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Paediatric Nephrology

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Statement

Welsh Health Specialised Services Committee (WHSSC) commission paediatric nephrology for children and young people aged 0-18 years old in accordance with the criteria outlined in this document.

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

Disclaimer

WHSSC 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.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this document.

1. Introduction

This policy has been developed as the Service Specification for the planning and delivery of paediatric nephrology services for children and young people aged 0 to 18 years old and resident in Wales. This service will only be commissioned by the Welsh Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

Plain Language Summary

Specialised children's renal (nephrology) services provide care for a wide variety of conditions. Many children with uncomplicated general renal conditions for example urine infections may be managed locally without the need to refer to specialist services. However, some children may develop complications of common conditions or have rare conditions benefitting from specialist expertise, whilst others may require specialist diagnostic and treatment including dialysis and transplantation that can only be provided in specialist centres.

This service specification is for those specialist centres where children are diagnosed and managed.

Paediatric Nephrology Services for Children and Young People in Wales¹

Many children have renal disorders, which need clinical care throughout childhood to prevent or minimise the progression of disease; some require intensive management including paediatric urological intervention.

Children at risk of chronic kidney disease (CKD) include those with neonatal and congenital problems and acute kidney injury (AKI). More and more infants with or at risk of CKD and end stage renal failure (ESRF) are being diagnosed in the antenatal period, and some go on to need renal replacement therapy (RRT) in the first two years of life. AKI in childhood is highest in neonates and infants.

Many children with kidney problems in early life will grow up into adults with CKD and will develop ESRF. The number of children reaching ESRF per annum is around 2 per million of the total population. In Wales this is approximately 6 new cases per year. There are approximately 50 children on RRT in Wales at any one time, many with a renal transplant².

¹ Welsh Assembly Government (2009) [All Wales Nephrology Standards for Children and Young People's Specialised Healthcare Services](#)

² Welsh Assembly Government (2009) [All Wales Nephrology Standards for Children and Young People's Specialised Healthcare Services](#)

Current management of ESRF in children has resulted in improved growth and Quality Adjusted Life Years (QALY).

1.2 Current Service Model

South and Mid Wales

Children and young people requiring specialist care are admitted to the Noah's Ark Children's Hospital for Wales, Cardiff, which provides inpatient, services for acute kidney injury (AKI), end stage renal failure (ESRF) and other tertiary renal disease. An outpatient service including outpatient peritoneal and haemodialysis programmes and support is provided from Noah's Ark Children's Hospital for Wales. Outreach clinics with shared care in local acute hospitals are in place. Local acute services can access telephone support and advice at any time from the specialist centre.

Transitional care between the ages of 16 and 18 is run jointly by Paediatric and Adult services with specific clinical leads for both in University Hospital of Wales.

Renal Transplants

Children and young people requiring a renal transplant receive their pre-transplant care at Noah's Ark Children's Hospital for Wales. Transplantation and immediate post-transplant inpatient care takes place in the Bristol Royal Hospital for Children (BRHC).

Outpatient and subsequent inpatient care is shared between BRHC and Noah's Ark Children's Hospital for Wales. For children between the age of 16 and 18 years of age, the aim will be to transplant them at the Cardiff adult unit after discussion with the transplant team. However, if clinicians feel that a child in this age group needs more support, then the transplant would be undertaken at the paediatric centre (BRHC).

North Wales

The Royal Liverpool Children's Hospital (RLCH) is the lead centre for inpatient renal services, for North Wales' patients and provide pre and post-transplant care. Transplantation takes place in the Royal Manchester Children's Hospital (RMCH). The paediatric nephrology team provide outpatient outreach services and clinics in some North Wales District General Hospitals.

Highly Specialised Care

More complex patients who require highly specialised care will receive this in Great Ormond Street Hospital. Patients requiring highly specialised care must be referred through the relevant, WHSSC approved clinical gate keepers.

1.3 Proposed Service Models

South, Mid and North Wales

The current arrangements in these geographical areas should continue with all elements of the service fully planned and resourced.

1.4 Aims and Objectives of the service

The aim of this Service Specification is to define the requirements and standard of care essential for delivering paediatric nephrology services for children and young people with renal disease.

The objectives of this policy are to:

- detail the specifications required to deliver nephrology services for children and young people who are resident in Wales
- ensure minimum standards of care are met for the use of paediatric nephrology services
- ensure equitable access to paediatric nephrology services
- identify centres that are able to provide paediatric nephrology for Welsh patients
- improve outcomes for people accessing paediatric nephrology services.

1.5 Relationship with other documents

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

- **NHS Wales**
 - All Wales Policy: [Making Decisions in Individual Patient Funding requests](#) (IPFR).
- **WHSSC policies and service specifications**
 - Welsh Renal Clinical Network: [Renal Service in Wales 2016-2020 Delivery Plan](#)
- **National Institute of Health and Care Excellence (NICE) guidance**
 - [COVID-19 rapid guideline: acute kidney injury in hospital](#). NICE Guideline (NG175), May 2020.
 - [COVID-19 rapid guideline: chronic kidney disease](#). NICE Guideline (NG176), May 2020.
 - [Acute kidney injury: prevention, detection and management](#). NICE Guideline (NG148). December 2019.
 - [Renal replacement therapy and conservative management](#). NICE Guideline (NG107). October 2018
 - [Transition from children's to adults' services for young people using health or social care services](#). NICE Guideline (NG43), February 2016.

- [Chronic kidney disease: managing anaemia](#). NICE Guideline (NG8). June 2015.
- [Chronic kidney disease \(stage 4 or 5\): management of hyperphosphataemia](#). NICE Clinical Guideline (CG157), March 2013
- **Relevant NHS England policies**
 - Department of Health, [The National Service Framework for Renal Services Part One: Dialysis and Transplantation](#). 2004.
 - Department of Health, [The National Service Framework for Renal Services, Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care](#). 2005.
- **Other published documents**
 - Welsh Assembly Government (2009) [All Wales Nephrology Standards for Children and Young People's Specialised Health Care Services](#).
 - [Report of a Working Party of the British Association for Paediatric](#)
 - Welsh Assembly Government (April 2007) [Designed to Tackle Renal Disease in Wales: A National Service Framework](#).
 - Renal Association (2002) [Treatment of Adults and Children with Renal Failure; standards and audit measures](#).

2. Service Delivery

The Welsh Health Specialised Services Committee commission paediatric nephrology for children and young people aged 0-18 years old with renal disease and resident in Wales, in-line with the criteria identified in the policy.

2.1 Access Criteria

Paediatric Nephrology Services

This service specification is aimed at delivering safe and effective care for children and young people with renal disease. Recognising that these needs can continue into early adulthood, the scope is for the 0-18 year old age range, and defines the management of the transition of young people from children's units to adult renal units by achieving a smooth and efficient transition of care between 16 and 18 years.

The service specification builds on the Renal Services Delivery Plan³, Renal National Service Framework and its Strategic Frameworks which relate to:

- Preventing the development of Acute Kidney Injury (AKI) in children and young people
- Early identification and management of AKI
- Preventing the development of Chronic Kidney Diseases (CKD)
- Early identification and management of CKD
- Delivering fast, effective care as close to the family's home as possible
- Supporting Living with Chronic Kidney Disease
- Caring at the end of life
- Improving Information
- Targeting research and;
- Transition services.

This document will make reference to, and should be read in conjunction with, the Renal Service Delivery Plan² which builds on the Renal National Service Framework (NSF) for Wales⁴ and the All Wales Nephrology Standards for Children and Young People's Specialised Health Care Services⁵. Many children with CKD and ESRF in Wales receive some, or all of their care in England. Therefore the standards set out in the Renal Service Delivery Plan should ensure that the care of children with AKI, CKD, and ESRF conform to the standards.

³ Welsh Renal Clinical Network: [Renal Service in Wales 2016-2020 Delivery Plan](#)

⁴ Welsh Assembly Government (April 2007) [Designed to tackle Renal Disease in Wales: A national Service Framework](#)

⁵ Welsh Assembly Government (2009) [All Wales Nephrology Standards for Children and Young People's Specialised Health Care Services.](#)

The Renal Network⁶ has described many of the standards for the care of children in the Renal Service Delivery Plan. The outcome of care is monitored by the Paediatric Renal Registry organised by the British Association for Paediatric Nephrology and UK Renal registry⁷ and the European Dialysis and Transplantation Registry⁸.

2.2 Service description

In addition to the standards required within the contract between WHSSC and the provider, specific quality standards and measures will be expected. The provider must also meet the standards as set out below.

2.2.1 Clinical Standards

The provider needs to meet the following standards and the associated key actions as set out by the Welsh Government, All Wales Nephrology Standard for Children and Young People's Specialised Healthcare Services⁹:

- **Standard 1: Access to Renal Services**
All children and young people identified with a renal disease will have access to high quality, evidence based care provided by appropriately trained multi-disciplinary teams.
- **Standard 2: Resourcing of Renal Services**
Renal services are staffed with appropriate, multi-disciplinary professionals who are fully trained. Services are fully equipped to deliver appropriate and equitable care across the network.
- **Standard 3: Delivering Quality Care**
All children with renal disease receive high quality care. Each child at risk of, or with CKD or ESRF has regular, systematic, assessment and follow up and appropriate management to reduce the risk of disease progression, co-morbidity and developing complications of chronic renal disease.
- **Standard 4: Care of the Child and Family**
The child and the family receive holistic, child and family centred care based on the individualised needs of the child, young person and their family.

⁶ [Welsh Renal Networks](#)

⁷ <https://www.renalreg.org/>

⁸ <https://www.era-edta-reg.org/index.jsp?p=1>

⁹ <http://www.wales.nhs.uk/sites3/Documents/355/Nephrology%20Eng%20web.pdf>

- **Standard 5: Communication**
There is effective two-way communication from local to specialist care and back, and between professionals and children, young people and their families.
- **Standard 6: Evidence Base, Professional Education and Training**
All professionals caring for children and young people are trained to the required standard to deliver high quality evidence based services.
- **Standard 7: Transition to Adult Services**
Services for young people are provided to adequately address the issues of growing up with CKD with particular support for the transfer from paediatric to adult renal units.

2.2.2 Staffing Requirements

Children and young people that need paediatric renal and urology services should have access to:

- all the specialist paediatric services that they require, including specialist multidisciplinary outreach services where indicated
- the Multidisciplinary renal team including:
 - Paediatric nephrologist
 - Adult nephrologist
 - Specialist paediatric renal nurses to include dialysis nurses
 - Paediatric renal dietitian
 - Clinical psychologist
 - Specialist paediatric renal social worker
 - Youth worker
 - Designated paediatric pharmacist
 - Play specialist
 - Dedicated teacher
 - Dialysis technician
 - Transplant co-ordinator
 - Paediatric physiotherapists
 - Occupational therapists

2.2.3 Nephrology Equipment for Paediatrics

- All providers should have access to age appropriate equipment for anaesthetic and surgical placement of access for peritoneal, haemodialysis and transplantation.

2.2.4 Protocols and Procedures

- Each renal unit should have clear guidelines and pathways for referral to palliative medicine services.
- Each provider should have guidelines to ensure established AKI is actively managed across Wales.
- Each provider should ensure radiological investigations and treatment are performed according to National guidelines.
- The quality of dialysis needs to meet the Renal Association Standards for Children¹⁰.
- Each provider should ensure protocols are in place to cover the full range of drugs used in children with renal disease. Shared protocols are available and used where indicated.
- The transition planning for children from paediatric services across to adult services should start from 12-13 years old.

2.2.5 Paediatric Surgery and Anaesthesia

Dialysis access surgery is carried out by a surgeon with training and expertise in carrying out the procedure and by an anaesthetist with training and expertise in the management of children.

Anaesthesia

Anaesthesia must be provided by an appropriately trained and experienced anaesthetist. They should have advanced training in paediatric life support and maintain these competencies by annual training that is, ideally, multi-disciplinary and scenario based.

All the above competencies must be assessed through the annual appraisal process and reevaluation.

In addition to the above there must be in place:

- Lead theatre practitioner/Operating Department Practitioner
- Pre-anaesthesia assessment
- Appropriately trained recovery staff
- Standard and established pathway for paediatric resuscitation
- Standard and established pathway for paediatric intensive care retrieval and transport if critical care is required.

All those anaesthetising children must have up-to-date level 2 training in child protection. This must be maintained by annual updates of current policy, practice and case discussion.

¹⁰ Renal Association, Treatment of Adults and Children with Renal Failure

2.3 Interdependencies with other services or providers

The care of children with renal disease overlaps and interfaces with many other specialist children's service including neonatal, intensive and palliative care, CAMHS services, educational support and respite and palliative care.

2.4 Exclusion Criteria

Patients will need to meet residency and age requirements as stated within section 2.1 of this document.

2.5 Acceptance Criteria

The service outlined in this specification is for patients 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 resident in England who are registered with a GP Practice in Wales.

2.6 Patient Pathway (Annex i)

The patient pathway for children and young people presenting with Acute Kidney Injury is detailed in Annex i.

It is expected that the tertiary specialists will work with general paediatric consultants with a special interest in nephrology in each Health Board, to ensure that all patients can receive their care safely and as locally as possible.

2.7 Service provider/Designated Centre

South Wales Providers

- **Noah's Ark Children's Hospital for Wales**
Cardiff and Vale University Health Board
Heath Park Way
Cardiff
CF14 4XW
- **Bristol Royal Hospital for Children (Transplantation)**
Upper Maudlin St
Bristol
BS2 8BJ.
- **University Hospital of Wales**
Department of Nephrology and Transplantation
Cardiff and Vale University Health Board
Heath Park Way,
Cardiff
CF14 4XW

North Wales

- **Royal Liverpool Children's Hospital,**
Prescot Rd
Liverpool
L14 5AB

- **Royal Manchester Children's Hospital (Transplantation)**
Oxford Rd
Manchester
M13 9WL

3. Quality and Patient Safety

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

The specialist centre should enable patients, carers and advocates informed participation and should be able to demonstrate this. Provision should be made for children, teenagers and young adults with communication difficulties.

3.1 Quality Indicators (Standards)

Locally defined outcomes

The service should aim to deliver the following:

- Paediatric Patients in Wales to have a minimised risk of developing CKD and, where it does occur, a minimised risk of developing End Stage Renal Failure (ESRF) and requiring Renal Replacement Therapy.
- Children at risk of CKD should have regular assessment of markers of CKD.
- Wales to have rates of CKD and RRT comparable with the best in Europe.

Provider outcomes

- All patients with ESRF to have an annual review of their management.
- Where renal replacement therapy is required, transplantation to be considered for all patients who would benefit.
- Patients to have a minimised risk of developing Acute Kidney Injury (AKI) following admission to hospital.
- Maintenance of good patient (and family) experience of treatment
- Ability to minimise and reduce the short and long-term side effects of treatment.

3.2 National Standards

There should be routine data submission to the Renal Association Renal Registry Paediatric data set (www.ukkidney.org).

Ensure protection of children and other vulnerable people in line with national standards:

- Safeguarding Vulnerable People in the Reformed NHS - Accountability and Assurance Framework, 2015.
- Royal College of Anaesthetists: Guidance on the provision of paediatric anaesthesia services, 2017

3.3 Other quality requirements

- The provider will have a recognised system to demonstrate service quality and standards.
- The service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site.
- The quality system and its treatment protocols will be subject to regular clinical and management audit.
- The provider is required to undertake regular patient surveys and develop and implement an action plan based on findings.

3.4 Renal Delivery Plan Outcome measures

1	<p>Domain 1: Preventing people from dying prematurely</p> <p>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</p>	Peritonitis rate in patients undergoing peritoneal dialysis (PD)	ISPD	Clinical outcome	Peritonitis rate is Peritoneal dialysis patients	Episodes of peritonitis in PD patients.	Number of patients days on PD	Individual units	Lower incidence is better	<p>1. An effluent count of >100 WBC/ ml after a two hour dwell, with more than 50% polymorphs</p> <p>2. Excludes episodes where there is another cause</p> <p>3. Excludes relapsing peritonitis (infection with the same organism). This should be counted as a single episode</p>
2	<p>Domain 1: Preventing people from dying prematurely</p> <p>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</p>	Rate of bacteraemia	Renal Assoc. KDOQI	Clinical outcome	Episodes of bacteraemia occurring in Haemo-dialysis (HD) patients	Number of episodes of bacteraemia in HD patients	Number of patient days on HD	Individual units	Lower incidence is better	Rate of bacteraemia per 1000 patient days on haemodialysis

3	Domain 2: Enhancing quality of life for people with long-term conditions	Units to submit data on transplant and dialysis patients to UKRR	Renal registry	Clinical process	Submission of data to UKRR	Number of eligible patients registered on UKRR	Number of patients eligible to be registered on UKRR	UKRR/Individual units	Higher is better	
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4. Performance monitoring and Information Requirement

4.1 Performance Monitoring

WHSSC will be responsible for commissioning services in line with this service specification. This will include agreeing appropriate information and procedures to monitor the performance of organisations (providers).

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

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

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

In particular, the provider will be expected to monitor against the following target outcomes:

- Peritoneal dialysis peritonitis rates
- Rates of Staph aureus bacteraemia in haemodialysis patients
- Access to transplant listing for patients starting haemodialysis or peritoneal dialysis.

4.3 Date of Review

This document is scheduled for review before 2024 where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services 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 and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

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. Putting Things Right: Raising a Concern

6.1 Raising a Concern

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 the LHB for [NHS Putting Things Right](#). 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 WHSSC.

6.2 Individual Patient Funding Request (IPFR)

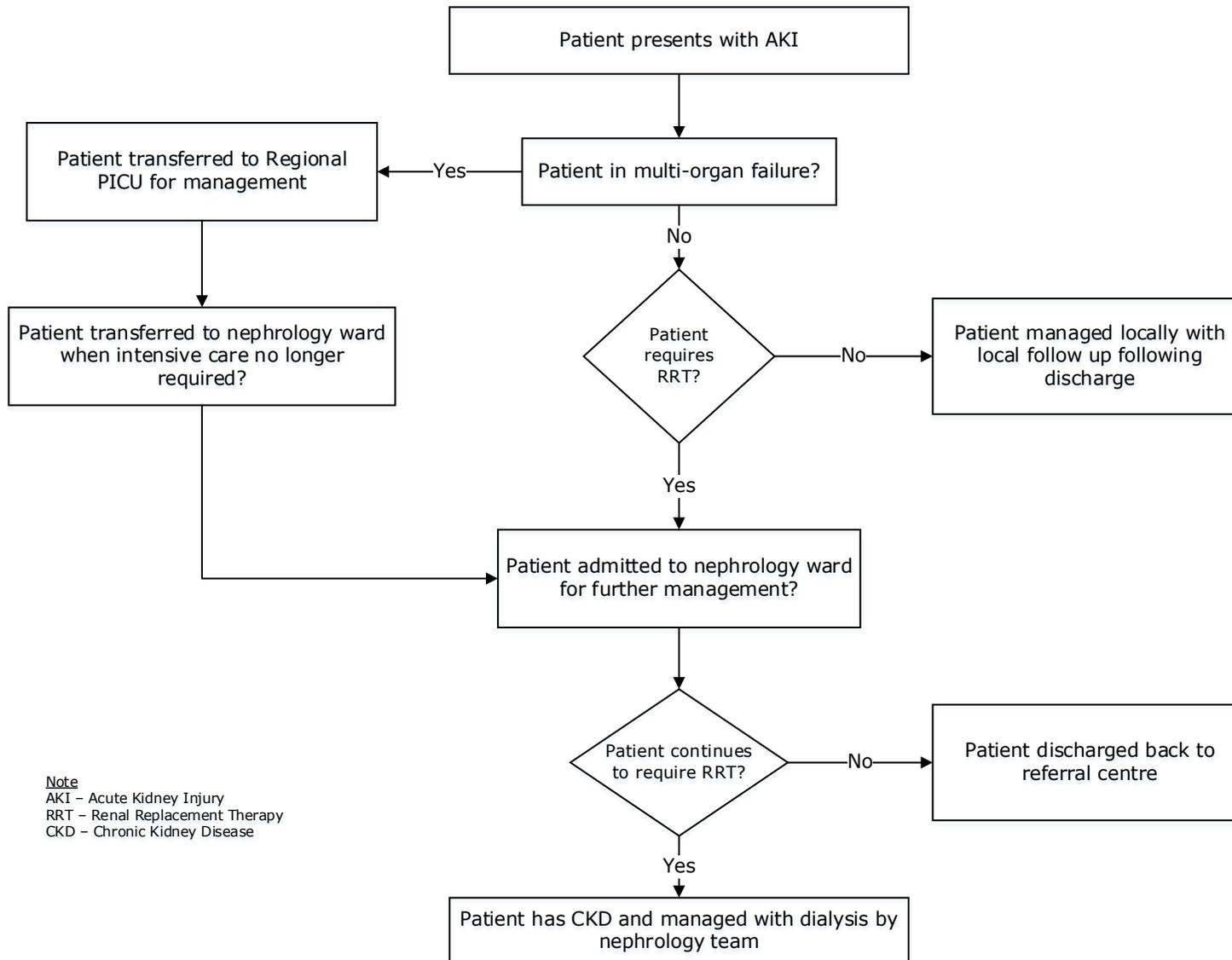
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All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

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

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

Further information on making IPFR requests can be found at: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

Annex i Patient Pathway



Annex ii Abbreviations and Glossary

Abbreviations

AKI	Acute Kidney Injury
AWMSG	All Wales Medicines Strategy Group
CKD	Chronic Kidney Disease
ESRF	End Stage Renal Failure
IPFR	Individual Patient Funding Request
RRT	Renal Replacement Therapy
SMC	Scottish Medicines Consortium
WHSSC	Welsh Health Specialised Services

Glossary

Acute Kidney Injury (AKI)

Rapid onset of kidney failure. May require specific treatment and is frequently reversible.

Chronic Kidney Disease

Abnormality of the structure and function of both kidneys, lasting more than 3 months and is often progressive.

End Stage Renal failure

End-stage renal disease (ESRD), is the last stage of chronic kidney disease. Chronic kidney disease has progressed so far that renal replacement (RRT) is needed to maintain life.

Individual Patient Funding Request (IPFR)

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

Renal Dialysis

A blood purification treatment in which waste products and excess water are filtered out of a patient's blood artificially. It is used when the patient's kidneys no longer function sufficiently to maintain life.

Renal Replacement Therapy

Treatment to augment or replace the function of failing kidneys, by dialysis or transplantation.

Pre- Renal Failure

Pre-renal means the cause is before the kidney or glomerulus.

Transplantation

The process of taking an organ or living tissue and implanting it in another part of the body or in another body.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC is a joint committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services 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.