                                                                 |
| congenital defects of phagocytes                                                                                                                                 |
| defects in intrinsic and innate immunity                                                                                                                         |
| autoinflammatory diseases                                                                                                                                        |
| complement deficiencies                                                                                                                                          |
| Bone marrow failure                                                                                                                                              |
| phenocopies of inborn errors of immunity                                                                                                                         |
| hyposplenism and asplenia                                                                                                                                        |
| work up for immune deficiency in recurrent/unusual infections                                                                                                    |
| <b>Infectious Diseases</b>                                                                                                                                       |
| HIV                                                                                                                                                              |
| Tuberculosis (pulmonary, extra-pulmonary, CNS, congenital, complicated, drug resistant)                                                                          |
| Atypical (nontuberculous) mycobacterial species disease manifestations                                                                                           |
| viral hepatitis                                                                                                                                                  |
| complicated/severe/unusual or drug resistant bacterial, viral and fungal infections                                                                              |
| health care associated infections (HCAIs), e.g. ventilator associated pneumonia, central line infections, MRSA, C difficile, VRE, multi drug resistant organisms |
| pyrexia of unknown origin                                                                                                                                        |
| persistent cervical lymphadenopathy                                                                                                                              |
| common infections in the immune compromised host                                                                                                                 |
| opportunistic infections in the immune compromised host                                                                                                          |
| Kawasaki's disease and similar (e.g. PIMS-TS)                                                                                                                    |
| Toxic shock syndromes (staphylococcal, streptococcal and other)                                                                                                  |
| <b>congenital infections:</b> CMV, syphilis, chlamydia, HSV 1 and 2, VZV, Hepatitis B and C, HIV, toxoplasmosis, TB ea                                           |
| <b>Newborn:</b> complex and unusual neonatal infections                                                                                                          |

<sup>2</sup> [PAEDIATRIC MEDICINE: IMMUNOLOGY AND INFECTIOUS DISEASES E03/S/d NHSE 2013](#)

<sup>3</sup> [Human inborn errors of immunity: 2024 update on the classification from the International Union of Immunological Societies Expert Committee | Journal of Human Immunity | Rockefeller University Press](#)

|                                                                                                                                |
|--------------------------------------------------------------------------------------------------------------------------------|
| <b>CNS:</b> meningitis, encephalitis, brain abscess, slow CNS infections (SSPE, spongiform encephalopathies e.g. CJD)          |
| <b>ENT/Ophthalmology:</b> severe/unusual sinusitis, mastoiditis, eye or other infections or inflammatory conditions            |
| <b>Cardio/Respiratory,</b> endocarditis, empyema ea.                                                                           |
| <b>Gastro/Renal:</b> unusual GI infections or inflammation, abdominal sepsis, complicated unusual renal tract infections       |
| <b>Dermatology:</b> severe, unusual or complex skin and soft tissue infections                                                 |
| <b>MSK:</b> complex infections                                                                                                 |
| <b>Trauma:</b> serious post-operative and trauma related infections                                                            |
| <b>GUM:</b> sexually transmitted infections in CYP                                                                             |
| <b>Vaccination</b>                                                                                                             |
| vaccine preventable diseases (measles, pertussis, ea.)                                                                         |
| complex vaccine advice for passive and active immunisation, e.g. non-response, failure, immune compromised,                    |
| vaccine hesitancy ea.                                                                                                          |
| <b>Travel/global</b>                                                                                                           |
| Fever in the returning traveller                                                                                               |
| Rare, imported, tropical or emerging diseases e.g. malaria, typhoid, leishmaniasis, Lyme, schistosomiasis, dengue, chikungunya |
| zoonoses (acquired from animals) e.g. leptospirosis, coxiella burnetti, bartonella, brucella, toxoplasmosis, psittacosis       |
| <b>HCID</b> High Consequence Infectious Diseases: SARS, MERS, monkey pox, viral haemorrhagic fevers including Ebola            |

## PIID research

The landscape of PIID changes rapidly, and inclusion in research studies is a vital part of provision of contemporary clinical care with the newest and best treatment options<sup>4</sup>.

Importantly, child health inequalities, especially with regards to infectious diseases and their spread, are strong linked with social deprivation<sup>5</sup>. The NIHR recognises children in general, as well as people from socio-economically disadvantaged groups, as underserved groups when it comes to inclusion into research<sup>6</sup>. Welsh Government are committed to an equitable health system which achieves equal health outcomes<sup>7</sup>.

In order to provide an equitable health system, this requires access to clinical care and clinical research that provides them with the opportunity to achieve their right to health. In 2012 the Royal College of Paediatrics and Child Health highlighted the importance of research for the paediatric population publishing *Turning the Tide: Harnessing the power of child health research* and this was followed up in 2018 with *Turning the tide: five years on* stating children need designated biomedical and health research services that takes

<sup>4</sup> [Research Inclusion Strategy 2022-2027, NIHR, published September 2022 updated July 2025](#)

<sup>5</sup> [Child health inequalities driven by child poverty in the UK - position statement RCPCH August 2024](#)

<sup>6</sup> [National Institute for Health & Care Research \(NIHR\) Annual Report 2024/25](#)

<sup>7</sup> [A healthier Wales: long term plan for health and social care Welsh Government published 2018 updated July 2025](#)

account of their changing physiology, and addresses their problems directly, generating evidence to improve the quality of the treatments in healthcare they receive, and the policies that affect their wellbeing.

Tertiary PIID services are commissioned to ensure timely and accurate assessment, diagnosis and management of CYP with immune deficiency and complex infectious diseases, fully integrated with clinical research<sup>8</sup>, irrespective of postcode.

### **Public Health Wales**

Many PIID conditions have important public health implications for the wider population and are commonly linked to (inter)national and global policy e.g. WHO communicable disease control and eradication targets. For example, HIV, TB, Hepatitis B and C, new entrant screening, perinatal CMV and HSV, and the rise of syphilis, pertussis and measles outbreaks etc.

Close collaboration with Public Health is required and alongside adult colleagues, PIID specialists provide paediatric expertise across the wide range of communicable disease programs.

Wales, due to the relatively small scales involved, has uniquely short lines of communication and opportunity for agile and responsive collaboration between specialist PIID team(s) with Public Health Wales, both at policy and delivery level.

Key shared work streams include (antenatal) screening, eradication, prevention and surveillance programs, specialist vaccination issues, outbreak response planning, and emerging disease preparedness, including High Consequence Infectious Diseases (HCID, e.g. Ebola).

### **Managed Clinical networks for PIID**

PIID conditions can present in a wide range of manner, organ systems and settings. To provide care as close to home as possible, PIID specialists are required to collaborate extensively with colleagues in secondary (and by extension primary care), as well as tertiary specialists across the full spectrum of medical and surgical subspecialties, certain quaternary services as well as Public Health teams and research and development services. Depending on what is locally appropriate, this can take the form of managed clinical networks, or other frameworks, through which tertiary PIID specialists support clinical colleagues across the region to provide PIID care, facilitate development and sharing of guidelines and care pathways, access to research studies for CYP closer to home, and support their local collaborations with relevant public health work streams.

### **PIID service resilience and sustainability for Wales**

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<sup>8</sup> [PAEDIATRIC MEDICINE: IMMUNOLOGY AND INFECTIOUS DISEASES E03/S/d NHSE 2013](#)

PIID is a newly funded small specialty. With general recruitment challenges into Wales, small services like PIID are vulnerable<sup>9</sup> and require a proactive strategy to build resilience and sustainability of provision of PIID expertise for all CYP in Wales. Key elements of this strategy should include;

- medical Paediatric Immunology and Infectious Diseases training at GRID and SPIN level, and PIID training for specialist nurses
- workforce and succession planning
- PIID specialist continuing professional development,
- a comprehensive teaching portfolio for colleagues in paediatric and other closely affiliated specialties and
- joint audit and other governance activity through relevant regional clinical networks.

## 1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standards of care essential for delivering specialist Paediatric Immunology and Infectious Diseases (PIID) services for children and young people (CYP) aged up to 16 years and resident in Wales.

The objectives of this service specification are to:

- detail the specifications required to deliver PIID services for CYP resident in Wales, including clinical services fully integrated with research, antimicrobial stewardship, collaboration with Public Health Wales, and PIID expertise capacity building for Wales.
- identify a network of centres and care pathways for provision of PIID services as close to home as possible
- ensure equitable access to clinical PIID expertise, relevant research studies, and public health programs irrespective of postcode
- ensure optimal standards for PIID services are met, and outcomes for people accessing PIID services are continually improved

## 1.3 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
  - o All Wales Policy: [Making Decisions in Individual Patient Funding requests](#) (IPFR).
- **NHS Wales Joint Commissioning Committee policies and service specifications**

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<sup>9</sup> [NHS Wales faces workforce challenges despite positive developments National Health Executive, February 2025](#)

- o [Specialised Immunology Service Specification SS78 October 2024](#)
- o [Children Services - All clinical policies](#)
- o [Rare Diseases - All clinical policies](#)
- o [Genomics - All clinical policies](#)
- o [Specialist Paediatric Imaging Service \(excluding neuroimaging\) \(aged up to 16 years\), Service Specification \(SS161\), February 2025.pdf](#)
- o [Services for Children with Cancer SS86 December 2024](#)
- o [Specialised Paediatric Rheumatology Service CP172 November 2021](#)
- o [Specialised Paediatric Gastroenterology, Hepatology and Nutrition \(PGHAN\) May 2023](#)
- o [Specialised Paediatric Neurology SS213 June 2024](#)
- o [Paediatric Nephrology SS169 August 2025](#)
- o [Cleft Lip and or Palate including Non-Cleft Velopharyngeal Dysfunction All Ages, Service Specification \(CP186\), July 2023.pdf](#)
- o [Specialised Paediatric Orthopaedic Surgery SS230 March 2025](#)
- o [Neonatal Services \(Intensive Care, High Dependency and Special Care\), Commissioning Policy \(CP263\) August 2024](#)
- **Relevant NHS England policies**
  - o [Paediatric Medicine: Immunology and Infectious Diseases NHSE 2013](#)
  - o [High Security Infectious Diseases Unit \(all ages\) NHSE 2013 -](#)
  - o [Specialised Human Immunodeficiency Virus Services \(children\) NHSE 2013](#)
  - o [Paediatric Medicine: Specialised Allergy services NHSE 2013](#)
  - o [Human T-cell Lymphotropic Virus Type 1 and 2 \(HTLV1/2\)\(all ages\) NHSE 2013](#)
  - o [Adult specialised services for people living with HIV NHSE 2024](#)
  - o [Specialised services for infectious diseases \(adults\) NHSE 2025](#)
- **Other published documents**
  - o [UN Convention on Rights of a Child \(UNCRC\) - UNICEF](#)
  - o [Turning the Tide: Harnessing the power of child health research RCPCH 2012](#)
  - o [Turning the tide: five years on RCPCH 2018](#)
  - o [Improving inclusion of underserved groups in clinical research: Guidance from INCLUDE project NIHR August 2020](#)
  - o [Antenatal Screening Wales Quality Manual](#)
  - o [Well-Being of Future Generations \(Wales\) Act 2015: the essentials, Welsh Government, updated January 2025.](#)

## 2. Service Delivery

This NHS Wales Joint Commissioning Committee Service Specification sets out how a comprehensive Paediatric Immunology & Infectious Diseases (PIID) service for Wales, as described in Chapter 1, will be delivered through the newly commissioned Paediatric Infectious Diseases specialist service for South Wales existing Paediatric Immunology services within the All Wales Immunodeficiency Centre, existing arrangements for PIID services in North Wales, and collaboration between PIID services and Public Health Wales. It also identifies existing or anticipated commissioning gaps.

### 2.1 Acceptance and Exclusion Criteria

The specialist PIID service is for CYP with suspected or confirmed paediatric immunology and/or infectious disease conditions requiring tertiary expertise, as outlined in section 1.2 and Table 1. Some conditions have overlap with other services, notably rheumatology and haematology, and arrangements on which service leads their management may vary between Children’s Hospitals (e.g. Kawasaki’s Disease, HLH).

The service outlined in this specification is for children and young people ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients who are resident in England who are registered with a GP Practice in Wales.

Referrals are accepted for children and young people up to their 16<sup>th</sup> birthday. For CYP aged 16-18 years new referrals should be made to adult services. Adult clinicians may liaise with paediatric counterparts if required, depending on the nature of the young adult’s care needs, on a case by case basis. The arrangements for transitional care are noted in 2.2.

Based on a 2024 mid-year estimate, the CYP population aged 0-15 years in Wales is 546,361 (17.1%)<sup>10</sup>. Table 2 shows the breakdown by health board.

**Table 2 CYP aged 0-15 years in Wales by Health Board**

| Health Board        | Number and %    |
|---------------------|-----------------|
| Betsi Cadwaladr UHB | 116,749 (21.4%) |
| Powys THB           | 20,341 (3.7%)   |
| Hywel Dda UHB       | 62,358 (11.4%)  |
| Swansea Bay UHB     | 66,432 (12.2%)  |

<sup>10</sup> [Population estimates by local health boards and age, Stats Wales, Welsh Government](#)

|                       |                |
|-----------------------|----------------|
| Cwm Taf Morgannwg UHB | 79,453 (14.5%) |
| Aneurin Bevan UHB     | 109,436 (20%)  |
| Cardiff and Vale UHB  | 91,592 (16.8%) |

Referrals, including requests for guidance, to specialist PIID services will usually be accepted from paediatric tertiary subspecialists, secondary care paediatricians, and specialists caring for pregnant women.

Referrals from Primary Care can be accepted in specific circumstances, including, but not limited to, transfers into Wales of CYP with known conditions requiring PIID expertise, e.g. immunodeficiencies, HIV, viral hepatitis.

The PIID service will not accept referrals for people who are aged 16 years or older, or live outside the above described areas, or for conditions that fall outside the scope discussed in section 1.2 and Table 1.

The commissioned providers are responsible for ensuring that referrals to the PIID service follow locally agreed pathways based on national evidence based guidelines and are managed in accordance with agreed response times.

The commissioned providers are also responsible for ensuring that PIID referrals to and collaboration with quaternary services outside Wales follow agreed pathways (details in 2.4).

## 2.2 Transition Arrangements

Transition arrangements should be in line with [Transition from children's to adults' services for young people using health or social care services, NICE guidance NG43](#) and the [Welsh Government Transition and Handover Guidance](#)

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence 12-13 year olds. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service.

The way this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

For the specialised paediatric services it commissions, the JCC will routinely commission treatment up until a patient is 16 years old. The JCC does not commission specialised paediatric services for patients aged 18 years and older. For patients aged 16 or 17 years of age, the JCC will continue to commission ongoing specialised treatment initiated before the patient's 16th birthday and under the ongoing care of a specialised paediatric team.

The commissioned PIID providers, together with their adult counterparts, and where appropriate third sector agencies, should have shared pathways to deliver timely, coordinated transition to the relevant adult services for all children and young people with immunological or infectious conditions expected to continue into adulthood<sup>11</sup>

## 2.3 Service description

The geographical arrangements are set out in section 2.5.

### 2.3.1 Staff<sup>12</sup>

#### Core Specialist PIID team:

- Consultant PIID - a case load appropriate number of consultant(s) in tertiary Paediatric Immunology and Infectious Diseases\*<sup>13</sup>, or equivalent, with adequate experience in the management of PIID conditions, and who maintain up to date Continuing Professional Development (CPD) in their area of practice.
- Clinical Nurse Specialist - an appropriate number of Specialist Nurses with expertise in Immunology and/or Infectious Diseases, who maintain up to date Continuing Professional Development (CPD) in their area of practice to provide specialist paediatric nursing care, including training and support for families to run the full range of relevant self-care and home treatment services.
- A clinical and operational PIID leadership team, with the appropriate skills and sufficient capacity, including data management, who provide a service plan for

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<sup>11</sup> Tertiary Adult Immunology is JCC commissioned for Wales, Tertiary Adult Infectious Diseases is not, and only exists in Cardiff, Swansea and Liverpool. Resultant inequities and their effects on patients, e.g. living with HIV, Hepatitis B or C, from Aneurin Bevan, Cwm Taf Morgannwg and Hywel Dda should be monitored and reported to JCC to inform future planning.

<sup>12</sup> Paediatric Immunology is commissioned as part of the Immunodeficiency service for Wales (SS78), which currently does not include services for children or adults with secondary immune deficiency, which therefore require consideration on an individual basis via the IPFR process outlined in 2.5. Numbers of patients with secondary immune deficiency in Paediatrics are small compared to Adult services but are expected to grow and exceed current service capacity, and this will require data collection and monitoring/future business case. Similarly, introduction of Newborn screening will cause a significant increase in Paediatric Immunology workload and will require data collection and monitoring/future business case.

<sup>13</sup> \*Tertiary trained PIID specialists (GRID or equivalent), and paediatrician(s) with a PIID special interests (SPIN or equivalent) subject to their level of expertise.

their region and a responsive and accountable governance framework for activity, quality & safety and PIID service resilience and sustainability.

- Administrative support – appropriate level of clinical co-ordinator and secretarial support.

### **Essential co-delivering staff and services:**

- Adult Clinical Immunologist(s) Paediatric Microbiologist/Virologist Antimicrobial pharmacist
- Access to MDT forum of clinical geneticists, bioinformatician and clinical scientists in Genetics
- Access to clinical psychology and play specialists
- Access to safeguarding liaison, social services, community and peer support workers
- Access to a central intravenous line service
- Access to PIID research and development support
- Defined links with the relevant Public Health divisions at policy and delivery level
- All Wales Immunoglobulin Strategy Group
- HEIW support for PIID training at GRID and SPIN level

### **2.3.2 Diagnostics**

Specialist PIID services require timely access to:

- Specialised Immunology Laboratory services with UKAS accreditation or equivalent
- Comprehensive genetics testing and tissue typing
- Accredited Microbiology, Virology, Mycology and TB pathogen laboratories
- Diagnostics for rare and emerging immunological and infectious diseases through accredited UK/European/USA highly specialist and reference laboratories
- Comprehensive paediatric radiology including neuroimaging services

### **2.3.3 Pharmacy and/or Blood Bank**

Appropriate storage and dispensing facilities for timely provision of antimicrobials, immunological drugs and blood products, notably including immunoglobulin and C1 esterase inhibitors.

Documentation systems allowing reliable traceability to individual patients must be in place for all products.

Enhanced batch tracking systems must be in place for immunoglobulin and C1 esterase inhibitors products, meet the Medicines and Healthcare Products Regulatory Agency (MHRA) accreditation and blood regulatory requirements, irrespective of whether such products are provided via pharmacy or blood bank.

#### **2.3.4 Hospital Facilities and equipment**

All facilities and equipment should be provided according to standards set by regulation and accreditation bodies.

- Access to sufficient and appropriate clinic rooms for hospital based outpatient clinics.
- Access to an appropriately equipped and staffed day-case space that is safe for immunocompromised patients and can provide immunoglobulin and biologicals infusions, as well as family training for home therapy of intravenous and subcutaneous therapies.
- Access to admission pathways with individualised care plans and in-patient beds, including a negative pressure facility suitable for children.
- Appropriate clinical and office working environments for PIID staff.

#### **2.3.5 Shared care, self-care and home therapy**

Where possible, subject to patient's care requirements, wishes, abilities and circumstances, shared care closer to or at home should be facilitated.

Many immunology and some cohorts of infectious diseases patients have chronic conditions requiring complex life-long treatments, such as immunoglobulin replacement therapy. Provision of such therapies at home or at local services demand continuous significant support from the specialist nursing team, including initial training for families, ongoing monitoring, troubleshooting when issues arise, and governance processes to ensure safety and adherence.

#### **2.3.6 Digital Medicine**

There is a growing use of digital medicine such as virtual consultations, which can support shared care and reduce travel burdens for families in geographically remote areas.

Commissioned providers of PIID services should be committed to incorporation of appropriate digital solutions for all aspects of service provision.

As part of this, staff should be provided with suitable equipment, software applications, access to IT support and training, and working environments that comply with protection of confidentiality for patients and carers.

#### **2.3.7 Range of PIID Services provided**

**Acute clinical PIID service:**

As per the NHS England guidance (2013) a PIID service should provide for all secondary and tertiary care services within their geographical remit:

- Consult service Monday to Friday 9.00-18.00 hrs for telephone and email advice; 24 hours service for emergency support<sup>14</sup>.
- Rapid access day case or clinic review at the tertiary centre for urgent stable inpatients and outpatients within 1 week.

For services located at the Children's Hospitals only:

- Timely and regular complex inpatient review for PIID consults
- PIID input into microbiology rounds on PICU, NICU, Haematology-Oncology and other areas as required.

### **Inpatient care**

PIID services operate primarily as consultative services, providing specialist input for patients admitted under other specialties. However, occasionally, patients with complex immune deficiencies and infections require admission directly under tertiary PIID. Tertiary PIID services both in Cardiff and Liverpool are not resourced to provide a dedicated ward team, and such patients require shared with General Paediatrics<sup>15</sup>.

### **Scheduled care clinical PIID service:**

- Timely outpatient assessment and ongoing management of non-urgent cases in Paediatric Immunology and Infectious Diseases clinics at the tertiary centre.
- Provision of designated specialist MDT clinics at the Children's Hospital(s) with relevant tertiary/quaternary specialist medical, nursing and allied professionals for chronic and complex conditions at an appropriate frequency
- Where feasible and clinically appropriate outreach PIID clinics to bring care as close to home as possible, jointly with secondary care clinicians in local paediatric units at an appropriate frequency and format.
- Supporting secondary care colleagues and local health inclusion services with new entrant infection screening and treatment and related aspects of migrant/asylum seekers' health.
- Ongoing specialist nursing support to outpatients, including home therapy support, nurse led clinics and home visits.
- Joint clinics with specialties with whom PIID commonly share complex patients, e.g. Rheumatology, Respiratory, Gastro-enterology.

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<sup>14</sup> The PIID service at Alderhey meet this acute cover guidance. The PIID service at CHfW is currently not resourced to offer out of hours cover and are only available on normal working days 0900-1700 hours. This inequitable situation will be monitored and mitigated by clear expectation setting across the region, including clinical guidance and pathways for presumptive treatment for PIID conditions and advance weekend planning.

<sup>15</sup> In South Wales this represents a commissioning gap as Cardiff and Vale UHB General Paediatrics (secondary care) are not currently commissioned for the input they provide to PIID patients admitted to the CHfW from the four other UHBs.

- Antenatal and Fetal Medicine MDTs with Obstetric, Sexual Health, Adult ID and Neonatal Colleagues for birth planning for prevention, diagnosis and management of perinatal/congenital infections.
- Any other relevant regular multi-specialty MDTs.
- PIID specialists will, when required, also access highly specialist advice through UK wide virtual MDTs, and the (international) PIID peer network, for complex case discussion as required. Examples include the National HLH MDT, St Mary's International Paediatric HIV MDT, paediatric Hepatitis C ODN for England, National Leishmaniasis MDT, UCL Hospital for Tropical Diseases advice line, and others.

### **AMS, HAIs and p-OPAT**

Paediatric Antimicrobial Stewardship (PAS aka AMS), prevention of Healthcare Associated Infections (HAIs) and Outpatient Parenteral Antimicrobial Therapy (OPAT) programs in regional children's hospitals are jointly provided by AMS pharmacists, microbiologists and virologists, infection control teams, paediatric infectious disease consultants and Public Health Wales laboratories.<sup>16</sup>

PIID providers should aspire to share AMS, HAI and p-OPAT guidance with their respective local secondary care units in a coordinated approach, ensuring consistency and equity.

### **Managed Clinical networks for PIID**

- To provide care as close to home as possible, PIID specialists are required to collaborate extensively with colleagues in secondary (and by extension primary care), as well as tertiary specialists across the full spectrum of medical and surgical subspecialties, certain quaternary services as well as Public Health teams and research and development services.
- Depending on what is locally appropriate, this can take the form of managed clinical networks, or other frameworks, through which tertiary PIID specialists support clinical colleagues across the region to provide PIID care, facilitate development and sharing of guidelines and care pathways, access to research studies for CYP closer to home, and support their local collaborations with relevant public health work streams.

### **Secondary care paediatric services**

All secondary care units across Wales are should have agreed referral and care pathways with one of the tertiary PIID services.

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<sup>16</sup> Alder Hey currently has paediatric AMS and pOPAT programs set up, whereas CHfW currently doesn't. The South Wales PIID service is committed to supporting their development. Additional resources and MDT involvement of allied specialties would be required for full implementation at CHfW

The tertiary PIID service for South Wales will develop a managed clinical network with link consultants with a PIID interest in each of the paediatric units across the 5 UHBs. The Alder Hey Children's NHS Foundation Trust PIID service will develop a locally appropriate framework for sharing and governance of agreed clinical guidance and joint care pathways with the paediatric units in Betsi Cadwaladr UHB, to ensure consistency and equity in North Wales.

### **Primary care links**

Discharge and clinic letters, care plans, and information about home therapy arrangements should be shared with the primary care provider.

Where appropriate provision for repeat prescriptions, vaccinations and other treatments should be arranged close to home in liaison with the primary care provider.

### **Third sector and private sector links**

The PIID services maintain strong links with relevant patient groups, signpost patients to appropriate support organisations and seek their input into continual service improvement and policy.

The commissioned PIID service provider should also ensure that services are available, which may be contracted out to third party suppliers, for home delivery of medicinal products.

### **Other Key collaborators**

- Health and Care Research Wales, UHB Research and Development services, and the [Children and Young Adults Research Unit \(CYARU\)](#) at the [Noah's Ark Children's Hospital for Wales](#) in Cardiff
- Health Education and Improvement Wales (HEIW)
- Public Health Wales

## **2.4 Interdependencies with other services or providers**

PIID services have a wide range of mutual interdependencies with other tertiary services, some quaternary services, and a requirement for close collaboration with secondary care, and primary care services, third and private sector organisations.

### **Tertiary Services**

The following tertiary paediatric services should have access to PIID services, and vice versa, PIID patients should have timely access for their support also (both adult and paediatric):

- Paediatric Intensive Care (PICU) and High Dependency

- Level 3 Neonatal Intensive Care (NICU) units
- Fetal medicine
- Maternity Services
- Sexual Health
- Adult Infectious Diseases
- Adult Clinical Immunology
- Immunoglobulin Strategy group for Wales
- Syndrome without a name (SWAN) service
- Respiratory Medicine
- Ear, Nose and Throat Medicine
- Cleft Service
- Psychiatry
- Ophthalmology
- Haematology/Oncology
- Rheumatology Services
- Gastroenterology
- Hepatology
- Neurology, Neurosciences, Neurosurgery
- Renal Services
- Cardiology and Cardiac Surgery Services
- Dermatology
- Allergy Services
- Paediatric Surgery
- Paediatric Trauma and Orthopaedics
- Paediatric Spinal Surgery
- Burns Care Services

### **Quaternary Services**

Quaternary services are required for a number of PIID conditions and treatments:

- Bone marrow transplant for immune deficiency
- Thymic transplant
- Gene therapy for immune deficiency
- Complicated or treatment resistant Hepatitis B/C (for investigation including liver biopsy)
- Miscellaneous bespoke scenarios

PIID currently accesses such services on a case by case IPFR basis, except for the Birmingham Liver service.

## 2.5 Service provider/Designated Centre

The following centres are commissioned by NWJCC to provide specialist PIID services for Wales:

### **South Wales** (Immunology & Infectious Diseases)

Noah Ark Children's Hospital  
University Hospital of Wales  
Heath Park Way  
Cardiff  
CF14 4XW

Serves: Aneurin Bevan, Cardiff and Vale, Cwm Taf Morgannwg, Hywel Dda, Swansea Bay University Health Boards and Powys Teaching Health Board.

### **North Wales**

Alder Hey Children's Hospital (*Immunology & Infectious Diseases*)  
East Prescott Road  
Liverpool  
L14 5AB

### **Mid Wales (Powys)**

Birmingham Childrens Hospital (Immunology & Infectious Diseases)  
Steelhouse Lane  
Birmingham  
West Midlands  
B4 6NH

The primary hospital for tertiary referrals from Powys residents is Birmingham's Children's Hospital, but they can also be referred to Alder Hey Children's Hospital, Liverpool or Noah's Ark Children's Hospital, Cardiff depending on where they live.

The commissioned tertiary PIID providers should triage and identify patients requiring onward referral to highly specialised national services for specialist investigations and procedures which the tertiary PIID services do not provide.

## **Key Quaternary providers**

### **Manchester University NHS Foundation Trust**

Complex Immunology from North Wales is managed here, in conjunction with Alder Hey. Some paediatric haematopoietic stem cell transplants are also performed here.

### **Newcastle Upon Tyne Hospitals NHS Foundation Trust**

South Wales through the All Wales Immunodeficiency service, and North Wales through Manchester have established shared care pathways with the haematopoietic stem cell transplants (HSCT also termed BMT) for Severe Combined Immune deficiency and other immune disorders in Newcastle.

### **Great Ormond Street Hospital NHS Foundation Trust**

Both South and North Wales would refer to GOSH for Gene therapy and Thymic transplant. Neither have shared care pathways with GOSH for HSCT but on specific patient request referral to GOSH instead of Newcastle can be considered.

### **National Amyloidosis Centre at the GOSH and Royal Free Hampstead NHS Trust**

South Wales liaises with or refers to this centre for specialist lab testing or clinical review of complex or treatment resistant auto inflammatory conditions, including cryopyrin related periodic fevers.

### **Birmingham Children's Hospital – Paediatric hepatology service**

Both the South Wales PIID service and Alder Hey accesses this service for Hepatitis B and C advice, and referral of complex cases for further investigation and management.

## **2.6 Exceptions**

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

## 3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The quality framework should incorporate all Health and Quality standards for services in Wales, notably, safety, timeliness, effectiveness, efficiency, equitable access, person-centred care, leadership, workforce, culture, information, learning, improvement and research and a whole systems approach<sup>17</sup>.

The providers must enable the patients, parents/carers, families, advocates and patient organisations informed participation and to be able to demonstrate this. Validated feedback tools should be developed and implemented. Patient Reported Outcome Measures (PROMS) and/or Patient Reported Experience Measures (PREMS) should be reported to JCC quarterly through the contract monitoring process.

Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

### 3.1 Aims of the PIID Service

The providers will aim to improve both life expectancy and quality of life for children and young people with Immune Disorders and Infectious Diseases in Wales by providing access to prevention, early diagnosis and holistic expert management.

The providers should act as ambassadors for the service and service users, and work with patients/families, patient organisations and professional organisations, and the commissioners, to continually improve support and care for the conditions under their remit.

### 3.2 National and UK Standards

The commissioned PIID providers should provide their services in accordance with the quality framework and national standards for all Children, Young People and maternity services.

All overarching health policy documents relevant to the commissioners and the PIID service providers are outlined in section 1.3 and not repeated here. The following standards apply specifically to clinical PIID services. As the scope of PIID services is wide, rapidly evolving and includes rare disease, the list below is not exhaustive.

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<sup>17</sup> [Health and Care Quality Standards NHS Wales Shared Services Partnership 2023](#)

- [Paediatric Medicine: Immunology and Infectious Diseases NHSE 2013](#)
- [Wales Rare Diseases Action Plan 2021-2026 NHS Wales Performance and Improvement](#)
- [Quality in Primary Immunodeficiency Services \(QPIDS\)](#)
- [Consensus Document — Max Appeal](#)
- [British Society for Immunology Competency Framework for Immunology Nursing May 2023](#)
- [Chiva | Standards of Care and Clinical guidelines](#)
- [Clinical Guidelines – BHIVA](#)
- [HIV testing: increasing uptake among people who may have undiagnosed HIV \(NG60\) December 2016](#)
- [Guidelines | BASHH](#)
- [Reducing sexually transmitted infections \(NG221\) June 2022](#)
- [Tuberculosis \(NG33\) updated February 2024](#)
- [BAPT Publications](#)
- [Overview | Hepatitis B and C testing: people at risk of infection | Guidance | NICE](#)
- [Hepatitis B \(chronic\): diagnosis and management \(CG165\) updated October 2017](#)
- [BVHG Perinatal HBV 3.3.21.pdf](#)
- [BVHG Guidelines FINAL](#)
- [Clinical Guidelines and Standards RCPCH](#)
- [Suspected Sepsis: recognition, diagnosis & early management \(NG51\) updated March 2024](#)
- [Overview | Meningitis \(bacterial\) and meningococcal disease: recognition, diagnosis and management | Guidance | NICE](#)
- [COVID-19 rapid guideline: managing COVID-19 \(NG191\) updated May 2024](#)
- [High consequence infectious diseases \(HCID\) - GOV.UK](#)
- [Pandemic Preparedness & Exercise Pegasus NHS England July 2025](#)
- [Antimicrobial stewardship | Topic | NICE](#)
- [Antenatal Screening Wales Quality Manual](#)

For standards and targets for communicable disease screening, surveillance, prevention and eradication programs we refer to the policy documents of Public Health Wales, UKHSA and WHO.

### 3.3 Quality Indicators

#### Leadership

- The PIID providers should have a visible clinical and operational leadership team, at their base institution, with the appropriate skills and sufficient capacity, including data management. These teams, from here on termed 'the providers', should develop a service plan for their region and a responsive and accountable

governance framework for activity, quality & safety and PIID service resilience and sustainability.

- This framework should include structures for joint governance with key collaborators, notably clinical units across the UHBs, Public Health Wales departments, and the All Wales Immunoglobulin Strategy Group. Joint audit and performance monitoring is mandatory and should be supported by their respective operational teams.

### **Activity data**

- The provider shall aim to ensure that PIID service activity is measured using hospital systems. This includes outpatient referrals, referral outcomes, numbers and outcomes of new and follow up outpatients, PIID inpatient care, face to face patient consults at the base hospital, in person, telephone and email advice both at the base hospital and with all UHBs within their region.

### **Related essential data management**

- Activity monitoring systems should include or link to a PIID clinical patient data base, which should be developed and includes patient identifiers, and a search facility for diagnosis, including ICD code where one exists.
- Data should be submitted to all relevant (inter)national (rare) disease registries. For Paediatric Immunology cohorts, the provider should work with BSI-CIPN to populate national and international disease registries including the UK PID Registry and the Congenital Anomalies Register and Information Service (CARIS).
- The provider should monitor finance reports on (1) high cost investigations, including those performed by UK reference- and quaternary laboratories, and (2) expensive therapies, notably, but not exclusively, immunoglobulin, C1 inhibitor, biologics, and other high cost drugs, as well as disposables, delivery and nurse time for patient training and lifelong monitoring and (3) other non-staff costs, both as provided through the JCC contract and outside this through IPFRs.

### **Clinical**

- The PIID providers should aim to practice in line with the (inter)national standards and targets for conditions for which these exist. Providers should support active staff engagement in peer accreditation processes, including acting as inspectors.
- PIID has a wide remit (Table 1) and it falls outside the scope of this document to list quality indicators for all conditions exhaustively.
- As part of the QPIDS accredited All Wales Immunodeficiency centre, tertiary Paediatric Immunology services at CHfW should align with standards set within the All Wales Immunodeficiency service specification and aim for paediatric QPIDS accreditation. Whilst QPIDS accreditation is not mandatory, all PIID providers should practice in line with QPIDS standards Outcome measures will be monitored in line with the UK PIN requirements.

- The PIID providers should work closely with the Immunoglobulin Strategy Group for Wales which manages Ig supply in Wales.
- Many PIID conditions are rare and do not have (inter)national guidance. The commissioned providers should aim to deliver their services in accordance with the Wales Rare Diseases Action Plan and aim to ensure bespoke care (shared) plans, including transition plans, are jointly developed with patients, carers and relevant professionals.
- Patients/families should be offered a choice of route and location of such treatments where multiple products and options exist (e.g. intravenous versus subcutaneous, and hospital versus home based, immunoglobulin replacement therapy).
- The service should aim to ensure all patients have equitable access, irrespective of their postcode, to PIID expertise, treatment options, including relevant home therapies such as intravenous antibiotics, biologics, immunoglobulin replacement therapy, hereditary angioedema treatments and others, patient education and support, and participation in relevant clinical trials and other research studies as part of their clinical care.
- The providers should aim to provide regional referral and care pathways, including referral criteria, which are compliant with national standards and guidance, including early recognition and management of complications, and deliver good practice and care as close to home as possible.
- The provider should monitor the appropriateness of referrals and consults and provide regular feedback to referrers, identifying any trends, need for pathways or potential educational needs.
- The provider, should provide specialist MDT support from, medical PIID specialists, specialist nurses, allied therapists, including dietetics, physiotherapists, psychology, and work with education and social care, to limit and, where possible reverse, psychological and educational damage and disability.

### **Shared Care**

- All shared care, self-care and home therapy packages should meet the required standards relevant to the condition and its management.
- Shared care arrangements should be pre-agreed with the local centre and the child and parents/carers and underpinned with a comprehensive individualised care pathway, including arrangements for provision of medications and consumables, clinical monitoring and outpatient reviews locally and/or at the PIID centre, and information about when and how to escalate and seek advice from the PIID centre. Such care demand continuous significant support from the specialist nursing team, including initial training for families, ongoing monitoring, troubleshooting when issues arise, and governance processes to ensure safety and adherence.
- Care provided in shared-care hospitals closer to home, is subject to the same requirements for appropriate facilities, equipment, pharmacy and blood bank as the PIID centres.

- Providers should have agreed care pathways for assessment, referral, and post-transplant management, long term follow-up, including late effects monitoring, and transition for patients requiring HSCT or thymic transplantation in close collaboration with transplant centres.

### **Patient and public engagement**

- The providers should have a patient and public engagement strategy that ensures that patient/family/public views of the service are measured and used by the service, the UHBs and the commissioners, with patient group involvement, to inform action plans for continual service improvement and national policy development.
- This should include regular surveys of patient/family reported experience and outcomes measures (PREMS and PROMS), using validated tools, as well as active engagement with relevant patient organisations.
- Condition specific Patient information should be developed, where possible in collaboration with patient organisations and harmonised with other PIID centres, and used to underpin service and policy development.

### **Workforce**

- All patient care is led and overseen by specialist consultants trained in tertiary Paediatric Immunology and Infectious Diseases and Immunology, or equivalent, with adequate experience in the management of PIID conditions<sup>18</sup>.
- Specialist Nurses deliver PIID care within their scopes of practice.
- Paediatric Infectious Diseases should maintain, or work towards, relevant training for their areas of responsibility.
- Specialist paediatric immunology nurses are either compliant with, or working towards, the British Society for Immunology Competency Framework for Immunology Nursing.
- PIID staff should up to date Continuing Professional Development (CPD) in their area of practice.
- The PIID service should complete risk assessments for staff as required.
- Caseloads should be monitored to ensure medical and nursing staffing levels remain appropriate. See also PIID resilience and sustainability.

### **Continuous professional development (CPD)**

- The PIID service should support staff training and professional development according to the CPD requirements for clinicians, the BSI (British society of Immunology) competency framework for Immunology Nursing, the All Wales

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<sup>18</sup> \*Tertiary trained PIID specialists (GRID or equivalent), and paediatrician(s) with a PIID special interests (SPIN or equivalent) subject to their level of expertise.

Immunodeficiency service specification, and other relevant staff competency frameworks.

- PIID providers should actively participate in regional, national and international clinical peer medical and specialist nursing network meetings, educational events and conferences, to review and compare practice, and share expertise. A minimum of 50% attendance to regional/national PIID network meetings will be required, noting that for rare disease, attendance at International meetings is also required, but this will be at the discretion of the health board as they would be funding attendance.

### **Equitable inclusion in relevant PIID research**

- In collaboration with local research and development (R&D) services and the Children and Young Adults Research Unit (CYARU) at the Noah's Ark Children's Hospital for Wales in Cardiff, the PIID providers should provide clinical leadership through an MDT model supporting clinicians across the region to provide equitable access, irrespective of postcode, to National Institute of Health Research (NIHR) portfolio clinical trials in PIID, and other relevant PIID research.
- PIID providers should also ensure submission of data to all relevant (inter)national registries including the Congenital Anomalies Register and Information Service (CARIS)

### **PIID collaboration with Public Health Wales**

- PIID providers and Public Health Wales should collaborate closely so that paediatric expertise is included in across the wide range of communicable disease programs within Public Health Wales (PHW).
- PIID providers should collaborate with Public Health Wales surveillance teams, such as the Congenital Anomalies Register and Information Service (CARIS) surveillance registry.
- The PIID provider for South Wales shall have membership to the relevant PHW forums to provide their expertise at policy level to all programs relevant to PIID. This provider shall liaise with their counterparts at Alder Hey to ensure both PIID providers are aligned with regards to Welsh policies.
- Have membership to the relevant Networks with NHS Wales Performance and Improvement e.g. Rare Diseases.
- At health board level, PHW health protection teams shall work with local paediatric clinicians, who can liaise with their tertiary PIID service for advice and support as/when needed with local implementation or delivery.
- With regards to HCIDs, tertiary PIID services should aim to be involved at both policy and delivery level across their region, and work alongside PHW and paediatric units at local health boards to endeavour that guidance and pathways are put in place for these rare but serious urgent scenarios.

### **PIID service resilience and sustainability for Wales**

- As part of their service plan, the PIID providers should have a proactive strategy to ensure resilience and long term sustainability of access to highly specialist PIID expertise for all CYP in Wales, which includes the following key elements.
- Jointly with HEIW commissioned PIID services should support medical Paediatric Immunology and Infectious Diseases training at GRID and SPIN level, and PIID training for specialist nurses in Wales.
- The provider, their base institution, and commissioners should have a workforce development and succession plan.
- The provider, base institution and their commissioners support continuing professional development of PIID staff, active participation in relevant clinical networks, their training events and meetings, noting that for rare disease expertise this requires (inter)national travel.
- PIID providers should deliver a comprehensive teaching portfolio for colleagues in paediatric and other closely affiliated specialties, such as microbiology, virology, maternity, adult ID and Immunology across Wales.
- The provider should have/develop frameworks for joint Quality & Safety governance with co-delivering colleagues, for audit, to further support increased awareness and deliver education of best practice in the diagnosis and management and shared care for PIID conditions.

## 4. Performance Monitoring and Information Requirement

### 4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

The service provider is defined as the clinical and operational PIID leadership team, PIID staff and their base institution. Where applicable, contributions for quality and performance monitoring from key collaborators will be expected and included.

NWJCC will conduct performance and quality reviews on an annual basis.

National Reportable incidents (NRIs) and other events of similar gravity, including exceptional surges in PIID activity, e.g. large or serious disease outbreaks, must be escalated via the UHB Quality team to the JCC Quality Team in real time, with the expectation that where these exceed the commissioned capacity, emergency planning and extra resource will be required.

### 4.2 Activity, coding and data registry monitoring reports

- The provider shall aim to monitor and report on activity, namely outpatient referrals and referral outcomes, numbers of new, follow up and discharged outpatients, PIID inpatient care, face to face patient consults at the base hospital, in person, telephone and email advice both at the base hospital and with all UHBs within their network.
- They shall also aim to report on their review the appropriate appropriateness of referrals and consults to the service, identify trends, need for pathways or potential educational needs and actions planned or taken.
- The provider shall aim to develop a PIID clinical patient data base, with search facility for diagnosis, including ICD code where one exists.
- The provider shall submit their data to all relevant (inter)national (rare) disease registries. This would include reporting to the Congenital Anomalies Register and Information Service (CARIS) surveillance registry.

### 4.3 Key Performance Indicators

The providers will be expected to monitor against the full list of quality indicators of the service description components described in Section 3.3.

The PIID provider will be expected to report annually to the commissioners against the selected Key Performance Indicators (KPIs) below.

This document is reviewed 3 yearly. PIID is a rapidly evolving service with a wide scope. The provider will contact the commissioners when updates are required prior this, to ensure the selected KPI measures remain contemporaneous and reflect key elements of the PIID service.

#### KPI 1 HIV and Syphilis in pregnancy

|                                                                                                                                                                                                                                  |                                                                                                                                                                                                                     |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>All pregnant women in Wales testing positive for HIV or syphilis are discussed at a multiprofessional antenatal MDT and a birth plan is produced and uploaded on their electronic record prior to delivery. |                                                                                                                                                                                                                     |
| <b>Rationale</b>                                                                                                                                                                                                                 | To ensure all pregnant women in Wales have access to the highest standard of care as regards to prevention of transmission of HIV and syphilis.                                                                     |
| <b>Assessment Criteria</b>                                                                                                                                                                                                       | % of pregnant women testing positive for HIV or syphilis that are (1) discussed at a multi-professional antenatal MDT and (2) have a birth plan produced and uploaded on their electronic record prior to delivery. |
| <b>Target</b>                                                                                                                                                                                                                    | 90%                                                                                                                                                                                                                 |
| <b>Data Source</b>                                                                                                                                                                                                               | Lab results, MDT notes, birth plans on electronic record prior to delivery                                                                                                                                          |
| <b>Validation</b>                                                                                                                                                                                                                | Annual audit in collaboration with the antenatal MDTs and Public Health Wales of positive screening tests across all UHBs                                                                                           |
| <b>Reporting Arrangements</b>                                                                                                                                                                                                    | To be reported annually to the NWJCC Information Team.                                                                                                                                                              |

#### KPI 2 TB in children and young people

|                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>All children and young people (CYP) in Wales exposed to an index case with TB receive timely assessment, screening and treatment. |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Rationale</b>                                                                                                                                       | To ensure all children and young people in Wales exposed to TB are managed according the UK clinical standards ( <a href="#">BAPT Publications</a> )                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Assessment Criteria</b>                                                                                                                             | <b>For sputum smear positive pulmonary TB index cases</b> <ol style="list-style-type: none"><li>1. % (by UHB) of asymptomatic CYP exposed to an index case with sputum smear positive pulmonary TB screened and assessed by a TB nurse within 1 week of identification.</li><li>2. % (by UHB) of CYP with a positive TST (Mantoux <math>\geq 5\text{mm}</math>) or IGRA seen by a paediatric consultant from the TB team within 2-4 weeks of the test results.</li><li>3. % (by UHB) of children aged under 2 seen by a paediatric consultant from the TB team within 2 weeks irrespective of results of TST/IGRA.</li></ol> <b>For sputum smear negative pulmonary TB index cases</b> |

|                               |                                                                                                                                                                                                   |
|-------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                               | 4. % (by UHB) of asymptomatic children exposed to an index case with sputum smear negative pulmonary TB assessed and screened by a TB nurse within 2-4 weeks of identification of the index case. |
| <b>Target</b>                 | 85%                                                                                                                                                                                               |
| <b>Data Source</b>            | Welsh TB cohort data (Public Health Wales), referral pathway data and case notes.                                                                                                                 |
| <b>Validation</b>             | Annual audit in collaboration with TB teams, Public Health Wales of all paediatric contacts of all index cases.                                                                                   |
| <b>Reporting Arrangements</b> | Quarterly at All Wales TB cohort meetings<br>To be reported annually to the NWJCC Information Team.                                                                                               |

### KPI 3 Hepatitis C eradication

|                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                         |
|----------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>Achieving global hepatitis C (HCV) eradication by 2030, as per WHO and Welsh Government targets |                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Rationale</b>                                                                                                     | To ensure that all children and young people in Wales are captured in case finding and treatment pathways, as per UK clinical guidance ( <a href="#">Who to screen/test</a>   <a href="#">Diagnosis</a>   <a href="#">Hepatitis C</a>   <a href="#">CKS</a>   <a href="#">NICE</a> )                                                                                                                                    |
| <b>Assessment Criteria</b>                                                                                           | <ol style="list-style-type: none"> <li>1. All HCV positive pregnant women are discussed at a multiprofessional antenatal MDT.</li> <li>2. All children born to HCV positive mothers complete follow up testing.</li> <li>3. All Looked-After-Children (LAC) children and young people are tested.</li> <li>4. All HCV infected CYP are seen, treated and managed by the PIID service (Cardiff or Liverpool).</li> </ol> |
| <b>Target</b>                                                                                                        | 90% in each UHB for all criteria                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Data Source</b>                                                                                                   | <ol style="list-style-type: none"> <li>1. Monthly Hep C reports from Public Health Wales, multi-professional antenatal MDTs minutes.</li> <li>2. Electronic patient records.</li> <li>3. LAC services records.</li> <li>4. PIID centre patient data base, Public Health Wales and UKHSA HCV registries.</li> </ol>                                                                                                      |
| <b>Validation</b>                                                                                                    | Annual audit by PIID service, jointly with antenatal MDTs, PHW and LAC services.                                                                                                                                                                                                                                                                                                                                        |
| <b>Reporting Arrangements</b>                                                                                        | To be reported annually to the NWJCC Information Team                                                                                                                                                                                                                                                                                                                                                                   |

### KPI 4 Immunoglobulin replacement therapy

|                                                                                                                                                                       |                                                                                                                                                                                                                                                                                       |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>All Children and Young People (CYP) in Wales on Immunoglobulin replacement therapy (IgRT) should receive care according to the highest standard. |                                                                                                                                                                                                                                                                                       |
| <b>Rationale</b>                                                                                                                                                      | To ensure all CYP in Wales on IgRT are managed according to UK clinical standards ( <a href="#">OPIDS</a> )                                                                                                                                                                           |
| <b>Assessment Criteria</b>                                                                                                                                            | <ol style="list-style-type: none"> <li>1. All patients have evidence of informed consent</li> <li>2. All patients have at least 6 monthly through IgG levels</li> <li>3. Number who have moderate to severe adverse events*</li> <li>4. All patients have an annual review</li> </ol> |
| <b>Target</b>                                                                                                                                                         | By criteria:<br><ol style="list-style-type: none"> <li>1. 100%</li> </ol>                                                                                                                                                                                                             |

|                               |                                                                                                                                        |
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|                               | 2. 90%<br>3. Less than 0.01 per 1000 treatment days<br>4. 90%                                                                          |
| <b>Data Source</b>            | PIID centre patient data base and electronic patient records<br>*UHB and JCC Quality Teams records for serious adverse events and NRIs |
| <b>Validation</b>             | Annual Audit of all CYP on IgRT by PIID team                                                                                           |
| <b>Reporting Arrangements</b> | To be reported annually to the NWJCC Information Team.                                                                                 |

## KPI 5 Specialist PIID MDT professionals' support

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|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>All CYP with PIID conditions and their families should have access to support from specialist MDT professionals, notably including specialist doctors, specialist nurses, dieticians, play therapy, counselling/psychology, as well as CAMHS and social care support. |                                                                                                                                                                                                                                                                                                       |
| <b>Rationale</b>                                                                                                                                                                                                                                                                           | To evidence that MDT care needs and HC-QoL are assessed and provided for CYP with HIV, Hepatitis B/C or chronic immunological disorders.                                                                                                                                                              |
| <b>Assessment Criteria</b>                                                                                                                                                                                                                                                                 | 1. Assessment of MDT needs and provision in clinic<br>2. Patient Reported Outcome Measures (P-PROMs) measuring Health Related Quality of Life (HR QoL) are collected before and 6-monthly after key interventions/treatments and outcomes are reviewed and actioned quarterly by the service provider |
| <b>Target</b>                                                                                                                                                                                                                                                                              | 1. 90% completion<br>2. Within the first year, validated tools are identified and data collection has started (aiming for 30% completion) and a data review process with UHB management has been set up.                                                                                              |
| <b>Data Source</b>                                                                                                                                                                                                                                                                         | PIID centre patient data base and electronic patient record<br>Validated P-PROMs tools reports (supported by UHB Value in Health team)                                                                                                                                                                |
| <b>Validation</b>                                                                                                                                                                                                                                                                          | Annual Audit reporting numbers, themes, good practice and shortfalls, actions taken and proposed further mitigations.                                                                                                                                                                                 |
| <b>Reporting Arrangements</b>                                                                                                                                                                                                                                                              | To be reported annually to the NWJCC Information Team                                                                                                                                                                                                                                                 |

## KPI 6 Patient and Public Engagement

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|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b><br>The PIID service should have a patient and public engagement strategy that ensures that patient/family/public views of the service are measured and used by the service, the UHBs and the commissioners to inform action plans for continual service improvement and national policy development. |                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Rationale</b>                                                                                                                                                                                                                                                                                                       | To evidence patient reported experience measures (PREMs) from immunology, HIV, TB and Hepatitis clinics, are collected, reviewed in the relevant forums and acted upon.                                                                                                                                                                                                                                        |
| <b>Assessment Criteria</b>                                                                                                                                                                                                                                                                                             | 1. Patients/families are offered paediatric PREMS assessment using a validated tool supported by the UHB Value in Health team<br>2. Review of results by PIID team with UHB management (quarterly), regional clinical network meetings and in Q&S meetings.<br>3. Annual discussion of PREM results with relevant patient organisations<br>4. Review of relevant report data in National Policy Group meetings |

|                               |                                                                                                                                                                                                                                                                                                                            |
|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Target</b>                 | Within the first year, validated PREM tools are identified, data collection has started (aiming for 30% completion) and a data review process with UHB management has been set up                                                                                                                                          |
| <b>Data Source</b>            | <ol style="list-style-type: none"> <li>1. Validated Patient Reported Experience Measures (PREMS) tools</li> <li>2. Minutes of action points from UHB management meetings</li> <li>3. Patient organisation correspondence, meeting agendas and minutes</li> <li>4. Policy group meeting minutes of action points</li> </ol> |
| <b>Validation</b>             | Annual audit summarising PREMs findings and outcomes of discussions in the above forums.                                                                                                                                                                                                                                   |
| <b>Reporting Arrangements</b> | To be reported annually to the NWJCC Information Team                                                                                                                                                                                                                                                                      |

## KPI 7 Quality and Safety

|                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b>             | PIID services should have a Quality and Safety framework, firmly embedded in their base institution and the regional clinical PIID network, which reports, reviews, learns and informs action plans for continual service improvement and national policy development.                                                                                                                                                                                                                |
| <b>Rationale</b>              | To evidence that the commissioned service, their base health board, the regional clinical PIID network and commissioners are engaged with and respond through their Q&S frameworks.                                                                                                                                                                                                                                                                                                   |
| <b>Assessment Criteria</b>    | <ol style="list-style-type: none"> <li>1. Engagement with PIID base institution processes for incidents, concerns and complaints response, morbidity and mortality, and Q&amp;S meetings (aka staff forum).</li> <li>2. Forums for joint Q&amp;S review of relevant cases shared with counterparts outside the Children's Hospitals frameworks, e.g. with adult Immunology &amp; ID, multi professional MDTs, and paediatric units in other UHBs, and quaternary services.</li> </ol> |
| <b>Target</b>                 | 90% for criterium<br>Within the first year, forums and processes for joint Q&S review have been identified, agreed and begun.                                                                                                                                                                                                                                                                                                                                                         |
| <b>Data Source</b>            | <ol style="list-style-type: none"> <li>1. Base institution Q&amp;S reporting systems</li> <li>2. UHB and JCC Executive Quality and Safety Team records (for NRIs)</li> <li>3. Minutes of joint meetings</li> </ol>                                                                                                                                                                                                                                                                    |
| <b>Validation</b>             | Annual Audit by PIID service and JCC Q&S teams reporting numbers, trends, themes, good practice, learning and actions taken.<br>Description of agreed joint Q&S review forums, and outcomes thus far.                                                                                                                                                                                                                                                                                 |
| <b>Reporting Arrangements</b> | To be reported annually to the NWJCC Information Team                                                                                                                                                                                                                                                                                                                                                                                                                                 |

## KPI 8 PIID service resilience and sustainability for Wales

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|----------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Definition</b>          | To increase resilience and safeguard sustainability of small highly specialist PIID service provision for Wales, the providers must have a proactive strategy to maintain their PIID expertise, including rare disease management, attract and train their future workforce, plan succession, and broaden the PIID knowledge base of allied professionals across all regions. |
| <b>Rationale</b>           | To demonstrate defined key elements of this strategy are being delivered consistently.                                                                                                                                                                                                                                                                                        |
| <b>Assessment Criteria</b> | <ol style="list-style-type: none"> <li>1. All PIID staff meet specialist CPD standards as per section 3.3</li> <li>2. PIID service supports specialist medical and nursing training</li> </ol>                                                                                                                                                                                |

|                               |                                                                                                                                                                             |
|-------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                               | 3. PIID service delivers a comprehensive PIID teaching portfolio to allied professionals                                                                                    |
| <b>Target</b>                 | 1. 95%<br>2. Training supports sustainability and succession planning for Wales<br>3. The teaching portfolio is comprehensive and responds to identified educational needs. |
| <b>Data Source</b>            | 1. Appraisals, PADRs, PIID staff CPD logs.<br>2. HEIW and CSAC, trainee feedback.<br>3. PIID service teaching calendar and participant feedback.                            |
| <b>Validation</b>             | Annual audit by PIID service providers summarising the above                                                                                                                |
| <b>Reporting Arrangements</b> | To be reported annually to the NWJCC Information Team                                                                                                                       |

#### 4.4 Date of Review

This document is scheduled for review every three years, unless information is received which indicates that the policy requires revision.

If an update is carried out, this version of the policy will remain extant until the revised policy is published.

## 5. Equality Impact and Assessment

The Equality and Welsh Language Impact Assessment (EWLIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable NHS Wales Joint Commissioning Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity, socio-economic duty and language (Welsh).

This policy has been subjected to an EWLIA.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

## 6. Listening to People:

### 6.1 Complaints, Incidents and Redress Process

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to [Listening to People, The NHS Wales Complaints, Incidents and Redress Process – People's Guidance 2026](#). For services provided outside NHS Wales the patient or their representative should be guided to the [NHS Trust Concerns Procedure](#), with a copy of the concern being sent to NWJCC.

## Annex i Glossary

### **Individual Patient Funding Request (IPFR)**

An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

### **NHS Wales Joint Commissioning Committee (NWJCC)**

NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.

## Contact Us

If you have a question related to this document you can contact us using one of the methods outlined below.

If you would like this document in an alternative format and/or language, please contact us for assistance.

### Email:

NWJCC consultation mailbox – [NWJCC.Consultation@wales.nhs.uk](mailto:NWJCC.Consultation@wales.nhs.uk)

### Telephone:

General Enquiries – 01443 433112

### Website:

[Contact us - NHS Wales Joint Commissioning Committee](#)

### Writing:

If you wish to contact the NHS Wales Joint Commissioning Committee, you can write to us at one of our locations below, we welcome correspondence in Welsh or English:

#### South Wales Office

Unit G1 The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

#### North Wales Office

Unit 3, Media Point - Unit 3, Mold Business Park, Mold, CH7 1XY