



Rare Care Centre Regional Hubs - Eligibility and Access Procedure

1. Purpose

The Rare Care Centre Country Hubs (Country Hubs) provide cross-sector, multi-agency care coordination for children with diagnosed and undiagnosed rare diseases living in rural and remote communities serviced by WA Country Health Service (WACHS).

This procedure provides the eligibility criteria to access services provided by the Country Hubs in health districts where they have been established. The procedure reduces variation to eligibility criteria across WACHS which may impact equitable access to services. The procedure sets out that access to services delivered by the Country Hubs must be based on existing gaps in care and presenting concerns identified in collaboration with the family.

2. Procedure

2.1 Key considerations

When reviewing a referral to determine eligibility and access to the Country Hubs services, the following factors must be considered:

- The child is the focus of care, and their best interests are paramount. Clinicians must use critical judgement and the best available evidence when determining access to the service and care provision.
- Newly referred clients must meet all eligibility criteria before receiving cross-sector care coordination within the parameters of the Country Hubs.
- There may be circumstances where a referral that does not meet all the eligibility criteria may still be considered appropriate for services. This is assessed on a case-by-case basis through the service intake meeting and approved by the multidisciplinary team.
- A referral that is out of scope for the Country Hubs must be re-directed to a relevant service. The Country Hubs staff must ensure there is a 'no wrong door' approach for families to access services:
 - If the referral is not intended for the Country Hubs, e.g. child does not have a diagnosed or undiagnosed rare disease. Local processes will be followed to redirect the referral to the appropriate team.
 - If the referral is intended for the Country Hubs and following intake it is determined the service is not the most appropriate care provider, the Country Hubs staff will discuss the redirection of the referral with the referrer and the family, e.g. to [WACHS Child Development Service](#).
- When consultation with an external stakeholder is required, consent from the client must be obtained and documented within the digital medical record (DMR) prior to any consultation.
- The Country Hubs strive to provide culturally safe services to children and their families. Staff must consider the cultural context and use the best available resources and local supports (e.g. Aboriginal Health clinicians) to make informed decisions about eligibility and access to services and care provision. Refer to strategies on priority areas in [WA Aboriginal Health and Wellbeing Framework 2015-2030](#).

- The Country Hubs prioritise engagement with children and families experiencing increased vulnerability and disadvantage, delivering services that are timely, acceptable, affordable, accessible, and appropriate for families.
- Eligibility and service access may change over the client journey. When appropriate, service conclusion and handover to ongoing primary service providers must be discussed with parents/guardians and agreed as a shared decision between the family and Country Hub teams.

2.2 Eligibility to receive services

To access Country Hubs services, the child must meet the following eligibility criteria:

- have a rare disease **OR** be suspected of having a rare disease **OR** have an undiagnosed rare disease
- live in a rural or remote location where a Country Hub has been established
- be under the age of 18 years at the time of referral
- have an existing gap in care provision
- be eligible for Medicare, e.g. Medicare cardholder, listed on a Medicare card, visiting Australia from a country with a Reciprocal Health Care Agreement (RHCA) **OR** be an asylum seeker or displaced person as outlined in the [WA Health Fees and Charges Manual](#) (section 1.3).

Clinicians are responsible for monitoring ongoing client eligibility. Active clients are deemed ineligible when they no longer meet any one of the eligibility criteria. In these circumstances, the client must be referred to an appropriate service for continuation of care. The Country Hubs staff will continue to actively support the client until the receiving service has accepted the referral. Clients may be re-referred and re-enter the service.

2.3 When eligibility criteria are not met

There may be circumstances where a referral that does not meet eligibility may be considered for Country Hubs services. This is to be assessed on a case-by-case basis at the service intake meeting and approved by the multidisciplinary team.

Where eligibility and/or access decisions are contested, the referrer may be contacted to provide additional information. Parents/guardians should be advised to contact their primary referrer for further support.

Child does not have a diagnosed or undiagnosed rare disease

A child that does not have a diagnosed or undiagnosed rare disease should be redirected to an appropriate service that is able to meet the needs of that client and family, e.g. child development service, child health nurse, school health nurse, general practitioner or paediatrician.

Child does not live in a location that has an established Rare Care Country Hub

A child that has a diagnosed or undiagnosed rare disease that does not live in a location serviced by an established Country Hub should be referred to the statewide Child and Adolescent Health Service: Clinical Centre of Expertise for Rare and Undiagnosed Diseases (Rare Care Centre).

Medicare ineligible persons who are not asylum seekers or displaced persons

At times, a referral may be received for a Medicare ineligible family or child, including:

- overseas visitors (not covered by a Reciprocal Health Care Agreement)
- international students on a student visa.

If the child is Medicare ineligible, this is to be recoded appropriately in the patient demographics and documented in the incoming referral.

In line with the [WA Health Fees and Charges Manual](#), where a person is Medicare ineligible and is not an asylum seeker or displaced person, a fee may apply. When a Medicare ineligible child is identified who is not an asylum seeker or displaced person, a discussion must be had with the parent/guardian to inform them of the fees and to determine whether they would like to proceed with the Country Hubs services.

Alternative service provider options (if available) must be discussed with the parent/guardian.

If the parent/guardian wishes to proceed with the Country Hubs services, they must provide informed financial consent, and this must be documented in the DMR.

Refer to the following resources for further information:

- [WA Health Fees and Charges Manual](#) (Medicare ineligible non-admitted fees are provided in section 5.14)
- [Information for Overseas Visitors and Students brochure](#) (available in English and other languages); and
- WA Country Health Service [Debt Recovery Policy](#).

Declined referral: letter templates

Letter templates are available to support communication with a referrer when their referral is not accepted. Templates cover the following reasons:

- Parent/legal guardian consent is not indicated on the referral.
- The child lives in a location that is not serviced by an established Rare Care Country Hub.
- The child is ineligible for Medicare and not an asylum seeker or displaced person.
- The Country Hubs services are not considered the most appropriate service for the child's needs.

2.4 Service access when eligibility criteria are met

Once a child is deemed eligible to receive services from the Country Hubs, clinicians determine service access and whether the Country Hub is the most suitable service option for the child.

When sufficient information is provided in the referral for the intake team to determine appropriate Country Hubs service options, the parent/guardian will be contacted to undertake a triage assessment.

Where insufficient information is provided, a clinician will review available medical records, contact the referrer to obtain further information, and may contact the parent/guardian to discuss their concerns and priorities to determine appropriate service provision.

Clinicians are to discuss alternative service options with the parent/guardian when it becomes evident that an alternative service would be more appropriate. Country Hub staff must not specifically promote or recommend any individual external provider.

Access to services is generally considered appropriate when the child presents with identified gaps in their care journey that are not being met by another service provider. The Country Hubs provide time-limited support to improve access to, and quality of care. It is not designed to duplicate existing services or assume ongoing responsibility for client care.

3. Roles and Responsibilities

Clinical staff working in the Country Hub are responsible for:

- Working collaboratively with children and families to deliver services in accordance with relevant policies and related procedures.
- Creating and maintaining a safe, welcoming environment to enhance service engagement with children and families.
- Understanding reporting obligations and escalating any concerns about a child's safety or wellbeing to the appropriate team leader or manager.
- Participating in required/recommended training and developing clinical competencies to deliver effective services for children and families.
- Adhering to obligations regarding information sharing and record-keeping requirements and maintaining confidentiality standards and accurate documentation.

All staff are required to comply with relevant WACHS policies and procedures, consistent with their role and responsibilities. Guidelines outline the recommended course of action within WACHS, and staff are expected to use the information to inform and guide practice. Where staff are unsure which policies, procedures, or guidelines apply to their role or scope of practice, and/or how to apply them, they should consult their manager in the first instance.

4. Monitoring and Evaluation

Monitoring and evaluation of this procedure is to be carried out by the Rare Care Country Hubs Cross Sector Governance Groups to assess its effectiveness and ongoing relevance. The procedure will be reviewed annually using methods including feedback from clients and stakeholders.

Implementation of this procedure is to be discussed in team meetings and monitored by managers and staff. Staff are to be oriented to relevant policies on commencement with the program, with ongoing assurance supported through audits of clinical practice.

5. Definitions

Term	Definition
Access to services	Determined collaboratively with the parent/guardian and based on the suitability of the Country Hubs specialist services for the client's presentation and/or needs.
Active client	A client who is currently open to receive services from the Country Hubs.
Eligibility	Criteria for engagement with Rare Care Country Hub services.
Rare disease	A disease that has a prevalence of 1 in 2,000 people or less.

Suspected rare disease	A client who has more than one of the following criteria: • family history • group of congenital anomalies • extreme or exceptional presentation of common conditions • neurodevelopmental delay or degeneration • extreme or exceptional pathology • surprising laboratory values.
Undiagnosed rare disease	A medical condition without known cause or specific diagnosis despite specialist investigation.

6. Document Summary

Coverage	WACHS district locations where Country Hubs are established
Audience	Rare Care Country Hub staff and referrers
Records Management	Clinical: Health Record Management Policy
Related Legislation	Health Services Act 2016 (WA)
Related Mandatory Policies / Frameworks	Clinical Governance, Safety and Quality Framework
Related WACHS Policy Documents	Consent for Sharing of Information: Child 0-17 years Procedure Child Development Service – Eligibility and Access Procedure
Other Related Documents	CAHS Guidelines for protecting Children-2020 WA Health Fees and Charges Manual WA Aboriginal Health and Wellbeing Framework 2015-2030
Related Forms	Nil
Related Training	Available from MyLearning: • Digital Medical Record (DMR) eLearning Series • webPAS: Outpatient Training for Clinicians and Clerical Staff (WPOIA EL1) 2022 Available through Medics for Rare Disease • Rare Disease 101 - Australia
Aboriginal Health Impact Statement Declaration (ISD)	The completion of an Aboriginal Health Impact Statement and Declaration (ISD) is required for all new and revised policy documents. For further information, please see the ISD Guidelines. ISD Record ID: 5089
National Safety and Quality Health Service (NSQHS) Standards	2.06, 2.07
Aged Care Quality Standards	Nil
Chief Psychiatrist's Standards for Clinical Care	Nil

6.1 Document Control

Version	Published date	Current from	Summary of changes
1.00	6 October 2026	6 October 2026	New procedure

6.2 Approval

Policy Owner	Executive Director Strategy and Change
Co-approver	Executive Director Nursing and Midwifery
Contact	Clinical Nurse Specialist – Rare Care Pilbara Hub
Business Unit	Rare Care Country Hubs
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